

SIN Colorado is a Gay Poz Men's Social Network supported by Treatment Educat10n Network

Upcoming & Recurring Events
Sunday Coffee Talk/Brunch
Panera, 13th & Grant Street
First Sunday of each month 11am to 1pm

Free Yoga Tuesday 4:30pm (2670 Gilpin) Wednesday 5:15pm (770 Broadway) Saturday noon (770 Broadway) Yoga Questions? Call Phil 303.358.3563

> WINTER 2010 Volume III, Issue XI

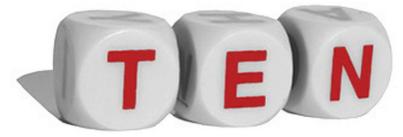
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#### MISSION STATEMENT

The Mission of OnTheTen Newsletter is to provide educat10n and information for HIV-positive individuals in Colorado

The publication is a peer-based collaborative effort, and we encourage material written and contributed by poz individuals to achieve our goal of being "by the community, for the community." We believe that "knowledge is power" and that HIV positive individuals have a lot to learn and gain from each other by sharing their experiences and information. In addition, we strive to empower individuals to be proactive in their mental and physical health and well-being.



### www.ontheten.org

The Newsletter of Treatment Educat10n Network—TEN

## THE WOMEN'S LIGHTHOUSE PROJECT SAYS GOODBYE

By Shannon Behning

ear friends, colleagues, community members, and most especially, women living with HIV that have been served through The Women's Lighthouse Project: In early 1997, four women from Denver created an amazing team and submitted a grant to WORLD (Women Organized Responding to Life Threatening Diseases), hoping to be chosen to implement their HIVU (HIV University) program.



This team was the first chosen from many applicants across the United States to travel to WORLD's offices and spend eight days receiving training on developing this exciting program for Colorado. Mary Ross, a former LCSW from University Hospitals ID Clinic, and I jumped on that plane and headed west.

I remember when I entered the room for the first day of training, as women began introducing themselves and stating that they had been living with HIV for eight, nine, or even 10 years or more. I had just "celebrated" my 5 year diagnosis; this was one of my own moments of hope that I could survive this.

When Mary and I returned, we met with the other two members of our team, another HIV positive woman and MeriLou Johnson from the AIDS Education and Training Center. Mary and I shared what we had learned and what we wanted and needed to do for the community of HIV positive women in Colorado.

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#### ! IMPORTANT ALERT!

#### **ADAP PROGRAM CHANGES IN 2011**

We strongly urge you to attend a Special Information Session (a special Community Educat10nal Forum)

Tuesday January 11th 2011 6pm

(complimentary dinner followed by presentation)

Our Saviors Community Room \* 9th & Emerson (enter on the side from Emerson)

All the information about the changes & programs will be presented by Bob Bongiovanni, Manager of HIV Care and Treatment; and Todd Grove, Insurance Assistance Coordinator; both from the Colorado Department of Public Health & Environment.

Up until now, no one has paid for medications from the Colorado AIDS Drug Assistance Program (ADAP), and very few persons with HIV could get individual health insurance. 2011 will bring a new era for ADAP.

- Some current enrollees could get health insurance, with ADAP assistance.
- Some may begin making monthly payments to stay on ADAP.
- Lower income ADAP enrollees will stay "as-is".
- These changes are being implemented very soon.
- How will this affect you or people you know? Come find out.

#### WE OWE THIS TO OURSELVES

By Rod Rushing

s the 1<sup>st</sup> decade of the 21<sup>st</sup> century recedes into the background, I am humbled by the myriad of events that have transpired. The toppling of the twin towers. Americans elected an African American president. A national discussion on gay marriage as well as a thoughtful and long-overdue mentoring campaign for struggling lgbt youth was started by Dan Savage. Sobriety and recovery entered my life after it had become a grass roots national movement. And the conversation around HIV shifted from what's not working to what does work including the challenges of aging with the virus.



Hopefully, this issue will illustrate several local examples of these home-grown best-case scenarios (out of the thousands here in Colorado). Pozlings who were once newly-diagnosed and devastated souls have confronted their fears, taken some punches, taken their meds, and found a way to let their inner lights shine. This remains **the** story of the decade

in my eyes. There is recovery from alcohol and drugs and then there is this recovery from the depths of diagnosis.

Story after story, issue after issue, TEN highlights local examples of a how-to guide to personal success. If you find yourself reading this, take note- it is completely possible

to be healthy, to contribute, to overcome -even to surpass. And it can be done on your own terms.

I dare say (following the lead of sage Pat Gourley) that a cure could readily be in sight this coming decade. Until that time, TEN hopes to continue to bring to light these individual stories of strength and triumph. Courage is rampant among our poz community, but not often recognized. I believe not only that we were once heroes, as Mark S. King so lovingly states, but that there are still many, many more heroes among us. Certainly this includes you, doesn't it?

Since when did bullets stop to sing? (It didn't have to end like this) Is this the end of everything? (It didn't have to end like this) I feel, I feel, we can't stop here, I feel, I feel, we won't stop here, It didn't have to end like this, We owe this to ourselves, We owe this to ourselves, We can't just let this go, Anberlin

#### THE C-WORD

By Pat Gourley

he most effective ways to address HIV infections in late 2010 remain staying uninfected and if you are already infected getting on medications as soon as possible. The evidence for early intervention is now convincing but decades of being on the available potent chemotherapeutic agents certainly has its downsides.

What has proven to be very illusive over the past thirty years is of course the C-word, a cure. In the 1980's it was felt by many activists involved in the epidemic that it was simply a matter of will, the willingness to devote adequate resources and a cure could be found. Many felt that all that kept this from happening was that it was infecting disenfranchised populations who lacked the political clout to mobilize enough resources make it happen. If only straight white men had been a significant at-risk-group. Though the analysis that it was infecting the powerless still has some cache and credibility it also turned out that this little virus was very crafty in how it infected human beings. Western medical hubris aside this was a daunting infection that the science of the early years was simply not up to solving.

The reality of how our very sophisticated immune systems handled this particular virus was different and in ways less "effective" than how other viral infections were handled. The virus has the ability to hide away in a dormant fashion in reservoirs that the current medicines can't crack. The current therapies do a great job of keeping the amount of circulating virus in the blood very low but if they are stopped the virus comes quickly out of hiding.

In the last few years however there has been resurgence in the effort to find a cure and certain of these efforts look quite promising though severely under funded. This is where a resurgence in AIDS activism is sorely needed at this time. The link below is to an organization based in Philadelphia (continued on page 7)



#### **COMPAS**

t the beginning of 2010, Denver Public Health initiated COMPAS, a support group for Spanish-speaking men living with HIV. Though language appropriate HIV services and case management were available in Denver for those who speak Spanish, there were limited options for support services.

Starting with a core group of a few clients receiving care at Denver Public Health, COMPAS began. (The word "compass" means "buddy".) With their own ideas, suggestions, and needs, the project began to take form as these men met every other week. They talked about their own experiences. Some had never told anyone that they were living with the virus. Others had distanced themselves from friends, experiencing isolation and shame.



There were those who had grown accustomed with their life's routine of work and sleep, never missing an appointment with their health care provider nor a dose of meds, and resigning themselves to a life of limited friendships and abandoning the thought of a loving relationship. And there were those who because of romantic heartache, depression, or substance abuse had been absent from care and meds for months.

The original plan for COMPAS was for the biweekly meetings to transition into monthly meetings for on-going support and education. However, the group soon decided that they wished to meet weekly. They had discovered new friends who were experiencing things similar to their own experiences. There were others who were living not only with the same virus, but also with the same feelings of solitude and unvoiced sorrow. Some spoke of failed relationships and the difficulty of finding new ones. They discovered that they were not alone and their journey was not unique. At the same time, however, there were those who spoke about how HIV had not put an end to loving relationships with discordant partners. Others talked about long-term relationships that had endured despite the stress of HIV. As the year progressed, similar journeys shared began to lead to new traveling companions and new reservoirs of strength and courage.

