POSITIVE VOICES - January 2013

Your Newsletter by Positive People for Positive People

A New Year - Another Request :

This newsletter is for us, the clients of STAP, and is a forum for us to have our voices heard. Unfortunately, so few take the time to contribute "anything" to this newsletter. It makes me wonder if anyone out there really cares one way or the other if this newsletter was to continue ? Each month I battle to find something that might be interesting to print and that usually is something that would be an interest to me. I have helped "friends" write articles and pestered others to do the same. I have heard it said that we should have more events or activities, but how can these type of things happen when no one wants to participate or willing to submit ideas ?

Yes, I am frustrated that so many of us just sit on the sidelines and complain that more should be done. What is "it" that should be done for those who will not speak up? Has our community just given up? Every week I drive 40 miles each way to come to Binghamton to be part of the support group and Friends Dinner - because it means something to me to be part of this community. Why does it mean so little to others that they find no reason to try? I bring this up because it is crossing my mind to "retire" from these newsletter duties and leave it up to someone else (or should I say no one else). I can put my time and effort to better use and give of myself to those friends who are willing to give back, instead of being disappointed each month that no one has made an effort to contribute to this newsletter.

**Update: "New" Retreat/Camping Weekend has been offered.

One of the churches that attends our Friends Dinner became aware of how our yearly "Sky Lake" retreat had come to an end. They have the ability to offer us a weekend camping trip (tent camping) at their place in Windsor.(* This is not a S.T.A.P. event, some things will be different.) They will have a Nurse for us, just like all the other times. Details are being worked out. The dates would be June 28/29/30 (Friday @ 3pm → Sunday @ 12noon) and they need to have a "headcount" no later than March 2013. Vickie Trayes # 607-669-4039 for additional information or any questions

R.S.V.P. Vickie with your interest to attend A.S.A.P.

Updates will be available and posted in the newsletter until the March deadline, after - only those attending will get updates.

<u>I thought of you</u>

I thought of you today, but that is nothing new.
I thought about you yesterday, and days before that too.
I think of you in silence, I often speak your name.
All I have are memories and a picture in a frame.
Your memory is a keepsake, from which I'll never part.
God has you in his arms, I have you in my heart.

Gay men, HIV and Stigma

By David Fawcett PHD,LCSW

Positively Aware, December 2012

When John failed to arrive for his psychotherapy session, I became concerned. He had been living with HIV for years and had always been responsible with appointments, medications, and self care. A call to his roommate revealed he hadn't arrived home the night before, and after several worrisome days, he was found in a hospital in another county. He had become disoriented while driving and had run his car off the road.

Medical tests were troubling: John was diagnosed with HIV encephalopathy complicated by hepatitis. His cognitive processes were in decline and, alone and unable to care for himself, John was placed in a nursing home to begin what would sadly be his final months. After a lifetime of effectively combating discrimination, John's last days were filled with gay and HIV-related stigma. At 42, he clearly stood out from the other geriatric residents. He ate by himself and interacted with no one. His own frailty prevented him from reaching out. While other residents were unaware of his diagnosis, staff certainly knew but were unaccustomed to HIV/AIDS. Some refused to touch John or provide any care at all. Others confronted him directly, stating that, as a gay man, he got what he deserved, while others went out of their way to whisper their hateful words. Complaints to the facility administrators resulted in reprimands and a brief training event, but nothing significantly changed. In his final months, John was driven back into the closet under the crushing weight of stigma.

This is not a scenario from the early years of the AIDS epidemic. Unfortunately, this occurred recently and is just one representation of a broad range of stigmatizing attitudes and behaviors that impact both the growth and trajectory of the HIV epidemic. Despite campaigns to address it, there continues to be no safe refuge from

stigma and in fact, in some ways the situation is deteriorating. Societal attitudes actually appear to be backsliding, a growing divide is separating negative and positive gay men, and the critical chatter of self-talk and self-judgment keeps the pain of stigma alive among those living with the virus.

