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by

Christina Michelle Burke

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Stigma: The Negatives of being HIV Positive

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# **Stigma: The Negatives of being HIV Positive**

by

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# Report

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## **Dedication**

For the survivors of the HIV/AIDS pandemic and for Mike and the memory of those who have lost the battle.

## Acknowledgements

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#### **Abstract**

Stigma: The Negatives of being HIV Positive.

Christina Michelle Burke, M.A.

The University of Texas at Austin, 2010

Supervisor: Dennis Darling

This report addresses the issue of stigma surrounding people living with the human immunodeficiency virus and the acquired immunodeficiency syndrome or HIV/AIDS. It examines the relationship between the disease and a person's willingness to seek treatment and how an HIV diagnosis affects self-acceptance, family relationships, friendships and well being of people living with HIV/AIDS. In many cases the self-imposed stigma is just as menacing as external stigma. The global pandemic of HIV/AIDS affects every class, color and creed. It is a public health crisis that quietly infects new victims daily. In the thirty years since its discovery there is still no known cure. The passage of the Ryan White act was the federal government's first official response to the issue. While the disease is manageable for many who can afford expensive anti-retroviral medication, the side effects and psychological turmoil they face is oftentimes unbearable. This report, and the accompanying video, *Stigma*, which can be found at http://christinaburkephoto.blogspot.com/ examines the social and psychological effects on people living with HIV/AIDS.

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## **HIV/AIDS Today: An Introduction**

"Pray for the dead and fight like hell for the living," Mother Jones.

There is a knock on the door. On the other side is a man, his face buried in his hands. Unrecognizable. Sobbing uncontrollably tears run between his fingers and down his emaciated arms. His body is rocked with each wail.

"At first I had no idea who this person was because his arms were like skin stretched on bones," explained Dave Martin. "Somewhere in that very gaunt face I saw Keith and I didn't want to think that word. I kept pushing it back, I didn't want to think it."

Keith was Martin's first partner. They met in College Station in the late 1980's. Dave was a student who had just come out as a gay man. He and Keith hit it off when they met at the only gay bar in the small Texas town. They shared similar interest in movies and literature and soon were on their way to a relationship.

With the door ajar, Martin looked at Keith in disbelief. "[Keith] cried out to me. He said no one will come near me. No one will even give me a hug. Everyone keeps telling me I have AIDS but I don't. I can't. I don't have AIDS."

Without a second thought Dave pulled Keith into an embrace and held him until he finally calmed down and the sobbing stopped. "I felt every quake of his body, every tear down my neck," Martin recalled.

"Once he said that word I couldn't deny it myself, no matter how much he wanted to." When he and Keith dated, Martin did not insist on using protection or practicing safe sex. Dave was diagnosed with HIV 24 years ago. The disease progressed into AIDS in

November of 1999. When he tested positive doctors told him he could expect to live five to eight years at most. He jokes that his memoir will be titled, 'Three Times Past Dead.'

Forever etched in Martin's mind is the scene of Keith at his doorstep. "Those words that he said to me on my doorstep, I see them like my albatross from the rhyme of the Ancient Mariner, I have to tell his story. It's something that I have to do for him. Everything that happened that night changed me," said Dave.

Dave not only realized the he was at high risk of being HIV positive, he also became a champion of HIV/AIDS outreach.

Though he didn't expect to live this long Dave has seen the progression of the epidemic from the start. "It is tiring to look back at those early days when I saw AIDS erupting in this country in 1981 and realize how little has changed...Its become invisible again to the general population of this country."

A topic that has dropped out of our national conversation, HIV/AIDS continues to infect new people. As an openly gay man living with AIDS, Dave is compelled to do outreach and talk about this disease with as many people as will listen. "Invisibility is a detriment to the HIV community," contended Dave. He is working to organize a speakers bureau gathering a group of HIV positive people to speak up about their personal experiences with the disease. He hopes that together they can reach out to members of the community to raise awareness and decrease stigma.

A hot topic in the news of past decades, the subject no longer commands the attention of the media. Is our nation's apathy at fault? Some of the issues associated with the HIV/AIDS epidemic include sexual orientation, drug abuse, prejudice and public health.

