



THE POSITIVE QUARTERLY

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Graphics by Dan Kaufman Graphics (copyright 1996). Battle data from "The Defense Almanac" by the American Forces Information Services. AIDS data from the Centers for Disease Control. LATEST UPDATED AIDS MORTALITY STATISTICS FROM CDC THROUGH DECEMBER, 2000: 448,060 DEATHS.

Country at War Must Focus on Home Front

The theme for this year's World AIDS Day activities, "I Care—Do You?" captures my thoughts when I decided to withdraw from many social and civil rights activist activities earlier this year. This decision was made for many reasons—primarily because of my perception that I was spreading myself too thin (graduate school, GLBT equal rights, etc.) and that AIDS work requires paramount attention from those of us who consider ourselves to be AIDS activists. This decision to focus on AIDS activism is even more critical now that our country is at war.

As horrific as the attack on the World Trade Center was, I cannot help but wonder how many of those individuals who perished were living with HIV disease. New York City has one of the highest rates of HIV infection in the country. Therefore, it is easy to surmise that the HIV community was directly impacted by this tragedy. In considering the multiple challenges of living with HIV, maintaining hope, juggling medication schedules, HIV related stigma, and the amount of determination required to get on with life, it makes their deaths just that much more tragic. I am in no way implying that these individuals were more unique or special because of their HIV positive status; however, the futility of their lives lost due to the intersections of fate and hope must be recognized.

I am unable to recall the specific statistics of lives lost in prior wars, but I do recall reading that HIV disease has claimed more lives in the last twenty years than any of the wars fought within the twentieth century. Therefore it is incumbent that those of us involved in the war against HIV/AIDS make it our priority to not let our war get lost in the rhetoric of the war on terrorism. America has an annual HIV infection rate of about 40,000 new cases. These new cases of HIV disease are increasingly located in our nation's most vulnerable communities (communities of color, young men who have sex with men, and female partners of men who engage in behaviors that place them at risk). Now is not the time to retreat from the war on AIDS.

Funding levels for HIV/AIDS care and prevention must increase where critically indicated, and in no way should AIDS activists allow governmental funding to be held hostage to support the war effort. My prayers and condolences go out to all of those directly impacted by the September 11 terrorist attacks. I honor the patriotic responses from my fellow Americans in this time of crisis. However, I take this opportunity to emphatically remind my peers that there is still an AIDS crisis globally. Live the words of the World AIDS Day organizers, "I Care—Do You?" Show that you care by recommitting to AIDS activism... show that you care by acting on an opportunity to prevent further spread of this disease... show that you care by not shrinking away from this battle...show that you care by charging onward UNTIL THERE'S A CURE!

Pos Hetero Summit Disproves Stereotypes

But conference that targets fastest growing HIV-positive population is losing sponsors, in danger of being discontinued

By **BARB GARRISON**
Task Force Membership and Management/
Policies & Procedures Chair

On August 8, 2001, I left for an adventure by myself that I thought would bring me knowledge and, yes, even friendships. Where did I go? I went to Atlantic City, New Jersey, for what is called the Pos Hetero Summit! I must say that the three day summit, which helps to unite HIV-positive heterosexuals across the nation, was unlike any retreat or conference that I have ever attended.

It has been the mission of the internet website www.Heterochat.org to connect, unite, educate and empower HIV-positive heterosexuals across the nation. Heterochat and the Pos Hetero Summit are run entirely by volunteer HIV-positive heterosexuals.

They work hard to provide their peers with an interactive web-site and chat room. Soon they will open a web-based confidential server which will provide free emails and web-sites for HIV-positive heterosexuals who have internet access. [This server, PosHetero.net, was scheduled to premier in October. It was not yet accessible at the time of publication. -Ed.] They also provide the community based conference called the Pos Hetero Summit, which I attended this year.