Damaged goods

The concept of stigma became prominent with research in the 1960s by Irving Goffman who studied prisoners, mental health patients, and homosexuals. He found that stigma sprang from a perceived violation of shared attitudes, beliefs, and values, and that societal power was very much entwined with these beliefs and resulting discrimination. When certain attributes are deemed to be negative (such as HIV status, homosexuality, or substance abuse), the individuals who have those characteristics become deeply discredited and, in Goffman's words, are reduced "from a whole and usual person to a tainted, discounted one." This difference, or deviance, results in what he called a "spoiled identity" and which many of my gay, HIV-positive clients describe, with great personal pain, as the distinct feeling of being "damaged goods."

Stigma is often conceptualized as having two expressions: enacted versus felt stigma. When enacted by others, stigma results in very real discrimination which can be described as unfair treatment based simply on someone belonging to a particular group or having a certain attribute such as HIV. Enacted stigma can take the form of silence or rejection, as well as verbal or even physical abuse.

Felt or perceived stigma, on the other hand, is the real or imagined fear of societal attitudes. It is more insidious because it is, literally, an inside job and is rooted in shame, the deep belief that one is significantly and irreparably flawed. It often results in self-imposed discrimination, a defensive choice to act as if stigma has already been expressed. Many HIV-positive men, for example, won't date so to avoid the painful consequences of stigma or disclosure because of potential rejection.

As gay men, we are bombarded from an early age with negative messages that there is something wrong with us. This disconnects our internal feelings from our external presentation, and leads inevitably to the challenge of discovering our "authentic self." (This process and its healing are wonderfully described in Alan Downs' The Velvet Rage). Such a deep well of shame creates a fertile breeding ground for felt stigma, where the very real danger of discrimination fuses with one's internal negative beliefs, resulting in a destructive, self-sustaining pattern.

The experience of stigma for gay men is often compounded because they have multiple characteristics that are devalued by society: they may be gay, substance abusers, HIV-positive, and disabled. Some are sex workers, some have a diagnosed

mental illness such as depression, and others may be homeless. There are hierarchies among these stigmatized attributes. For example, many of my clients who have lived with HIV for many years are judgmental of those who are newly infected ("How could they be so stupid? When I was infected we didn't know any better."). Others remember when it was common to distinguish between the "innocent victims of AIDS" (acquired through transfusion) versus the not-so-innocent ones (those who must have been recklessly promiscuous).

Impact of stigma

Stigma extracts a heavy price not just on those unlucky enough to experience it, but on the shape of the epidemic itself. It impacts access to prevention, testing, and care. One's willingness (or not) to be tested for HIV is driven by stigma, which accounts for at least a portion of the estimated 20% of people living with the virus who don't know their status. Stigma-driven fears about being seen entering a testing site keep many away and even with their trusted physicians and health care providers, many people refuse to discuss high-risk sexual behavior that might have resulted in a health concern.

For others, there is the belief that HIV is someone else's problem, which can lead to dangerously high levels of the virus in a given community. This attitude occurs among both individuals and professionals. Many groups employ a denial mechanism, fueled by stigma, that blinds them to their own risks. A recent study found that black MSM (men who have sex with men) are less likely to use a condom with a man who appears very masculine because of a false assumption that such a man couldn't be HIV-positive. Many men continue to engage in high-risk sex because their partner looks healthy, while believing that those who don't appear healthy must have HIV.

These attitudes exist among professionals as well. When I recently conducted a training for 50 mental health workers in a major city with one of the nation's highest incidences of HIV, I asked how many had clients affected by HIV and only a few hands were raised. That itself is a form of stigma ("my clients or their family members couldn't have HIV...") since every one of them no doubt had clients directly affected by HIV. Their denial, discomfort, or prejudice was contributing to the shame and stigma of someone at risk for, or living with, HIV, as well as the quality of their professional care.