Even in our open society, people living with HIV/AIDS are discriminated against and stigmatized for their disease, which leads others to avoid testing out of fear of the

same treatment. It could be anybody. These are people we see in church, at the mall, in the movie theater, at the box store – living in our communities, stamping postage paid on your envelope, serving you your mocha. People living with HIV and AIDS (PLWHA) are leading normal lives in spite of the fact that they are carriers of one of the most infectious and deadly diseases of our time. They are discriminated against and stigmatized, often times seen as a disease and not human being. While the disease is manageable for many who can afford the anti-retroviral medication, the side effects and psychological turmoil they face are oftentimes unbearable.

The worldwide pandemic continues to be a public health risk to millions. Daily the infection rates increase while thousands of people die from opportunistic disease because of decreased efficiency of the immune system of a person infected with HIV/AIDS. Human immunodeficiency virus and Acquired immune deficiency syndrome represent a global epidemic that affecting more than 33.3 million worldwide, according to UNAIDS. <sup>1</sup>

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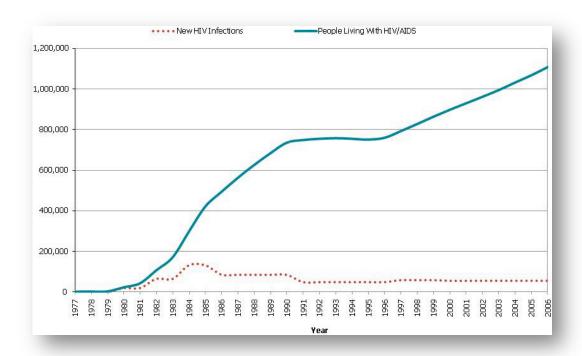
<sup>&</sup>lt;sup>1</sup>UNAIDS Report on the Global AIDS Epidemic 2010. Rep. Web. 28 Nov. 2010.



**Illustration 1. Dave Martin.** Dave Martin was diagnosed with HIV in 1990. He is works to reduce stigma and raise awareness about HIV&AIDS.

In the United States the Centers for Disease Control and Prevention "estimates that more than one million people are living with HIV. One in five (21%) of those people living with HIV is unaware of their infection....New infections continue at far too high a level, with an estimated 56,300 Americans becoming infected with HIV each year." <sup>2</sup>

<sup>&</sup>lt;sup>2</sup> "HIV in the United States | Factsheets | Resources by Format | CDC HIV/AIDS." *Centers for Disease Control and Prevention*. Web. 29 Nov. 2010. <a href="http://www.cdc.gov/hiv/resources/factsheets/us.htm">http://www.cdc.gov/hiv/resources/factsheets/us.htm</a>.



**Table 2. HIV Incidence and Prevalence, US, 1977-2006.** Hall HI, Song R, Rhodes P, et al. Estimation of HIV Incidence in the US. *JAMA* 2008;300: 520–529. CDC. <u>HIV prevalence estimates—US, 2006</u>. *MMWR* 2008;57(39):1073-76.

To break those numbers down even further, one in 378 Texans is living with HIV/AIDS, one in 112 African American Texans, one in 498 White Texans and one in 565 Hispanic Texans." <sup>3</sup>

One reason infections continue is a lack of discussion and awareness promotion necessary to prevent new infections. Today we have the tools to make HIV/AIDS one hundred percent preventable by promoting safe sex practices including abstinence, condom use, testing and preventative methods for women who are pregnant to stop the

<sup>&</sup>lt;sup>3</sup> Texas, United States. Texas Department of State Health Services. *HIV/STD Program Annual Report*. 2008. Print.

transmission of the virus to the unborn child, and the elimination of shared needles, razors or other utensils that may transmit blood.

The disease is not spread by daily contact with someone living with HIV/AIDS. Shaking hands, sneezing, hugging or sharing a bathroom with someone living with HIV/AIDS, cannot spread the virus.

The goal of advocacy groups is two fold; one to prevent new cases and two to reduce stigma. Abstinence, safe sex practices, dirty needle collection and clean needle distribution, along with prenatal drugs for pregnant women to prevent infecting their unborn children are encompassed in their message. They generate awareness by lobbying churches and government bodies while sending a message about prevention.