The serious aura surrounding the HIV diagnosis began to be replaced by serious sharing, serious friendships, and serious laughter. Though there was initial concern expressed that weekly meetings would soon lead to "burn-out" by participants, COMPAS grew in cohesiveness and in numbers. As one of the "compass" wrote during the summer, "Though all of us have the virus, we are not alone. Loneliness is the worst enemy that we have."

In response to a question about what he considered to be the most important thing he had learned through participating in COMPAS, another "compa" wrote, "I have learned to be more understanding toward my other friends. I have learned to be more faithful to my meds. I have learned to be more relaxed with my own situation of being positive. I have learned to enjoy the company of my 'compas'. I have learned more about HIV."

"For me, the most surprising thing has been the relationships that have formed among the group... because even though it is a informational program, it is social. We learn but at the same time, we enjoy our time together; though we share the same infection, we also share our lives and laughter."

COMPAS is a support group for Spanish-speaking men who are living with HIV; weekly meetings are complimented by social activities, educational forums, and mentoring. For more information call 303.602.3619.

#### **VIP FOR HIV**

By Scott McGlothlen

his last summer, I received a bit of a shocking surprise in the mail. I opened an unmarked envelope not sure whether it was going to be an advertisement or anthrax. Even worse, it was an incredibly unflattering photo of me in my car. Clearly I had been photographed by a speed trap and I must have hit their limit at a very awkward time. I had always

hoped that if this happened, I would look incredibly sexy while driving. But alas, my eyes were nearly shut and my jaw wide open. It did not take a brain scientist to understand that I was clearly singing in the photo. And there is only one band who can make me belt out tunes with a face like that: The Dresden Dolls.

Many folks in Denver were lucky enough to get exposure to this band at Red Rocks in the summer of 2007 during the first True Colors tour with Cindy Lauper. The Dresden Dolls describe their music as "punk cabaret." It has all the qualities of great show tunes with the essence of punk rock. Imagine Liza Manilli meets the Ramones. The listener can rock out while they wail out to lyrics in an exciting and vibrant sing-along kind of way.

The Dresden Dolls are made up of two parts. Amanda Palmer writes the music, plays the piano, and does the vocals. Her lyrics are wittingly filled with modern references and double entendres all while tied up in some unique emotional bows. The other half is Brian Viglione, the drummer. While it seems like anyone could drum for a piano player, somehow it is his own persona that really seals the two of them as a one of a kind musical creation.



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#### **EMBRACING CHANGE**

By Rev. Jim Chandler

s we move through this winter there is no better time to recognize the powerful and dramatic changes taking place. This change is touching those living with HIV/AIDS more profoundly and we are in the midst of that change. There has been a change in the face of disease and the way it is managed.

I remember, over 20 years ago, a medical doctor I knew returned from a world conference on AIDS. Upon returning we talked about what transpired there and he showed genuine excitement as he exclaimed that as of that week a major breakthrough had been made. He went on to state that for the first time the medical establishment wasn't referring to the disease as a "terminal disease." For the first time the pandemic was now being referred to as a "manageable condition." His excitement was based upon this change in thinking that for the first time death was not being discussed as a certainty, but rather that the condition was something to be dealt with.

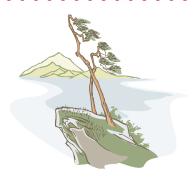
At the time I don't think I fully realized the shift which had taken place, but he was right. We have all heard the statement "change your thinking, change your life."

This perspective was being applied to persons with HIV/AIDS who were surviving longer. Even their caregivers were looking at the disease differently, the research started changing, and lives of all types which were touched by HIV/AIDS took a new path and a new enthusiasm of the possibilities which lay ahead. The possibilities of what could be done started to flow.



Right now we are going through another one of those shifts involving the entire world. The creative power of thought, faith, and possibility thinking has found a new place in our world. We are no longer held back by what had taken place in the past. Whether the conversation is about politics and government, business and trade, health and illness, relationships and its many individualized forms, science and the environment, religious traditions and spirituality, or just life itself in it's many forms, change is happening.

For the first time change is truly something to be embraced. As long as we are willing to embrace change we will find a future far surpassing what we have created in the past. Those of us stuck in old thinking, refusing to step out onto unformed potentiality, will be left behind. The rest of us will live in a new world. We should no longer state that "I will believe it when I see it," but change that old way of thinking to "I will see it, when I believe it." This is the power in embracing change.



# 2011 HIV Retreats at Shadowcliff July 28-31 & August 18-21

Shadowcliff Lodge
Grand Lake, Colorado
A 3-day weekend retreat in the mountains.
More information and registration at:
www.OnTheTEN.org/retreat
or 303.377.3127

## THANK YOU CYCLE SLUTS!

EN would like to thank the Denver Cycle Sluts for their incredible support of the HIV Retreat at Shadowcliff. In the last year, they raised \$3500 at Bingo Nights and Shows that were designated for The Retreat.

We applaud their targeted supportofsmallerorganizations with limited financial resources and smaller revenue streams. CS Bingo benefits a different charity on the second Friday of every month at Hamburger Mary's

for more info visit: www.denvercyclesluts.net

Check it out: OOOH SIXTY NINE!!!



#### "IF I CAN SAVE ONE LIFE"

By Penny DeNoble

"If I can't have you, then no one else will!," is what she said to me when I told her I no longer wanted to be in a relationship with her. And she made good on her threat. She "outed" me/disclosed my status to many people in the Black Lesbian Community at the time. Whenever I'd go out to social events, I would see the whispering and the finger pointing at me. No one took the time to come up to me and ask questions or offer help or comfort, or anything else; they just ostracized, judged and treated me as if I had the plague.

As a result, I began to isolate myself. My life consisted of going to work and going home and hiding away.

This proved to be a detriment more than an asset because I realized that I was dying....dying from a broken heart and the self-inflicted shame I had taken ownership of. I began to lose weight; I stopped eating; I stopped smiling and I stopped reaching out for support. I believed in my mind that I didn't really need anyone anyway, and I could navigate this unknown world of HIV all by myself. I was wrong. I realized I did need community. I did need love. I did need support, but I was just unsure about how to go about getting it, so I suffered in silence. My life began to ebb away and I didn't know what to do about it.

One fateful day, I was out walking (alone and in despair) and I heard The Voice say to me, "Penny, you've tried everything else and now it's time for you to come home." I knew The Voice; I didn't have to question it, and I knew where home was. The Voice was the Voice of God inviting me to come back under the protective, healing wing of His Mercy, and Home was getting me plugged back in to a spiritual community.

I knew that was the lifeline I needed to find me again and begin the healing process even though I was unclear about what that was supposed to look like, but I was hopeful!

I found a spiritual community that embraced me, loved on me and I felt the life force begin to re-enter my body. I established close relationships with a few women in the community, one being the Senior Pastor's wife, and I knew she was someone safe with whom I could share my status, my pain and my journey.

Years later, I began feeling a stirring within the very core of me, preparing me to share my story and I began to quiver in fear, thinking, "There's no way!" Shortly thereafter the Senior Pastor's wife approached me about being the guest speaker at a women's retreat that we were going to be attending, and I told her, "Thanks, but no thanks!", and she would not allow that to be my final decision. Every time she would approach me, my answer would be the same and her response would be the same (thank God for her!)