Stigma has a direct impact on risk behavior. Because of it, people are far less likely to disclose their serostatus. Many gay men have sex without any discussion of HIV, and, ironically, if someone does disclose, they are often rejected. One client, when creating a profile on a social dating site, noted that he was HIV-positive. An obviously attractive man, he was astonished to receive only one response in a period of months. He counted roughly 60 profiles of other gay men in the city, only two of

whom disclosed a positive status (a location where it is estimated that 30–40% of the gay men are HIV-positive). The shadow of stigma was present, evident more in what was not stated rather than what was directly expressed.

For those living with physical signs of HIV, such as lipoatrophy (loss of fat in the face, limbs, and buttocks), the impact of stigma can be unavoidable. Others with no outward signs find it easier to "pass," but often become highly attuned to any sign of judgment from others, a process which soon becomes internalized and develops into "felt stigma."

Whether one can "pass" or not, stigma impacts the health of those living with the virus in a number of ways. The perpetual experience of external and internal judgment and shame contributes to chronic stress, which has direct physical consequences. Stigma impacts medication adherence, as well. Many people won't take their meds in situations with a high potential for stigma, such as a dinner out with colleagues, visiting relatives who make uncomfortable inquiries, or a date with someone who doesn't yet know one's serostatus.

Gay-on-gay stigma

Our community has never been without internal divisions and social hierarchies. Many gay men come out expecting to find, at last, acceptance among their peers. Instead, many find a divided subculture rife with cliques and judgments. Now, a more ominous trend is evolving within the gay community: overt stigmatizing of HIV-positive gay men by other gay men.

Over the duration of the epidemic, many services have evolved for people living with the virus. For several years, I have heard increasingly vocal complaints from negative men about the abundance of such resources available to HIV-positive men. Fueled by growing stigma, these have recently developed into divisive stereotypes which are reminiscent of the "welfare queen" dialog (in which people are believed to exploit programs and services). They include beliefs that men become HIV-positive simply to enjoy the benefits and spend the day at the beach, or that gay men on disability all drive expensive cars, or that being gay and positive means all the steroids you want and lots of free time for the gym.

The notion of someone on disability and medications living the carefree good life is, of course, ludicrous. There are a minority of people who exploit services, but the great majority display a remarkable resilience which is devalued by such comments. Stereotypes further stigmatize those living with the virus and divide the community.

Evidence of this division among gay men can be seen in the stigmatizing short-hand of profiles on sexual networking sites, and it's not just limited to positive or

negative. “Drug and disease free—UB 2.” “Masc only.” “No fats, no femmes.” Some people attempt to temper this harshness by adding “just a preference.” While it is true that everyone has their own sexual template and the right to express themselves sexually with whomever they want, very real harm results from such dismissive comments that reinforce both stigma and the gulf between gay men. I was pleased to see one man address these comments with his own, empowering declaration: “HIV-positive and intend to stay that way!”

There are few quantitative data documenting this rift within the gay community, but most people feel it. One organization, men2mencollective.com, is researching this in Europe and Canada. I recently asked the HIV-negative men in a group I lead if they had HIV-positive men within their close social circle. Few hands were raised. I have had the same response with groups of positive men. Very often the majority of their close acquaintances are also positive. It is natural for men to socialize based on affinity. Someone who has been diagnosed with HIV, has disclosed to family and friends with varying consequences, has been taking medication with all the side effects, and perhaps experienced an opportunistic infection, will have a natural alliance with others who share these experiences. They also share the bond of stigma, discrimination, and its consequences, resulting in the tendency to limit social interaction. Many gay men living with HIV utilize substances or behaviors to numb painful feelings brought on by stigma, and they are at much higher risk for addictions, mental disorders, and even suicide. Drugs such as methamphetamine have a particularly dangerous appeal, despite devastating consequences, because they temporarily soothe the effects of stigma: low mood, lack of energy, feeling disconnected, isolated, and sexually unattractive. Stigma creates a perfect storm for those who feel like “damaged goods” to seek a way to numb these feelings. Chemicals are not the only negative coping mechanism. Behaviors such as sexual compulsivity also create a numbing effect while pushing the individual toward even greater isolation and despair. Some men attempt to reclaim their power by embracing the very taboo identities that are used to stigmatize them, such as “barebackers” or “slammers.” While this creates a sense of belonging and identity, it also perpetuates higher risk behaviors and, ultimately, stigma itself.