Historically, heterosexuals are an invisible and under-funded population in our world of HIV/AIDS. It is a constant battle for all AIDS organizations to acquire funding, but it is especially difficult for heterosexuals, because we symbolize what many consider to be an "unseen" population. Heterosexuals are not present in large numbers at AIDS walks or HIV training conferences, or at other public events. We don't have heterosexual-specific support groups at our local AIDS organizations. We aren't sitting at HIV community planning groups or Ryan White consortia, and on and on...As a result, many believe we do not exist and will not fund something they cannot see.

When we do gather 400 strong of this unseen population together, as we did the weekend of the Pos Hetero Summit, it is quite a wonder, and you'd think our funders would be happy.

At past Hetero summits I was told that their funders and their speakers have seen very few of the 400 or more attendees in the ses-

sions and in the exhibit hall. As a result they are steadily losing funding and support, and the summits won't last much longer. Dollar for dollar, if funders receive more attention at gay events than at heterosexual events, then that is where they will choose to spend their money, and once again heterosexuals will be left underserved.

Truthfully, the gay communities are great at raising and fighting for money, but hey—they are also great at showing their appreciation. This was very evident to me, since this year the Pos Hetero Summit only had four sponsors as compared to last year's ten sponsors.

This summit was extremely enlightening. I was able to see 399 other individuals who were heterosexual and in one place at one time. I listened to them and learned what they are accomplishing in their own communities. I found out that we have all experienced the same treatment, since most of us—if not all of us—have felt like outcasts because we do not fit the stereotype that most people believe concerning exactly what a person with HIV/AIDS should look like or act like.

Heterosexuals are lost in the system, and yet heterosexual women comprise the fastest growing population of persons converting to positive HIV status. It is my hope that funding continues to support this worthwhile experience.



What A Difference a Day Makes

In early September, I was putting the final touches on a press release that would formally introduce the Task Force to television, radio and print media throughout the state of Michigan. Our thought was to publicly sign on to the National Call to Commitment Day, an action orchestrated by a coalition of national, regional and local organizations to participate in a mass phone calling on October 1 to members of Congress in support of adequate funding levels for the Ryan White CARE Act. It would be the perfect vehicle for the Task Force to present itself to the public as a viable entity worthy of attention.

Then came September 11. After assimilating a day of shock, horror, and numbness, I took stock and asked myself, "What does this mean for HIV/AIDS funding? How can we effectively advocate for increased funding during such chaos?" I sent emails and made phone calls to the National Association of People with AIDS and AIDS Action, two Washington DC organizations who I have worked with in the past. Their response was that they had to rethink strategy and would keep me informed. When they did, the decision was to place the October 1st action on hold, with the belief that it would be "insensitive to so many who have lost so much to pursue the planned action." It was unknown when the attention of Congress and the country would be capable of returning to routine matters.

It didn't take me long to rethink this strategy. When President Bush urged Americans to get on with their lives, to not let the terrorists change our way of living, that meant to me that we also must not downplay the HIV/AIDS pandemic any more than we can let any other social cause be dismissed because of sudden global concerns. These problems will not go away and our country must attend to them regardless.

Thankfully, new strategies emerged. Communication from Congressional staffers assured DC organizers that it was "important and appropriate to move ahead with action in support of increased federal AIDS funding." The splashy media blitz was replaced by a methodical email communication that targeted specific calls to the House of Representatives and Senate at critical moments. Hopefully many of our readers received those email action alerts, and responded in kind with phone calls to senators and representatives.

As of this writing, final approved levels for the Ryan White CARE Act remain unclear. The House of Representatives approved higher amounts than the Senate, but negotiations to work out a compromise remain uncompleted. A flurry of ridiculous and inappropriate amendments were successfully stopped.

Repercussions from the terrorist attack will undoubtedly adversely affect HIV/AIDS philanthropic contributions for years to come. Matt Sharp, writing for the Bay Area Reporter (10-4-01) wisely noted that "There is great concern about the future of AIDS and how the government and public will respond in wartime...Government HIV research efforts will most certainly be affected if the National Institutes of Health begins prioritizing funds for research into the threat of biological warfare."

Charities raised half a billion dollars for victims and their families in two weeks. The telethon presented by the entertainment industry raised over \$150 million in a mere two hours. The government has committed \$40 billion to disaster relief.