Allies of people living with HIV/AIDS (PLWHA) and AIDS advocates alike also aim to de-stigmatize the disease. They want the public to understand that the stigma associated with AIDS only further contributes to new infections because of fear of a positive diagnosis.

Even in our open society, people living with HIV/AIDS are discriminated against and stigmatized for their disease, which leads others to avoid testing out of fear of the same treatment. It could be anybody. These are people we see in church, at the mall, in the movie theater, at the box store – living in our communities, stamping postage paid on your envelope, serving you your mocha. People living with HIV and AIDS (PLWHA) are leading normal lives in spite of the fact that they are carriers of one of the most infectious and deadly diseases of our time. They are discriminated against and stigmatized, often times seen as a disease and not human being. While the disease is manageable for many who can afford the anti-retroviral medication, the side effects and psychological turmoil they face are oftentimes unbearable.

The global pandemic of HIV/AIDS affects every class, color and creed. It is a public health crisis that quietly infects new victims daily. The thirty-year-old disease has no known cure.

## **Overcoming Stigma: Seeking Treatment**

Stigma can have negative effects including delays in diagnosis and treatment. People who are unaware of their status may not seek treatment for fear of rejection and judgment. "Additionally, early testing is critical in preventing the further spread of HIV/AIDS. Those unaware of their status are more likely to transmit the disease to others, resulting in missed opportunities for the prevention of new HIV infections." <sup>4</sup>

There are social detriments as well as psychological ones related to stigma.

Jonathan Carter didn't always know his status. In fact he was unwilling to get tested when he first suspected he might be infected. Some people just don't want to know. They fear the rejection and discrimination that go along with a positive diagnosis. There is disbelief among people who are infected with the disease so they fail to seek testing. If they knew that would also oblige them, legally, to disclose their status to sexual partner.

"If I didn't get tested, which a lot of people do, you kind of pretend like you don't have it," observed Joseph Carter. He waited, convinced himself he was fine, and when he was finally tested for the virus in 2000 it had progressed to the point of AIDS. This concurrent diagnosis is not uncommon.

Once infected with HIV, people typically have five to ten years without symptoms before they progress to AIDS. Early HIV/AIDS diagnosis allows HIV infected people to benefit from life-saving medication and treatment. Diagnosis of AIDS within a short time period from HIV diagnosis (concurrent diagnosis) is associated with poorer prognosis and decreased long-term survival.<sup>5</sup>

<sup>&</sup>lt;sup>4</sup> Texas, United States. The Texas Department of Health Services. 2010 Texas Integrated Epidemiologic Profile for HIV/AIDS Prevention and Services Planning: HIV/AIDS in Texas. Austin, 2010. Print.

<sup>&</sup>lt;sup>5</sup> Texas, United States. The Texas Department of Health Services. 2010 Texas Integrated Epidemiologic Profile for HIV/AIDS Prevention and Services Planning: HIV/AIDS in Texas. Austin, 2010. Print.

Jonathan had waited so long before his diagnosis to seek treatment that the virus was attacking his body making him extremely ill. He is not alone in this.

"One in three HIV infected Texans gets AIDS within one year of their HIV diagnosis, indicating that they were not diagnosed until late in the progression of HIV disease," according to the Texas Department of State Health Services. <sup>6</sup>

For Jonathan his HIV diagnosis sent him reeling.

It kind of put me in a whirlwind. I did not like the words HIV or AIDS so I had a hard time going to my doctors because I couldn't stand the people that were HIV positive. What it looked like to me was that you were real sick. I guess I actually stigmatized people that were HIV positive for a long time, Jonathan confided.

Jonathan had to come to terms with many issues in order to seek treatment. He says he stigmatized PLWHA. He saw them as dying souls, individuals with no life ahead of them. He didn't see his face represented in the stereotype of PLWHA. He thought he was not likely to catch the bug and held an 'it can't happen to me' attitude.

"Of anybody, African Americans are probably the most that don't really understand it because they believe it's not happening to them," he asserted.