The time of the retreat and the appointed day I was scheduled to speak came, and I was again quivering in fear and had worked myself up mentally that I became physically ill. Once again, The Voice spoke to me loud and clear and said, "Penny, you HAVE GOT to do this! And if they reject you,

it's not you they're rejecting, but Me in you, and they're the ones who have the leprosy." Wow! Well, after hearing that exhortation of reassurance from The Creator of the Universe, I was greatly encouraged and it gave me the strength to get up in front of a room full of women and begin to tell my story publicly, for the very first time! As I was nearing the end of my talk, I again heard The Voice say, "Now invite the women to come up and lay hands on you and pray for you." That was a tremendous risk for me because it triggered the memory of how I was treated by the women of my former social community and I was AFRAID! I was about four years into my diagnosis and I had never asked anyone to pray for me because rejection is not pleasant... nevertheless, I trusted and did what I was told to do, not expecting anyone to come forward. When I did, I was engulfed by a room full of women who were weeping with me and so filled with love and compassion for me that I was so totally overwhelmed with wonder, awe and gratitude!!! That day I knew it would be OK; I would be OK and my journey of inner and physical healing had begun!

As we returned to our normal lives after the retreat, a woman in my spiritual community would seek me out and say to me, "I love you!," and I would respond in kind. But she would emphatically say, "No, I REALLY love you and one day I'm going to take you to lunch and I'm going to tell you why!" That day arrived and as we sat and talked, she told me, "When you shared your story that day, you saved my life." She went on to say that after the women's retreat was over she was going to go out and kill herself. She said she had a plan, had already written the note and had even pinpointed the day she would do it. She said that after hearing me courageously tell my story that day, she realized there were people in the world who were suffering with issues far greater than her minor physical pain and if I could courageously stand up and tell my story, not knowing the outcome of people's responses, then she most certainly could live.

Needless to say, goose bumps traveled down my body and I wept! I wept because of the impact my story had on someone's life, but I wept also because I thought of the potential impact of how being paralyzed by fear of rejection and self-preservation could have had. I thought that if I would have allowed those thoughts and emotions to dictate my behavior that woman could have taken her life and I shudder to think of the blood that could have potentially been on my hands!!

That day I resolved that I would forever commit to telling my story, no matter how uncomfortable it may be for me!! I committed to dedicate my life to help save lives. If I can save one life by the telling of my story, then that's what I'll do. That was over 20 years ago that I was given the incredible privilege of saving one life and shall continue to commit to help save lives, simply by the telling of my story!

Be Well! Go Well! Live Well! Love Well!



#### THE HOPE PROGRAM AT CHIP

The HOPE Program was started in April 2005 as a collaborative effort between the University of Colorado ID Group Practice and CHIP Program to serve persons living with HIV who wanted to explore options for parenting. HOPE's mission is to provide comprehensive reproductive health counseling to individuals and couples who are hoping to conceive, and prevent transmission of HIV to both uninfected partners and newborns.

Since it's inception, the HOPE Program has counseled 51 individuals/couples (as of December 2010). Among these couples, 30 couples/individuals sought counseling where only the male partner was living with HIV, 17 couples/individuals were seen where the female partner was positive, and 4 couples were counseled where both parties were HIV positive. The HOPE Program has assisted in 12 pregnancies with 10 live births. There have been no reported cases of HIV transmission among partners and/or infants of families who have received consultation with the HOPE Program.

Moving forward, the HOPE Program continues to review the most current treatment options and strategies for persons living with HIV, to continue the goal of offering persons the opportunity to grow their families.

For more information, please contact:

The Children's Hospital Attention: Jennifer Pappas 13123 E. 16th Ave B055, Aurora, CO 80045 720.777.2841 Fax 720.777.7294 pappas.jennifer@tchden.org



## WOMEN'S CARE AT ROCKY MOUNTAIN CARES

By Benjamin Young, MD and Myra Young, DNP ocky Mountain CARES is Colorado's newest non-profit comprehensive HIV prevention, education, treatment and research center. RMC was established in 2009 with the mission to provide the highest quality individualized comprehensive care, treatment, supportive services and education for those affected by and infected with HIV in the Denver metropolitan area.

As HIV specialists with over 20 years of experience, we provide ongoing care for approximately 800 individuals, including a steadily growing number of women clients. Our care management and clinical services are provided within a single facility by a dedicated team of physicians, a nurse practitioner, and care managers. We provide timely linkage to client services, peer-education and medical care in an individualized, non-judgmental environment that is safe and compassionate, ensuring human dignity and freedom from stigma and discrimination.

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#### VIP FOR HIV

(continued from page 3)

After the True Colors show, I got a chance to briefly get autographs and a snap shot with Amanda and Brian amongst a mob of other fans. Although the quick meet was not intimate, it was still one of the most exciting moments of the summer. Unfortunately, I did not know that HIV was secretly surging through my body at the time. I felt on top of the world while hell was breaking loose in my veins. A couple months later, I received my diagnosis.

Similarly to others initially diagnosed with HIV, I faced major depression. However unlike most people in my shoes, the music geek in me turned to song for the emotional treatment. And much of The Dresdon Dolls' music took on new meaning for me. I connected in new ways with songs about life not happening in perfect, chronological order. I now understand other songs that tore into the notion of living with a complicated body that just won't seem to fix itself. Even if they were not meant to, so much of their music seem to speak to me about my experience with HIV. I would often curl up in bed and put my headphones on, listen to their music, clutch onto my pillow, and cry.

Amanda and Brian went on to split as a team in order to work on their own projects. Ms. Palmer released a solo album with Ben Folds titled "Who Killed Amanda Palmer?" It was dark, poetic, ironic and best of all still relatable. And I continued to connect with the music in a way that I wouldn't have if it were not for the HIV.



In the fall of 2010, Amanda and Brian got back together for a 10th anniversary tour. However the tour would not be stopping in Denver. While I liked them both individually, I knew this could be one of my last chances to see them as a team. Luckily, a long distance friend, who was also a fan, agreed to meet me in Atlanta to see their show.

But I knew that with all that I had been through, I needed to be able to meet them for actual moment rather than a few second photo opportunity.

A week before Atlanta, I emailed the address given on their website for fan contact. I wrote a brief story of how their music helped me struggle with my HIV, that I was traveling to Atlanta to see their show, and that I would like to meet them in person. It was a long shot but I had to try it. To boost our chances, my friend and I got the people in our lives to sign a petition to support our meeting with The Dresden Dolls. I attached it to the email and hit send. Later that evening, I checked my in-box and had a crushing delight. There was a response from Amanda Palmer. I excitedly opened it only to find out that it was an autoresponse. She wrote that she checks all fan mail but due to the overwhelming amount she gets, it could be up to a year before she responds. I could not wait a year. The show was happening in one week.

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#### **VIP FOR HIV**

(continued from page 6)

I continued to check my email constantly, even peering into the junk box to see if I had missed anything. Nothing had come in. On the afternoon of the show, I checked it one more time with a small glimmer of hope. Again, there was nothing. But this was okay. Because on this night, even with a filled concert venue, I knew that The Dresden Dolls would be playing just for me.

While waiting for the actual concert to start, I began feeling impatient and decided to play with my phone as a means to kill time. I hit the email button on the phone not really expecting to see anything. But I noticed a name popped up. I had never seen this name before but I recognized the subject line. It was what I had titled my email to Amanda Palmer. I opened it quickly. It was from her assistant. She started off by apologizing for the last minute notice but wrote that there were two VIP passes for my friend and I at the box office. "Oh my God," I gasped out loud. My friend leaned over my shoulder. "What is it?" He asked.

I turned the phone to show him. His response mimicked mine. We both began squealing out of excitement. Neither of us had been VIPs before and did not really know what this meant. I told him to stay there and save our spots. I ran back to the box office and awkwardly told them that I had just been notified that I had two VIP passes waiting for me. They asked my name and when I said it, the woman behind the glass began to smile. She didn't say anything, but her smile clearly said I'm so excited for you. The man asked to see my ID and upon inspection, he handed over the passes. They were not extraordinary. But for me, they were one of the most exciting things I ever held in my hand.