While it is phenomenal that private and governmental sectors of our country produce such free-flowing amounts of cold hard cash in response to the horrific deaths of 6000 people in the most brazen attack on civilization in modern history, one wonders where all this money has been hiding until now. It makes having to negotiate over the mere \$277 million increase needed to adequately fund the Ryan White CARE Act seem ludicrous and insulting.

Let's hope this national tragedy shocks us enough to make us recognize that serious needs will continue to be unmet in many sectors of our society, and not just when the sky has fallen on our heads.

Hats off to Task Force member Jim Baker who walked, bicycled and skated 125 miles from his Manistee County home to Grand Rapids for the annual Grand Rapids AIDS Walk. His effort brought attention to the lack of prevention in the smaller counties and rural areas that are largely overlooked. Rural HIV patients must travel 50 to 200 miles for treatment, Baker said. Such innovative and creative efforts are what is needed to bring attention to the cause!

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Success of a Community-Driven Needs Assessment Helps Set New Standards

By BILL QUINN

There seemed to be some glaring needs in Region 6, particularly when it came to African Americans and women's issues. To identify and address these problems, a series of community forums were held during the summer of 2000. With the guidance of the Michigan Department of Community Health, and particularly Laura Anderson, technical assistance coordinator of care consortia, five community forums took place in various locations in the region. They consisted of two each for African Americans and women, and one for youth. These gatherings of the infected and affected communities provided valuable information, which could be used to guide and direct this "consumer driven" needs assessment.

"We got some clear messages about needs being under served," stated Ricardo Bowden, past chair of Region 6 and the community forums facilitator. "They felt isolated, undereducated about HIV care, without support, mistrust of case management agencies as well as a misunderstanding of the roles of case managers," he added.

During the fall of a 2000 consortium meeting facilitated by Laura Anderson, a "Needs Prioritization" took place to determine how to allocate funds to address those issues. The clear message that was received from the needs assessment was to address PWA empowerment and education (as it related to HIV) and case management education (as it pertained to cultural and diversity differences). To ensure that this would happen, a line item was developed in the Region 6 budget.

The next step was to allow the consortium to plan and implement programs to address these issues. By taking it out of case management agencies' hands, it would not get lost in the day-to-day responsibilities of their duties. An ad hoc education committee was created and spearheaded by Mindy Beecher from Your Center of Flint, Michigan. The following programs or projects occurred as a direct result of the new committee.

1) **Navigator to Pilot**, a treatment adherence advocacy program that was geared to increase the efficacy of case managers (as it applied to client medication adherence). It

was through the help of Agouron Pharmaceuticals that this adherence management program was a success.

- 2) **More Power to Ya**, a retreat for PLWH/As. It was the first time that a retreat of this nature was held in this region, covering topics such as self-improvement and medical education, as well as providing a panel of PLWH/As and motivational speakers. It was well received based upon post-event surveys and summary discussion among participants.
- 3) **Cultural Diversity**, a workshop facilitated by Anita Bowden, director of education and training for Planned Parenthood of East Central Michigan in Flint. This training focused on diversity as it applies to women, people of color, case managers and anybody involved with HIV care.
- 4) **Bay Area Social Intervention Services, Inc.** (BASIS, Inc.) developed a survey and from this tool, a functional support group was created, where none previously existed.

"Because of the attention brought by this process, there was collaboration among pharmaceutical companies, area physicians, consumers, and other health care professionals," according to Bowden.

"Looking forward to 2002, we anticipate keeping that line item in place for further education and another

PLWH/A retreat. We are also in the beginning stages of planning an "Ask the Doctor" series of interactive sessions with a group of physicians from the Flint area to further educate the community at large, and particularly PLWH/As," Bowden concluded.

The success of this collaborative and imaginative endeavor exemplifies what a responsible regional network can accomplish if it wishes to truly serve the needs of the clients it has vowed to serve. Region 6 will hopefully continue to build on their success and prove to be a model for the rest of the state.