Coping with stigma

The effectiveness of programs or activities to combat HIV-related stigma is still largely unknown. Most involve change at a personal level, directed either at the person experiencing stigma or the individual perpetrating it. For those who experience stigma, interventions include modifying their critical, internal dialogue of self-doubt as well as their negative assumptions. Programs designed to increase awareness among those who stigmatize have had some benefit, the most powerful being combination approaches. For example, the impact of an HIV-positive speaker

“humanizing” HIV is enhanced when followed by an educational component clarifying misconceptions about the virus. Unfortunately, few programs address the structural sources of stigma expressed in laws, policies, and institutional discrimination.

Positive coping strategies which move an individual toward healthy empowerment are the most effective tools to address stigma. These involve a variety of methods aimed at reclaiming a healthy sense of self, a feeling of personal power, a shared identity with others, and a solid sense of self-acceptance in the face of painful stigma and discrimination. These range from dealing with specific interpersonal situations to confronting institutional power that enacts, legislates, and perpetuates stigma. Here are a few:

Join a group: The act of uniting with others living with HIV is a powerful way to learn self-acceptance and trust. Drawing on their power provides a mirror for one’s own struggles and creates a rich resource of wisdom and support that is invaluable when confronting stigma.

Commit to counseling: Every individual has great healing potential, but everyone, at times, needs guidance. Jung described the concept of shadows, those parts of ourselves which are too painful or too unpleasant to acknowledge. Sometimes we handle them by projecting them onto others, such as when someone who has made hateful, stigmatizing pronouncements about gay men is revealed to be struggling with his own gay identity. Each of us has shadows that make us vulnerable to stigma and fuel our potential to stigmatize others. Therapy greatly enhances the healing process, whether it be trauma, limited self-acceptance, or any situation or belief that is causing emotional distress.

Connect to others: HIV/AIDS frequently results in profound isolation. Whether related to shame, side effects of medication, energy level, or any number of other concerns, people living with HIV/AIDS can become disconnected from others, thus increasing their vulnerability to stigma as well as limiting their potential to help others. Sometimes these connections are structured (such as “joining a group” mentioned above), but those which are informal are equally valuable. Making a phone call, reaching out to someone in need, or simply having a casual conversation with a friend about nothing in particular can be profoundly healing and grounding.

Help others: Most of the services for people living with HIV/AIDS were initially created by individuals taking personal action, not by institutions. The ability to put compassion into action is the basis of countless lifesaving efforts. Personal emotional healing results from assisting someone else. It pulls you out of your own concerns and transforms your struggles and pain into a useful tool both for you and others.

Educate: Stigma about HIV, homosexuality, mental illness, or countless other

attributes is fueled by ignorance. People fear what they do not understand and, despite 30 years of crisis, the level of ignorance about HIV is astounding. According to the Washington Post/Kaiser Family Foundation 2012 Survey of Americans on HIV/AIDS, people are somewhat more comfortable interacting with coworkers who have HIV/AIDS (up from 32% in 1997 to nearly 50%), yet 25% of Americans do not know HIV cannot be transmitted by sharing a drinking glass, almost the same as 1987.

Learn from others: Chances are high that someone else has already faced your challenges. There are many people who share your experience and who can serve as role models. When such people are not geographically close, the Internet can be an effective resource for communication. Connect with others living with the virus—it will help you all heal.

Advocate: Finally, every person living with HIV/AIDS needs to challenge institutional structures that promulgate stigma. There are increasing and disturbing efforts to criminalize HIV, funding for essential services is in peril, and new waves of intolerance are rolling across the country. Stay informed, vote knowledgeably, and increase your advocacy.