I ran back to my friend hoping no one had worked their way into my spot. The show was about to start at any minute. I handed him his pass and we discretely admired them, not wanting any other nearby fans to know of our new opportunity. We joked that neither of us could lose them because we would absolutely have to go without the other if that happened. I slid mine in my pocket. I kept my hand tightly against my jeans; not for protection but as a reminder of what was to come. The lights dimmed and the show began to start.

Iked on stage in their classic noir fashion. They held armfuls of flowers and launched them into the audience before beginning their first song. The show played out amazingly. They sang a mixture of classics combined with many unknown tracks and covers. The pair pitted their instruments against one another to not only play their music, but to dare each other to make it amazing. And indeed it was.

By the last song, both of us were exhausted and had to honor the fact that we just were not as young as we used to be. As the crowd emptied the venue, we found a security guard and asked him how to use our VIP passes. He told us to simply wait outside of the door by the stage. We noticed there were a few other people with the same passes. I wondered if they had diseases too.

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#### THE C-WORD

(continued from page 2)

and San Francisco called the AIDS Policy Project. All of us currently infected with HIV owe it to ourselves to become familiar with and hopefully participate in their efforts.

A recent case of a German man with HIV and leukemia who was treated with a bone marrow transplant for his leukemia resulted in a resolution of not only the leukemia but also seemed to clear his body of HIV. Now three years out this man remains free of HIV and is considered to have been cured. In research parlance this is referred to as "proof of concept", in other words a cure is possible.

There are currently two cure approaches being looked at. The first is referred to as a functional cure and this involves the immune system being able to control HIV without drugs. The second approach is called a sterilizing cure that would be no HIV in the body any more at all. This is applicable to the Berlin man and I would again refer you to the website below for some easy to understand detail around this case.

#### http://www.aidspolicyproject.org/

Certainly bone marrow transplants are expensive and no walk in the park from a patient perspective but the cost I saw quoted was \$100,000. That is not chump change but the non-generic cost of HIV medicines in this country is often \$15,000-20,000 per year. You do the math but it doesn't take too many years to hit that amount.

Initially effective cures may be expensive but then so were (are) protease inhibitors. Outside the U.S. many AIDS medications are now available in generic form though and not prohibitively expensive. The very sad reality of course is that millions still do not have easy access to even these generic medications. Though daunting the initial monetary investment in finding a cure should not be prohibitive and may prove a more realistic avenue to all infected than the current lifelong treatments.

In a piece you can link to off the web site above the AIDS Policy Project hypothesizes a couple reasons why the pursuit of a cure has been so under funded and not getting the attention it deserves. The first is that hopes around a possible cure were raised repeatedly in the 1990's but did not materialize, optimists got burned. The second is that the drug companies that might be in the forefront of cure research have found it more economically advantageous to concentrate on the proven money-makers, current HIV medications.

AIDS activism has a long and very successful history. The activist agenda though has tended to be truncated in the past decade or so due to the effective, though in many ways problematic, medications available. It is time now to reactivate front line efforts around the fight for a cure. There are numerous ways to get involved that involve little more than access to a pen and paper. Please again visit the web site below for ideas on how to get involved. There is also information at this site to flesh out many of the issues and prospects surrounding a cure for HIV infection.

## WOMEN'S CARE AT ROCKY MOUNTAIN CARES

(continued from page 6)

Rocky Mountain CARES is associated with Denver Infectious Disease Consultants, housed on the Rose Medical Center campus, one of the most experienced HIV practices in the region. We have partnerships with many community organizations, including Planned Parenthood of the Rocky Mountains, Howard Dental, It Takes A Village, and many others. We accept all insurance plans, including Medicare and Medicaid, and in some circumstances persons are eligible without help insurance.

RMC offers the following services:

- · Care management designed to help clients navigate the many issues of access to treatment and coordination of care. We can help in accessing Ryan White Assistance programs such as financial assistance for medical coverage, emergency assistance for rent, mortgage and utilities, enrollment in ADAP, and pharmaceutical drug assistance programs. We can link you to legal services, and help you understand disability benefit programs, COBRA and CICP. We can assist you in accessing mental health and substance abuse treatment, transportation and food assistance. We provide peer support through The NET and one-on-one mentoring, coordinate your care and help you communicate with your healthcare providers. These services are partially funded by the Ryan White HIV/ AIDS Treatment Extension Act of 2009, through the Denver Office of HIV Resources.
- Education programs include peer-led support/education with The NET to learn about HIV, and deal with stigma, isolation and other issues about living with HIV. The NET offers both a "closed" 12-week structured program as well as a weekly drop-in group. New in 2011 will be a social networking group for positive women, and special programs for people struggling with issues of substance dependency.
- High-quality, individualized medical care utilizing the best evidence-based treatments. Our aim is to prevent HIVrelated or treatment-related complications and obtain the highest quality of life for all of our patients. We have expertise in sexual and reproductive health for both women and men, and offer a program in anal health care. Through a grant partially funded by the Ryan White HIV/ AIDS Treatment Extension Act of 2009, granted through the Denver Office of HIV Resources, we offer Early Intervention Services for persons without medical insurance who are recently diagnosed or who have not been in recent care to provide no-cost counseling, support, laboratory evaluation and medical care. The Northern Colorado Collaborative Care Clinic is a partnership with Northern Colorado AIDS Project and Salud Family Health Clinics that provides nocost care for uninsured, HIV+ patients in Fort Collins on the second Monday of the month.

Please don't hesitate to call let us know how we can help you. Someone is always available. We look forward to working with you to meet your health-care needs! You can reach us at 303.393.8050, or visit us on the web at rockymountaincares.org.

#### VIP FOR HIV

(continued from page 7)

"So how do you know Amanda and Brian?" One girl asked us. "We don't," I said. "We are just fans." She seemed a bit surprised and probably further so when we pegged her for details of how she knew them. Our conversation was interrupted by Brian Viglione himself walking off stage and joining the few of us remaining. They all hugged and began conversation as if they were all old friends. We stood there awkwardly and politely waited to introduce ourselves. It did not take a genius to tell that we were the only fans without any sort of connections.

Brian greeted us in manner so friendly, it did not seem like we were meeting a rock star. He shook our hands and took our overly eager compliments. Before I could forget, I lunged my arm forward at him to show off my tattoo that I had gotten of their symbol. The symbol was an outlined combination of a heart, an airplane, an arrow, and a fountain pen. It was always a beautiful image to me and their music had impacted me so much in my time of need that I only saw it fitting to get it scared into my skin for the rest of my life. "Wow, that is awesome, man!" he said.

I am sure I was not the first wacky fan to show up with their image tattooed on them. But he was very gracious about it. After a few more minutes of waiting around, Brian invited us back into the green room.

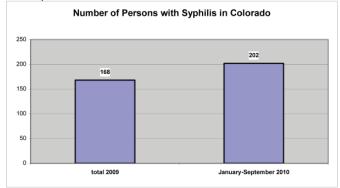
We walked in not knowing what to see on the other side. It ended up being nothing much. The room was actually green and there were some unknown individuals sitting and conversing on the couch.

(continued on page 10)

# DID YOU KNOW THE RISK OF ACQUIRING SYPHILIS IS INCREASING IN COLORADO?

From January 1-September 30, 2010, there were 202 cases of syphilis reported. That is an increase of 39% from all of 2009, and the year is not even over.

Of those 202 cases, 9 out of 10 are gay men and over half are HIV positive.