In early October a USFDA advisory panel endorsed a new HIV-fighting drug that promises to work effectively in those patients who have exhausted other treatment options. Reuters News Agency reports that Viread (tenofovir), introduced by Gilead Sciences Inc., would be the first drug approved in a class of drugs known as nucleotides, which are chemically similar to nucleosides. Differences occurred on the panel over whether to approve Viread for treating any adult with HIV or to restrict it to those who have failed other regimens. Regardless of these recommendations, doctors would be free to prescribe it for any patient once it was on the market.

An unfortunate accident, incompetent legal counsel, inevitable jail sentence, a false positive drug test, questionable medical attention, and a right-wing religious zealot all seem to converge in an attempt to break the will of this courageous couple...and they fight every step of the way while also battling HIV/AIDS. So you think you have problems?

Justice proves hard fight for Michigan couple

by GARY KARCH

Songwriter Steve Schalchlin has amassed a following of devoted fans who see his life as an example of how a person with AIDS can recapture their will to live simply by concentrating on what they hold near and dear.

Steve was weary from fighting AIDS when his longtime partner urged him to redirect his depression into song and story. The result was a small musical called *The Last Session* that ran off-off-Broadway, then off-Broadway, and finally had its West Coast premiere where it garnered several awards, including the LA Drama Critics Circle Award for Best Writing in 1999.

Its story line of a person with AIDS orchestrating his own suicide and being confronted with an enthusiastic born-again Christian, with a mission for conversion and repentance, strikes true to those who have experienced similar situations.

Devoted fans of Schalchlin's work find solace and friendship on his website, and keep up with this artist's life by logging onto his on-line diary, *Living in the Bonus Round*.

DJ, a Michigan resident, and Nick, from Florida, met on the Internet through Schalchlin's web site October 8, 2000 and immediately their personalities clicked. On November 15, DJ flew to Florida, where the couple poured out their hearts and then exchanged vows on the beach. Nick moved to Michigan on December 20. Yes, it really did happen that fast!

But no storybook honeymoon was in store for this couple. DJ had been involved in a horrible automobile accident three months prior to meeting Nick on the Internet. DJ was to be put on trial for manslaughter of an eight year old boy.

And what about the storyline of *The Last Session*,

Editor's note: All names have been changed to protect confidentiality.

where the lead character is confronted by a Christian with an agenda to convert the sinful gay gone astray? They would soon meet up close and personal with their own version of that character.

Complicating the whole situation was the possibility that the accident might have been caused by DJ's doctor's inappropriate administration of prescription medicine, lack of supervision of his reaction to that medicine



and not warning him about side effects.

As Nick tells it, "Danny was given Topral, a beta-blocker, in order to slow down his heart rate which was elevated due to the hyper functioning thyroid and Graves Disease. That drug can cause lots of problems and no warning was given to DJ regarding his driving and using that medicine.

Also, since he had taken a radiation pill which was

supposed to destroy the thyroid in about eight weeks, he needed to be supervised with routine thyroid panels, which did not take place.

After about six to eight weeks, he was still taking Toprol to reduce his heart rate, and by that time his thyroid was almost all gone, meaning that all that excess thyroid hormone he once had was replaced by a total absence of the hormone. By then, DJ should have been prescribed thyroid hormones to help him function properly, but due to not having proper levels of thyroid hormone in his blood and the Toprol which causes drowsiness and disorientation, Danny ended up collapsing behind the wheel and being involved in the accident.”

As luck would not have it, DJ ended up with a lousy lawyer who even the prosecuting attorney and judge agreed did not adequately defend DJ. It would be too hard to convince a jury to understand an argument for the drug interaction causation. He was urged to plea down to involuntary manslaughter.

First time offense, no criminal record, employed as a medical technician, DJ was a prime candidate for work release. The only problem was that his driver’s license had been suspended. His partner Nick would drive him almost 60 miles to and from his job, and stay all day in the town where DJ was working until it was time to pick him up and drive him back to the county jail, and then drive home alone. At least they had those hours traveling together. They could share emotions and help support each other through this ordeal. Little did they know their troubles were only beginning.