Stigma is powerful, painful, and often confusing because it resonates with our own internal fears. Overcoming it takes persistence, courage, a strong sense of self, and a willingness to work with others. Don't succumb to the false belief that you are "damaged goods," but rather expose your shadows, reclaim your power, and reach out to others making this journey with you.

DAVID FAWCETT is a psychotherapist and clinical hypnotherapist in private practice in Fort Lauderdale, Florida. He is active in the gay men's health movement, writes regularly for TheBody.com, and is a national trainer for the National Association of Social Workers' "HIV Spectrum Project".

FREE LAWYER? GOT IT!

Have you had the opportunity to meet Rob Lukow or Lyndsey McKinstry of the AIDS Law Project at Legal Services of Central New York (LSCNY) out of Syracuse? If not, you will have many more chances in the future! Beginning in November, the AIDS Law Project will host a regular schedule of clinic hours at STAP offices in Johnson City and Ithaca. To qualify for this free legal service you must be HIV+ or an individual with AIDS. Sign-up sheets will be provided at STAP locations for you to schedule to see an attorney during the clinic hours. You may bring any legal question or problem that you have to the attorneys, and they will do their best to help you. For further information, contact Stacy Nickerson at STAP, 607-798-1706, or Rob Lukow at LSCNY, 315-703-6529.

ON GOING MEETINGS AND COMMUNITY SERVICES

Join/ Attend: Consumer Advisory Committee [CAC] Meetings

The STAP Consumer Advisory Committee is a committee facilitated by and made up of STAP clients who welcome other consumers and their significant others, caretakers and family to join them at any Friends Dinner; the floor is open so concerns can be addressed as soon as possible. This collaborative effort provides a confidential space for clients to make recommendations regarding STAP services in a non-judgmental environment. The meetings are held during the Friends Dinner, Tuesdays @ 5:45 at Trinity Memorial Church (corner of Main St & Oak St) in downtown Binghamton. Call 1-800-333-0892 for directions or details. If you cannot attend, mail suggestions to STAP, 122 Baldwin St, Johnson City, NY 13790, Attention: CAC. CAC encourages consumers in other counties to organize meetings in their area.

Friends Who Care Support Groups

Broome County: "Friends Who Care" meets every Tuesday at 3 pm - 4:30/5:00 pm at Trinity Memorial Church located at 44 Main St. in Binghamton… Come join us for Binghamton's HIV/AIDS Support Group *(open to clients only). Also stay for a good (free) meal afterwards at the "Friends Dinner".

This group of Friends started up 4 years ago when we were unhappy with the "canned" therapy we were getting at our local mental health. Trinity came to our rescue and allowed us to hold our meetings prior to the Friends Dinners on Tuesdays. The bonds we have formed over time have us calling each other "family" - this is truly a "support group". We consider ourselves "Lucky" to be part of something so special. New members are welcome.

Chemung County: Men Living with HIV Support Group; 2nd Monday of each month; 6-7:30pm; Ivy Clinic, 600 Ivy St., Suite 206, Elmira. For more information people can contact: Lynn Bassler, LMSW Treatment Adherence Counselor, Ivy Clinic, 737-8188.

Tompkins County: The Ivy Clinic is pleased to let all HIV+ men in the Ithaca area know there is a support group that is held the 3rd Tues every month at Ithaca STAP office. Time for the group is 6-7:30 pm and topics vary. If you are interested in attending please e-mail Shannon Sprague at ssprague@aomc.org for information.

REMEMBER THAT TAX TIME IS COMING – DO YOU NEED YOUR TAXES DONE?

STAP has a volunteer that has offered to assist clients with completing their tax returns. If you are interested, please contact Candace for more information and she will get you in touch with Cynthia. Candace can be reached at **800-333-0892 x225**.