Want information on testing, symptoms, and treatment? Go to <a href="https://www.INSPOT.org">www.INSPOT.org</a>
Or call 303-692-2700.

#### THE WOMEN'S LIGHTHOUSE PROJECT SAYS GOODBYE

(continued from page 1)

We held several community forums with women living with HIV. We shared what we had learned and wanted to provide for women here in Colorado. We were given a \$5,000 grant to provide two educational series. We found a home in the PWA (People With AIDS) Coalition Colorado and our work began. The first group of women to gather and go through the workshop series were12 strong, incredible women. At the first meeting in the fall of 1997, these women chose the name they wanted for this group and The Women's Lighthouse Project was born. In March 2010, WLP graduated the 27th group of strong, fabulous, and incredible women! 270 women were served through this educational program.



During the summer of 1999, WLP held the first Statewide Summer Summit, an annual event reaching out to women living outside of the Denver Metro Area. 150 women were served through this program.

In 2000, The PWA Coalition Colorado started the Peer Advocacy Project and WLP served the women clients, which later resulted in the program known as the Client Treatment Advocacy Project. WLP served over 200 women in this program.

In 2001, WLP began serving women at the Denver Women's Correctional Facility. Approximately 60 women were served through this program.

WLP has provided countless educational programs and opportunities over the past 13 years. WLP has worked with numerous other organizations around the state and the country to provide services to women living with HIV.

WLP has done well! We have helped women learn to sail their ships! We have tested partners, family and friends, and the community free of charge. We have talked and provided education at schools, businesses and even the Art Museum when they held the HIV Awareness display.

I could go on for many more pages and describe and recount the work that WLP has done over these past 13 years. I am so very proud of the work that WLP has done, but am mostly proud of seeing that woman who initially walks in for services, unable to lift her head up high, living in shame and full of fear transform into a woman who can walk into any room, make her presence known and advocate for herself, and seeing her realize that there is life after diagnosis, that she can survive this, that she is not alone That is why I do the work that I do. Now, in the fall of 2010, WLP has reached a point of having to make tough decisions. The economic crisis that we find ourselves in has trickled down to WLP and it is time to start a new journey.

## The Women's Lighthouse Project will be closing our doors officially on November 30, 2010.

During the month of November we will be making sure that every client has a plan on how to continue on her path without WLP walking beside her. I am incredibly sad and am reminded of sitting around that table in 1997, meeting other women who are positive and living well and realizing that I can survive this. That's what inspired me to create this program for the community of positive women here in Colorado.

This is also why I'm not going away completely. The Women's Lighthouse Project's web site will remain as well as my phone number. I will continue to be an advocate for women, providing resources and referrals and information. I will always be just an email or phone call away.

There are just too many people to thank for the continuous love and support of WLP. But three groups of people I cannot send this out without saying thank you.

First, the Board of Directors, everyone who ever sat on the board gave completely and unselfishly to WLP and helped with the moving forward of the organization.

Second, the staff of WLP, Jackie Cole, Leslie Rogers, Crystal Walker Fulton, Kara Schmitt and Fran Cordell. They all gave 100% when working with WLP and added so much to the programs and the agency.

The last group of people to thank is the clients; you are who we did this for. I know we have seen women take themselves from living with shame and fright to being bold and learning how to continue after a HIV diagnosis. I am so proud of each and every one of you!

THANK YOU from every piece of my heart, my soul and my spirit. Continue to be a beacon of light in your own life and in others!!!

Shannon R. Behning Founder and Executive Director Shannon@thewlp.org 720.331.0408

## visit www.ontheten.org



Treatment Educat10n Network—TEN



visit www.beonecity.com

#### STRENGTH

By Deborah Johnson

y name is Deborah Johnson and I was diagnosed with HIV in 1992, but I could have had it before that.

In 1989, I was 21 years of age and I was staying with my mother. I had just come home after celebrating my 21st birthday, on a Saturday night. I was so full of joy as I settled down to go to sleep! It was a great celebration because my family was there and I was full of hope about what the future would bring. I went to sleep and woke up with a knife against my neck and a pillow over my face. Someone had broken into my mother's house robbing her and robbing me. He violated me. It seemed like hours, but it was just minutes. I passed out, woke up, and discovered he was gone. I ran into my mother's room and told her what happened. We called the police and it seemed like hours before they responded, but it was just 10 minutes.

I went through a very traumatic period where I constantly asked God, "Why me?" My family was very supportive of me during this time. I had to see a psychiatrist and my mind would go blank. When I tried to talk to him about the incident, all I could do was weep.

Even to this day, I still feel violated because the police still have not captured the man who did this atrocity to me.

The only thing that helped me to move beyond that situation somewhat was to move out of my mother's house and leave town for a few weeks. During my time away I felt safe because I wasn't in that home where the violation occurred.

The other miracle that happened was that my relationship with God was strengthened and that helped me tremendously; it game me strength. Life for me continued after the rape. I got married to a wonderful man who has been great and very supportive of me since the rape. After

the rape I tried to push him away and he wouldn't allow it. He hung in there; he was a trooper. And for that I am eternally grateful. We have been married for 28 years.

Before the rape, I had a son. At the time of the rape he was 4 years old. After the rape and my marriage, my husband and I had two girls. I conceived before I learned of my diagnosis. Both of my daughters are negative and so is my husband, praise God!

In 1992, I became ill with flu-like symptoms. I thought I had the flu and went to my doctor. She ran a variety of tests and they all came back negative. The last 2 tests she ran were for Hepatitis C and HIV. Two weeks later I was at home and received a phone call from the doctor. She told me over the phone that I had HIV. I knew nothing about HIV and didn't want to believe her because what I did know was that it was a deadly disease, but I was wrong! I had an emotional breakdown and asked the doctor to tell my brother the news. I was taking the news very hard and he was at my home and was able to receive the news far more coherently than I could. My brother called my family and friends that were in Colorado and had them come over to the house. Once again, my mind went totally blank as he was sharing the news. I sunk into another deep depression.

21 years later, I still struggle with bouts of depression, but I'm staying strong. I'm walking with faith, I keep myself surrounded by people with positive energy, I take my medication, and I attend various support groups for women that empower me to be a better woman who is living with HIV. I am grateful for the support groups, my support system, my family, and God, who have all given me the strength to live with strength.



#### VIP FOR HIV

(continued from page 8)

Brian continued to have conversations with us and we wondered whether or not we actually would meet Amanda. Seeing as how she was the one who wrote the lyrics I so heavily I identified with, she had become our main goal of the meeting.

Suddenly, the door open and Amanda Palmer walked out. Her hair was a mess. She still had not removed her swanky stage make up. And she only wore a small red robe. She looked exhausted as she saw the few people waiting to meet her. But before she said a word to anyone, her gaze fixated on my arm. Amanda seemingly floated her way over to me and without permission, grabbed my arm. The tattoo of her symbol obviously caught her attention. She began twisting my arm and stroking it. "These are the most beautiful tattoos I have ever seen," she said softly. In her line of work, I imagine she sees lots of tattoos. "What does this one mean?" She asked grabbing my forearm with the Aramaic Hebrew lettering. I was so nervous that I actually told her the wrong meaning. I stumbled over my own words to correct myself. "No, I am sorry," I laughed. "That is the wrong phrase. It says 'bleed like I do."

Before I could tell her it was about my HIV, she looked up deeply into my eyes. "I must have a photo with these tattoos!" she said. I quickly tossed my phone to my friend being that it was the best option for a camera. He took a photo of her practically wrapping herself around my arm. "That photo is bad ass," she said grabbing the phone. "I am going to email it to myself, okay?" As if she had to ask for permission. She clearly knew how to use an iPhone as she did not have to ask for directions. "Here," she said handing the phone back to me. "Type in your name in the subject line so I know who you are."