Nick had his own problems. Suffering from avascular necrosis (AVN), he was experiencing death of his bones from lack of circulation brought on by Protease Inhibitors and/or because of being treated with high doses of prednisone for PCP four years earlier. He desperately needed to have both his hips replaced. His symptoms found him wracked with pain any time he sat too long...such as all the time he spent in the car driving DJ to and from work. But devotedly he endured, cherishing the drives that allowed them moments of privacy and spending precious lunch

hours together in the medical complex cafeteria.

Soon DJ learned of a program called One Church One Offender that promised to offer non-violent offenders an alternative to jail time while being sponsored by a congregation that would oversee their adjustment to society.

Geared more toward the repeat offender caught in the trap of recidivism, DJ did not match this typical profile of prospective candidates, but he did have in place two churches ready to sponsor him in this program. Devoutly Christian, and knowing that God loved him as he was, DJ was sure that everything

long had they known each other? Did they have sex? If DJ wanted to get into the release program, he would have to sign an agreement not to have sexual relations with Nick. It was against God’s law, an abomination and a sin. He would have to disclose to any congregation who sponsored him his sexual orientation, his romantic relationship with Nick, and his health condition. He couldn’t have any gay friends. Why, Pastor Hex even had ex-sex offenders in his church, and knew how to reach the criminal mind and bring them back to God. But DJ was not in jail as a sex offender.

“How can you trust a doctor that doesn’t know? How can you trust a system that questions your integrity? One unfortunate incident and every thing in your life is compared to sex offenders and drug abusers, and nothing you say is ever taken seriously...because to them he is guilty and trying to cover up his tracks...” -Nick

would work out. Applications for the program were given to DJ and his probation officer to fill out. It looked like the process would stay on course.

Enter one hell-raising right-wing religious extremist, disguised as a caring volunteer come to minister to the needs of society’s troubling incarcerated population. Pastor Hex had self-appointed himself as chaplain of the program DJ was interested in, and was determined to make him see the error of his ways before any agreement would be made regarding his release.

Pastor Hex knew about DJ’s HIV status and about Nick who always showed up right on time to pick DJ up for work. There must be more to their relationship than just friends. They were living in sin! The interview process became a holy roller interrogation. Breaches of confidentiality were flagrantly broached. Lines between church and state became blurred.

Pastor Hex told DJ that his life “was not in accordance with what this program represented.” Did this roommate of his have HIV also? DJ answered yes. Did DJ give it to him? No. How

While this jockeying for mind control was playing out, DJ was given a routine drug screening, common procedure for those on work release and not unexpected. The test result was positive for cannabis. A second test was preliminarily judged positive and then changed to negative. DJ knew something was wrong. He did not smoke marijuana, or cigarettes for that matter. He didn’t even drink alcohol. Two weeks passed before a third test also came up positive.

From the time of his accident through his legal hassles, and during his incarceration and religious interrogation, DJ had one true friend who stuck by his side and was able to provide emotional support and act as his advocate.

Gina, a nurse with the health department, has been the county AIDS/STD coordinator for 16 years, and worked with HIV/AIDS since the beginning of the pandemic. Her responsibilities included working in the county jail where DJ was serving his time. She had already known DJ because they both
JUSTICE continued on page 8

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worked in the medical profession, and she was determined to prove his positive drug test to be false.

Based on her solid working relationship with the correctional facility and her reputation, Gina had been able to get DJ released to continue working, pending results of the third blood test. If he were unable to prove some cause for the negative test results, DJ would lose his work release, lose all accumulated "good behavior" credits, be sent to the regular cells, and serve the full time of his sentence.

There must be an interaction with some of his HIV medicine, Gina thought. She placed a call to DJ's HIV specialist. No help there. His answer was that none of DJ's meds would cause a false positive for marijuana, so he must be smoking pot! Undeterred, she called the one person she was sure would help her.