Friends Dinner

"Friends" meet every Tuesday for a time of fellowship and food. Join us at Trinity Memorial Church (corner of Main & Oak St. - across from the High School) in Binghamton. Doors open at 5PM and dinner is served @ 5:30. No charge, just come with a smile and a friendly attitude – ready to meet friends and have a hearty meal. Parking is on Oak St. behind the Church Annex. Use the Oak St. entrance for the cafeteria. Call your case manager for info. Free bus passes available for transportation to/from the dinner (STAP clients only). For more info about the "Friends Dinner", call STAP and they will get you in touch with Bill.

Free Anonymous Rapid HIV Testing

Walk-in *Anonymous* testing is available in the STAP Johnson City office Mondays from 1:00-4:30PM and Thursdays from 1:00-3:00PM. *Confidential* testing is available in the Johnson City office Thursdays from 9:00AM - 12:00PM at 122 Baldwin Street, Johnson City, NY 13790. Walk-in *Anonymous* Testing is also available Tuesdays from 9:00AM-11:30AM, and *confidential* testing is Thursdays, 9:00AM-11:30AM at STAP's Ithaca office located at 501 S. Meadow Street, Ithaca, NY. For more information and other testing opportunities available throughout the month, please call (607)798-1706.

Free EDUCATIONAL Lunch: January 2013.

* There is NO lunch for the month of January. February's lunch date is still being determined. From this point on, all these "lunches" will be held at Grandes' on Vestal Ave. If anyone is unsure where this is - Martha will help with that….

* As usual seating is limited (you & a guest only) and must be reserved with Martha at least a week before the event. *R.S.V.P. - Martha # 607-644-7586*.

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

** Please turn off your cell phones / important calls? Vibrate!

Leave the room if you take the call.

Get your flu shot now. If you're not due to see the doctor this month - call to make an appointment, be pro-active when it comes to your health!

Ask the Medical Advocate

C.H.O.I.C.E.S. is a self-paced educational series done with the Medical Advocates, designed for YOU to understand HIV and your body. Take one course or decide to go through the entire program and take charge of YOUR HIV today!

Medical Advocates: **Stacy** (607) 798-1706 Ext. 210 & **Autumn** (607) 426-9445

* Every 3rd Tuesday of the month at 4:30 pm - Come join us for our monthly educational program (open to everyone). We have found that we get more from the program when we learn as a group. Informative questions and discussions are raised.

Medical News

Dec 18, 2012 - Potent Antibodies Neutralize HIV and Could Offer New Therapy

Researchers at Rockefeller University, New York, appear to have found another approach to treating HIV infection. They have shown that it is possible to harness proteins from the human immune system to suppress the virus in mice without the need for daily application as is done with current antiretroviral drugs. Using a combination of five different antibodies, Florian Klein and colleagues at Michel Nussenzweig's Laboratory of Molecular Immunology were able to effectively suppress HIV-1 replication and prevent the virus for 60 days after termination of therapy. They used "humanized mice" as normal mice do not have the receptors to be infected with HIV-1. HIV-1 evades the human immune system's attacks by mutating; but with the combination of the new antibodies, mutation did not work. The antibodies target HIV-1's surface protein, gp160, a molecule that forms a spike that attaches to host cells. Five antibodies in unison were required to stop gp160. The five antibodies were too complicated for gp160 to mutate in time to avoid them. The antibodies, called broadly neutralizing antibodies, were recently discovered. They were identified and cloned from HIV-infected patients whose immune systems had an unusually high ability to neutralize HIV. These antibodies have been able to prevent HIV from infecting non-human primates, which leads to a possibility of a vaccine for humans. However, it was felt that they would have little or no effect on established infections. Klein stated that the results are encouraging enough to prompt an investigation of these antibodies in clinical trials. He surmised that a combination of antibodies and antiretroviral therapy may lead to a treatment for humans that will not require daily medication.

The study, "HIV Therapy by a Combination of Broadly Neutralizing Antibodies in Humanized Mice," was published in the journal *Nature*. *Excerpted from: Science Daily 12.10.2012*. Article provided by U.S. Centers for Disease Control & Prevention. It is a part of the publication *CDC HIV/Hepatitis/STD/TB Prevention News Update*.