I tried typing but my fingers were too jittery for the little touch screen key board. While I stumbled, my friend began praising her for an amazing show. I could hear them connecting and laughing together as I tried to re-spell my own name multiple times. I felt happy for him. By the time I finished and hit the send button, Amanda had started talking to some other VIP people. I quickly (continued on page 15)

#### GOT neg FRIENDS?

This is a great and hopeful time for HIV prevention research. The past 12 months has been a year of major milestones in the scientific effort to discover how to prevent HIV and AIDS. In September 2009, a study in Thailand found that the vaccine being tested provided 31% protection from HIV infection. In July 2010, a study with women in South Africa demonstrated that a microbicide gel reduced infection rates by 39%. Research is in progress to see if the same medicines that are used to treat HIV+ people can be used to prevent infection in HIV negative people. Results released in July 2010 showed early favorable data on the safety of this approach.

Now, Denver is part of the latest major HIV vaccine research study. University of Colorado Denver is one of 20 research sites in 17 US cities now screening potential participants for a nationwide HIV vaccine clinical trial (HVTN 505) being conducted by the HIV Vaccine Trials Network. The trial is designed to determine whether or not by taking a certain vaccine combination, there will be a lower amount of HIV in the blood of people who become infected with HIV. This could mean that HIV-infected people could stay healthy for a longer period of time. It is important to note that the vaccines do not contain live HIV; participants cannot contract HIV from the vaccine. Investigators are seeking to enroll HIV-negative men, 18-50 years old, who have sex with men (MSM), or transgender women who have sex with men.

Historically, vaccines have been key to ending viral epidemics. The CDC tells us that someone in the US becomes infected every 9 ½ minutes. In the last year, over 500 new cases of HIV/AIDS were reported in Colorado.

If you're interested in getting involved in the search for an HIV vaccine, you can:

- Participate in the study, if you're HIV negative.
- Tell your HIV- friends & buddies about it.
- Share info & dispel myths in the community.

More info about participating: www.hopetakesaction.org or 303-724-0801



#### MEET CHIDINMA

i, my name is Chidinma. I have been going to Camp Heartland for two years. I love it! Camp is a safe place to talk about HIV/AIDS. I am in the 4th grade. I am 10 years old. I have been living with HIV since I was a little tiny baby. I got HIV from my mom breast-feeding me. My mom didn't know she had HIV/AIDS so she had to stop breast-feeding. My dad had HIV. He lived in Lagos, Nigeria, West Africa. Since they didn't have the right medicine, he died. He died when I was just a baby. I don't remember him that well. When he died my mom was heartbroken. Now I'm living a new happy life. One way to get HIV is by sharing needles or breast-feeding at birth. It is important to take your medicine so you will not get sick. When I was little I took liquid medicine. Now I take pills; I take six pills in the a.m. and six and a half pills at night. You don't have to be afraid of people with AIDS. Thank you for listening.

"I Am" — By Chidinma, Age 9

I am nice and smart
I wonder how many animals there are
I hear beautiful Blue Jays tweeting
I feel sad when the dark winds blow
I see wolves hunting in the woods
I want to explore the world

I am a person who loves nature
I sometimes pretend I am an owl
I dream that I'm an Eskimo
I understand what I have
I hope good things come



#### MEET NKECHI

i, my name is Nkechi and I'm in the 4th grade. In the future I hope to go to college and be a vet. My favorite activities are ice skating and dancing. I love to draw. I have been living with HIV since I was born. I got if from my mother breast-feeding me. Having HIV is not fun because if I don't take my medicine, I could die. Everyday I take my meds in the morning and at night. When I was a baby my dad died from HIV. It's sad for me because I never really knew my dad. When he died my mom was very sad because she loved him very much. Don't ever be afraid of people with HIV because they are normal people like everyone else. If you're friends with someone that has HIV, you do not have to be afraid of them.

"I Am" - By Nkechi, Age 9

I am nice and smart
I wonder how many animals there are
I hear red robins singing songs
I see deer cross streets
I want my brother to visit some day

I pretend sometimes that I'm a fairy I feel excited when I go on trips I touch frozen snow on the ground I worry about my dogs sometimes I cry when I'm sad

I understand math in school
I say it's a nice day
I dream about living in Japan
I try to do my best in school
I hope someday I'll get another dog



### "UB2" SIN Happy Hour



Second Friday of every month 6-7 pm

Meet upstairs at The Skylark Lounge 140 S Broadway

SE corner of S Broadway & Maple Ave

## WOULD YOU LIKE TO CONTRIBUTE TO THIS NEWSLETTER?

The TEN Newsletter is a quarterly publication and welcomes submissions from anyone on anything HIV-related. Deadlines are usually a few weeks prior to publication. We appreciate articles that have a maximum length of 500-600 words. All submission are subject to editing for length and clarity. Send articles or ideas to:

rebuiltdenver@yahoo.com
Put "Newsletter" in subject line.



# COMMUNITY EDUCAT 10 NAL FORUMS

"By the Community For the Community"

Second Tuesday of the Month (usually)
\* free dinner 6pm \* presentation 6:30pm \*

#### Community Room at Our Saviors

9th & Emerson (enter on the side from Emerson) More info: www.OnTheTen.org or 303.377.3127

#### **Upcoming Forums:**

Tuesday January 11:

Special Informational Session on Changes to ADAP Tuesday February 15:

"Bone Health & HIV" (Dr. Ben Young)

Tuesday March 8:

Annual Tim Gill forum at Hamburger Mary;s (topic & speaker tbd)

#### **WOMEN & FAMILIES**

olorado AIDS Project (CAP) offers a variety of services to support women and their families. CAP welcomes any questions regarding our services, and we look forward to hearing from you. If you would like to become a CAP client, or just have questions, please contact our Admissions Coordinator Angela Keady at 303-837-0166, ext. 482.

CAP offers case management services for women and men, as well as their families. The most important goals of case management are to support you in your healthcare and address barriers to healthcare in a safe and welcoming environment. Case managers can also help connect you to services for housing, mental health, substance abuse, public benefits, employment, and more.



A fully stocked Food Bank supplements your resources and provides nutritious options that meet the unique needs of people living with HIV. You may qualify if your income is at or below 125% of the federal poverty level. CAP also provides bus tokens, as well as discounted bus passes to eligible clients. These transportation services further help you to attend medical appointments, as well as potential job interviews.

CAP has two permanent housing programs in the community, both of which are options for women. The CAP housing programs accept referrals for women who are currently experiencing homelessness. If you are a mother with children, we may also be able to help you locate housing opportunities in the community.

Our Employment Center offers various workshops to help prepare job seekers for the challenges of employment including: resume writing; interviewing skills, internet based employment searches, budgeting/financial literacy and basic computer skills.

CAP's counseling services provide mental health and substance abuse counseling to all individuals infected and affected by HIV. Services are available to individuals and in group settings. CAP has an ongoing weekly therapy group that is open to both men and women. If you want to know more about the counseling services we offer, please contact Mary Ann at 303.837.0166, ext. 490.

# TEN from TEN

Pope Benedict has said that for some people, such as male prostitutes and others at risk, using condoms could be okay if used to prevent the spread of HIV infection (even if it prevents pregnancy). The position was an acknowledgement that the church's anti-birth-control stance against condoms doesn't justify putting lives at risk.

Prince William calls Cate Middleton "Babykins".
Cate Middleton calls Prince William "Big Willie".
...hmmmm... What are you saying Cate? ...

Faced with performance problems, menopause, & mismatch of expectations, baby boomers are the unhappiest of all when it comes to making love.

The generation that promoted free love has grown old and cranky about sex with only 7% of people 45-65 extremely satisfied with their sex lives in a recent poll. Even seniors are more satisfied.