Jerry had been devoted to helping people with HIV/AIDS long before specialized HIV case manager certification even existed. Now case manager for a local AIDS service organization and with a stellar reputation as patient advocate, Gina was sure Jerry would know if a drug interaction was implicated. As Gina read off the list of DJ's prescribed medicines one by one, Jerry stopped her when she reached the drug Sustiva. That was the drug that could cause a false positive for cannabis!

Jerry faxed Gina information from the Physician's Desk Reference. Nick got on the Internet and found the Sustiva web site. Deep into a long report providing the manufacturer's complete research on the drug was proof that it can cause a false positive for marijuana. The full report was printed out and sent to the doctor who had dismissed DJ's test as proof he had been smoking pot. Upon being shown information substantiating his error in judgment, he remarked, "This is all news to me."

By this time DJ had all but given up hope that he would be able to access that church-sponsored release program. Refusing to agree to Pastor Hex's demands, he had staunchly decided that he would rather serve his full sentence

than to bend to this zealot's demand that he repent for something he did not believe God thought was wrong. "I was getting upset and it was ridiculous," DJ said. "No one is going to tell me how to live my life. Anyone else wouldn't be put through this. It was a load off my mind to say forget it... I'm not interested."

DJ's psychologist suggested a church for them to visit, one which he was sure would not have a problem with their sexual orientation, their relationship or their disease. Curiously, DJ and Nick had already attended that church earlier in the year. Not only did they find a welcoming congregation, but the church was willing to sponsor DJ in the One Church One Offender program.

A meeting was held to officially designate their new church as DJ's sponsor for the program that would get him released from jail. Pastor Hex was none too pleased, and tried every maneuver to not let it happen. Did they not know DJ was gay? Yes they did—and they were gay too, they said with the sunniest of smiles. Forms signed, DJ was free to go home at last.

As this article was being written, DJ still had not yet been given back his license to drive, so Nick still drives him to work every day. Nick's consultation with a respected orthopedic surgeon regarding his hip replacements were put on hold since the surgeon expressed concern about operating on "your kind of people."

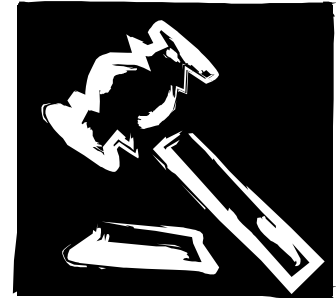
And yet, DJ and Nick's relationship has persevered through the most incredible barriers and obstacles that one could ever imagine in even the most fantastic New York Times bestseller scenario. The real tragedy is that, since DJ is still technically on probation, and due to other personal reasons, they chose to have their story told anonymously.

That means the identities of Gina, the savior who held fast to her beliefs and instincts, and Jerry, who knew more about HIV drugs than a prominent Michigan physician, must also be kept anonymous. Neither one would mind sharing their identities, but as Gina said, "It could happen anywhere."

Perhaps, when DJ's sentence is

complete and Nick has found a surgeon willing to perform his hip replacements and their lives get back to blissful normalcy, they will be willing to disclose their identities, and with them, the identities of the nurse and case manager who deserve such praise for their roles in this story.

And that doctor who didn't even know an AIDS drug he prescribes can cause a false positive for marijuana, and was willing to dismiss DJ as just another pot smoker? He's still practicing right here in Michigan.



"Maybe the first person a jail employee met was a bad example—maybe they tried to bite someone or spit on someone. Some jails are afraid of it [AIDS] and want to put it in isolation...they don't understand refrigerating medicine, high or no fat diets.... It's all a matter of education.."

- Nurse Gina

Some thoughts from Kendra Kleber of Michigan Advocates Exchange regarding this story:

"A program that is designed to intervene in a cycle of crime and incarceration, and that offers real alternatives and not just platitudes, could well turn out to be a rehabilitation effort that our correctional system alone is not able to provide."

"If a program uses its contact with clients, who have been ordered into the program by a court, to proselytize or otherwise wreak the influences of its full organizational mission (as opposed to the program goals), then it is acting incorrectly. And its connection to the court should be stopped or curtailed, to prevent it from sullyng the reputation of the court."