New recommendations say that much of the Vitamin D craze is unwarranted and most people should get 600 IUs daily. However, many specialists believe persons with HIV should get *at least* 1000 IUs and up to 4000 IUs daily.

When asked her opinion on the recent crisis with North & South Korea, Sarah Palin said that "the US should stand with our North Korean allies". ...hmmmm... no comment ...

Speaking of Sarah, Barbara Bush recently remarked "I sat next to her once, thought she was beautiful ... and I think she's very happy in Alaska ... and I hope she'll stay there".

Results from a "PrEP" (pre-exposure prophylaxis) clinical trial suggest that a once-daily dose of Truvada in HIV-negative individuals reduces the chance of getting infected by 40 percent (statistically significant). The protective benefit could be as high as 95% if doses aren't missed, according to the study conducted with 2,500 men on four continents. The results bring up a number of issues including the expense & how this would be paid and/or who would pay; what to tell doctors & patients who want to start this now; the ethics of providing drugs for prevention vs treatment; "use-swapping"; and a number of other concerns.

Speaking of HIV drugs, researchers have discovered that raltegravir (Isentress) could be effective against the herpes virus (human cytomegalovirus) by cancelling the function of an essential protein for the replication of herpes. So far

the assays have been conducted in test tubes, and now they need to be done with whole infected cells.

Astronomers recently discovered there are 3 times more galaxies in the universe. New technological analysis of light signatures pushes the total number of stars to 300 sextillion, which is 100 billion squared, multiplied by 30.

...hmmmm... sextillion ... that's really hot!

"Whoonga" is a concoction made by drug dealers in South Africa mixing HIV medicine with marijuana. There is no evidence that this does anything to enhance the marijuana high. Authorities are extremely concerned that this will deprive some individuals of receiving their lifesaving medications in the worst-affected nation.

SA is embarking on a massive distribution of HIV drugs.

Speaking of marijuana ... a USC study has shown that marijuana can suppress the body's immune system, which explains why pot-smokers are more susceptible than non-smokers to certain cancers and infections. This is due to chemicals in the drug that fire up the production of immune cells called myeloid-derived suppressor cells.

The FDA has approved a new HIV test that generates results in about 60 seconds, rather than the 20-30 minutes it takes with the current "rapid" tests. The new test is currently approved for use in 57 countries. It will be particularly beneficial in complex environments with challenges such as emergency rooms, correctional facilities, and dental & physicians' offices.

...hmmmm... let's get everyone tested ...

Hours before the service, huddling & shivering in the cold and dark, about 3000 people showed up to line the streets within a half-mile of a small-town church in Missouri. This prevented Fred Phelps and his Westboro Baptist Church group from shouting and disturbing the funeral of a soldier who was killed in Afghanistan. Learning by word of mouth and Facebook, people drove from 3 or 4 counties away, buses brought school kids and senior citizens, people took off work, and farmers parked trucks nearby. At a distance, the protesters got out waving their signs and ranting their slogans that soldiers' deaths were God's punishment for America's tolerance of homosexuals. The massive crowd drowned them out singing "God Bless America" and chants of "USA! USA!" and "Go home! Go home!"

#### RECOMMENDED CHANGES TO DISABILITY QUALIFICATION FOR PWHAS

Edited from a blog article by Tim Horn, Editor-in-Chief of AIDSmeds (www.AIDSmeds.com)

ot too long ago, HIV was considered to be a distressingly predictable disease. In almost all people infected with the virus, it was only a matter of time before the CD4 cell count dropped to a dangerously low level and opportunistic infections and cancers reared their life-threatening and life-ending head. While the use of drugs like AZT in the 80s & early 90s could slow this process, rarely was antiretroviral treatment (ARV) able to restore health for any significant length of time. Today's powerful ARV has virtually rewritten HIV's insidious script. Even those who don't find out they're positive for a long time can experience a return to immunologic health. In turn, AIDS as we've long known it is no longer an inevitable and progressive stage of HIV disease, but a seemingly avoidable and reversible condition.

PWHAs and their health care providers have known this, but so have administrators who oversee public programs intended to provide safety nets to those who become disabled and can no longer support themselves due to disease. The Social Security Administration (SSA) has been providing disability benefits (SSDI & SSI) to people living with HIV for decades, using early-year knowledge of the disease to determine qualification. But as times have changed, SSA is eager to overhaul its disability benefits criteria to reflect today's reality. In 2009, SSA asked the National Academy of Science's Institute of Medicine (IOM) to establish the Committee on Social Security HIV Disability Criteria—made up of experts in the field of HIV care, including community advocates—to recommend updates to the disability criteria for PWHAs. IOM's report was released in draft form on September 13 and is on its way to SSA for review. Not everyone is thrilled with its recommendations. It is now clear that the recommendations are only intended for new disability applicants. *The agency made it clear that it was not interested in revoking disability status of those living with HIV; a move which could have potentially thrown thousands of lives into an economic tailspin*. Yet there are concerns about how this will affect new applicants who might come to depend on disability status, not only for income, but also health care and other supportive services.

Currently, individuals must meet SSA's definition of disability defined as "an inability to engage in any 'substantial gainful activity" by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."

As part of the process, SSA adopted a list (The Listing) of serious HIV medical conditions which are applied at the third step of a five-step review process. It currently requires a diagnosis of an AIDS-related opportunistic infection or cancer. The list of allowable medical conditions for HIV-positive adults is, indeed, long and includes a variety of once-common bacterial, fungal, protozoan and viral infections; sepsis; meningitis; pneumonia; septic arthritis; endocarditis; and sinusitis. A frequent misperception is that a CD4 below 200 automatically qualifies for disability. This was true in earlier years, but is no longer the case.

What's more, SSDI and SSI determinations are a matter of administrative law -as much as they are about medical opinion. Even if an impairment doesn't clearly meet a disability criterion, they may still come to agree that it restricts employment. A complex process, to be sure. Still, things have changed considerably since the 1993 Listing was enacted.

#### **ACCORDING TO THE IOM REPORT:**

New drugs and the concept of drug combinations evolved dramatically after 1996. HIV infection is now considered a chronic condition which, in optimal settings, allows high levels of functioning and prolonged survival. Combinations of antiretroviral drugs suppress HIV replication, enabling a recovery of immune function as reflected in circulating CD4+ [cells] normal or near-normal levels in most persons. Success in treatment, however, is far from universal. Many HIV-infected persons harbor virus already resistant to one or more antiretroviral drugs, limiting CD4 recovery. Others are diagnosed at very advanced disease stages or at an older age, both predictors of poor response to treatment. Many others find the lifelong requirement for consistently excellent medication adherence to be impossible or are suffering from the side effects of current or previous antiretroviral therapy. Today, although many of the opportunistic diseases once common are now uncommon, they are still seen. Many patients respond well to treatment, but others, even in the era of potent HIV medications, fail to achieve control of HIV replication or are diagnosed in extremely late disease stages and have rapid progression or disabling complications. For all these reasons, the HIV Infection Listings are in urgent need of reconsideration and revision.

IOM's recommendations involve doing away with the current HIV Listing and replacing it with groupings of health complications associated with disability in people living with HIV. A diagnosis of one disabling condition in one group will be needed to qualify, according to the IOM committee report. The report brings CD4 count back into the picture, specifically at or below 50. However, the report recommends this allowance be reviewed about every three years, to assess the magnitude and stability of the individual's response to antiretroviral treatment. By contrast, the committee found several HIV-induced diseases that warrant permanent disability. These diseases are severely disabling, have a high short-term mortality risk, and respond minimally to conventional treatment.

(continued on page 15)

# RECOMMENDED CHANGES TO DISABILITY QUALIFICATION FOR PWHAS

(continued from page 14)

Diseases to be considered imminently fatal include:

- · HIV-associated dementia
- · Multicentric Castleman's disease
- · Pulmonary Kaposi's sarcoma
- · Primary central nervous system lymphomas
- · Primary effusion lymphoma
- · Progressive multifocal leukoencephalopathy (PML)

Disability allowance is also recommended for other conditions with HIV infection or side effects of treatment. To qualify, however, applicants will need to prove that these conditions limit their ability to function in the workplace. Because recovery from these is possible with ARV, they should also be reviewed every 3 years. This list would include, but would not be limited to:

- Diarrhea
- Distal sensory polyneuropathy
- · HIV-associated neurocognitive disorders
- · HIV-associated wasting syndrome;
- · Kaposi's sarcoma
- · Lipoatrophy or lipohypertrophy
- · Osteoporosis

Many people living with HIV experience a higher rate or earlier onset of diseases that are grounds for disability claims using various non-HIV listings. In turn, the report stresses the importance of cross-referencing other medical not specific to PWHAs when reviewing applications. It suggests a review of procedures to reduce the risk of HIV+people dealing with non-HIV-related complications from falling through the cracks. Examples include:

- Cardiovascular disease
- · Chronic kidney disease, including HIV-associated nephropathy
- · Diabetes
- · Hepatitis
- · Malignancies, not otherwise specified in the report

Because qualifying for SSDI or SSI is required for PWHAs to access Medicare or Medicaid, some community advocates are concerned that a huge swath of future HIV+people will face tremendous hurdles getting the care they need, if SSA overhauls its HIV Infection Listing based on the IOM recommendations. Presently, Medicaid covers approximately one-third of PWAs, while Medicare covers another third of those infected with the virus.

The SSA review process is just beginning and it is unlikely that the agency will take action until 2012. There will be a public comment period and plenty of discussion between activists and agency officials in the meantime. The future story of SSDI and SSI for people living with HIV has yet to be written.

#### **VIP FOR HIV**

(continued from page 10)

realized that while this was way more intimate than my previous meeting with them, I still did not have much time. I watched as Amanda laid her head on my Brian's chest.

"You are so tired," he consoled her. I knew we needed to get out of their way and not abuse what they had just given us. As soon as I locked eyes with Amanda for a second time, I chimed in with my final words.

"There are a thousand things I want to say to you right now," I started off. "But if I could only pick one thing, it would be to tell you that I recently co-started an organization to connect young people living with HIV together back in Denver. We called the group 'Gravity' after your song."

Her jaw dropped as she did a double take to what I just told her. "Wow. That is amazing," Amanda said. "And that song... it is filled with so many emotions on your body just not working the right way or working against itself and people not understanding what it feels like."

I jumped at her words. "That is exactly what it feels like to have HIV." Tears began to fill my eyes. "And so much of your music has helped get through this experience. I know your songs are not about HIV but your lyrics are so relatable to the struggles in which one endures with it."

Brian Viglione overheard our conversation and made his way back over to us. "This is you?" he asked. "You are the guy from Denver?" "Yes," is the only thing I could say. Apparently their assistant had told them my story.

"It is such an honor to meet you" he said, grabbing my hand and shaking it. By this time, Amanda herself began to shed tears. As soon as Brian finished shaking my hand, Amanda wrapped herself around me and gave me a hug. It was not a simple hug. It was intimate moment I craved. She held me and I held her back. I had just told her my darkest story. I officially admitted that I was living with one of the scariest communicable diseases of all time. And she did not recoil from me. Amanda Palmer did not reject me. Instead, she embraced me; physically and emotionally.

"Let's take another picture," she suggested. I was more than willing. We both wiped our eyes trying to look like we hadn't shed any tears at all. She draped her hands around me and held me tight as we smiled together for the camera. We separated to bid farewell to one another. "Thank you so much," she said, again looking straight into my eyes.

I thanked her back as I beamed with smiles walking out of the room. We were the first of the VIPs to leave. But I also knew we were the best she would meet all night and perhaps for much of the tour. As I had hoped, The Dresden Dolls probably wouldn't ever forget me.

Afterwards I was a mix of emotions. I had just told my saddest story in one of my most amazing moments. HIV was the lowest low of my life. And it now led to one of the highest highs of my life.

Without HIV, I would not have been a VIP. I would not have been able to make such an impression with one of my favorite bands. How was I supposed to feel? I was not sure. However one thing was for certain: I would soon be crawling back into bed with my headphones on. But this time, I would be smiling instead of crying.



#### CALENDAR of EVENTS

#### **January**

- 2 (Sunday) 11am: SIN Brunch at Panera (13th & Grant)
- 4 (Tuesday) noon: DHRPC Rebuilt+ (PLWH) Committee (a)
- 6 (Thursday 10am-4pm: DHRPC Annual Retreat at Rita Bass (6th & Bannock)
- 11 (Tuesday) 6pm: Community Educat10nal Forum (special ADAP session) (b)
- 14 (Friday) 6pm: SIN Happy Hour upstairs at the Skylark (Broadway & Maple)
- 26 (Wednesday) 5:30pm: Denver Health CAB (c)
- 28 (Friday) 11:30am: University of Colorado CAB (d)

#### **February**

- 1 (Tuesday) noon: DHRPC Rebuilt+ (PLWH) Committee (a)
- 3 (Thursday) 5pm: DHRPC Meeting at 1437 Bannock St Rm 389
- 6 (Sunday) 11am: SIN Brunch at Panera (13th & Grant)
- 11 (Friday) 6pm: SIN Happy Hour at Skylark (Broadway & Maple)
- 15 (Tuesday) 6pm: Community Educat10nal Forum (b)
- 23 (Wednesday) 5:30pm: Denver Health CAB (c)
- 25 (Friday) 11:30am: University of Colorado CAB (d)

#### March

- 1 (Tuesday) noon: DHRPC Rebuilt+ (PLWH) Committee (a)
- 3 (Thursday) 5pm: DHRPC Meeting at 1437 Bannock St Rm 389
- 6 (Sunday) 11am: SIN Brunch at Panera (13th & Grant)
- 8 (Tuesday) 6pm: Community Educat10nal Forum (annual Tim Gill forum)
- 11 (Friday) 6pm: SIN Happy Hour at Skylark (Broadway & Maple)
- 23 (Wednesday) 5:30pm: Denver Health CAB (c)
- 25 (Friday) 11:30am: University of Colorado CAB (d)

CAB = Community Advisory Board SIN = Strength In Numbers Colorado DHRPC = Denver HIV Resources Planning Council (Ryan White funded services)

- (a) CNDC 4130 Tejon St Suite A (Maria 720.865.5503)
- (b) Our Saviors Community Room 9th & Emerson (enter on the side from Emerson)
- (c) Denver Health 6th & Bannock Rm 245 (Julia 303.602.8742)
- (d) U of C 12401 E 17th Rm 360 (nr Colfax & Peoria) (Maiki 303.724.0797)

If you have an event for the calendar, send to: michael@OnTheTen.org







#### EDUCATIONAL FORUM

#### "New Treatments in Hepatitis C"

Monday January 31 2011 \* 6-8 pm (free dinner) Swedish Medical Center \* 501 E Hampden RSVP required (by 1-26-11):

Laura 720.917.3960 or lginnett@hepc-connection.org

#### SUPPORT GROUPS

OnTheTEN Newsletter would like to post a listing of support groups in future issues.

Please send information on any support groups to: michael@OnTheTen.org or call 303.377.3127



7<sup>th</sup> Annual Poz Cruise

\* November 5-12, 2011 \*

A 7-night sailing from Ft Lauderdale aboard the "Crown Princess" calling at Aruba, Curacao, & Bahamas Rates start at \$726

More info: www.HIVcruise.com



visit www.gravitydenver.com