In Texas, "The rate of Black PLWHA was consistently more than four times higher than rates for White and Hispanic PLWHA," according to the report 2010 Texas Integrated Epidemiologic Profile for HIV/AIDS Prevention and Services Planning: HIV/AIDS in Texas.<sup>7</sup>

This rate of infection is disproportionate among Black or African Americans. So much so that legislation was introduced in February of this year to address this disparity. This legislation, S.3011 or the National Black Clergy for the Elimination of HIV/AIDS

<sup>&</sup>lt;sup>6</sup> Texas, United States. Texas Department of State Health Services. *HIV/STD Program Annual Report*. 2008. Print.

<sup>&</sup>lt;sup>7</sup> Texas, United States. The Texas Department of Health Services. 2010 Texas Integrated Epidemiologic Profile for HIV/AIDS Prevention and Services Planning: HIV/AIDS in Texas. Austin, 2010. Print.

Act of 2009 has been referred to the Committee on Health, Education, Labor, and Pensions. If passed this bill will address HIV/AIDS in the African-American community making, "grants to public health agencies and faith-based organizations to conduct HIV/AIDS prevention, testing, and related outreach activities to reduce HIV/AIDS in the African-American community." <sup>8</sup>

"If I could just reach out to one group of people that would be them, not just because I am African American but because they really believe that it's a gay white disease, still, to this day. That's the ignorant part of it," said Jonathan.

"Compared with members of other races and ethnicities they continue to account for a higher proportion of cases at all stages of HIV—from new infections to deaths," according to the Centers for Disease Control and Prevention. <sup>9</sup>

An HIV positive diagnosis is a hard thing to face.

It seems like you've got to make this really big change in your life. If you're out using and out having fun and drinking and sexing and doing all that fun stuff then when you find out that you are diagnosed with HIV/AIDS it seems like the fun goes away. It seem like your life just ends right there. That's one reason why I went to drugs, he lamented.

Today he is undergoing physical and emotional treatment. He has a support network that he relies on, goes to groups for counseling, is coming to terms with the gravity of the disease, and is undergoing antiretroviral therapy.

Because of stigma and discrimination he feels no need to disclose his status in his day-to-day dealings. "I'm real careful about telling people. That rejection is really messed up. That's what gets me really mad. I go into a shell so I try not to tell unless

<sup>8 &</sup>quot;S. 3011 - Summary: National Black Clergy for the Elimination of HIV/AIDS Act of 2009 (GovTrack.us)." *GovTrack.us: Tracking the U.S. Congress*. Sen. Kirsten Gillibrand [D-NY]. Web. 29 Nov. 2010. <a href="http://www.govtrack.us/congress/bill.xpd?bill=s111-3011&tab=summary">http://www.govtrack.us/congress/bill.xpd?bill=s111-3011&tab=summary</a>.

<sup>&</sup>lt;sup>9</sup> "HIV among African Americans." *Department of Health and Human Services*. Centers for Disease Control and Prevention. Web. 28 Nov. 2010.

I've known them for a long time," he said.

At his last job as a manager in retail sales he opened up to his supervisor about his status. He was soon fired from the job. His supervisor stated his unwillingness to work 50-60 hours a week. He was sick and he needed to get well. Working those long shifts was taking a toll on his already poor health. "She actually got me booted off the job just for telling her I was HIV positive," he recalled. Fired from his job and unable to find work he now draws disability insurance which helps pay for expensive medication and treatment.

Support from his family plays a big part in Jonathan's life. Adopted as a child he had to tell both his birth family and his adoptive family. He considers himself lucky to have a supportive family. "I hear a lot of stories where a lot of people their families just forget about them. You see them back to being homeless because their parents won't help them out any more. Their parents just pretend like they never even existed, it's like you got this disease you take care of it yourself," he said. "But I was real lucky I had parents that they were still tough parents but if I ever needed anything they were behind me."



Illustration 2. Jonathan Carter. Jonathan Carter was diagnosed with AIDS in 2000.

Coming out to his birth family was met with fear. When he went for a visit to they were leery of his condition. "They were kind of put off because I was HIV positive. If I went to the bathroom they would sterilize the bathroom with bleach," recalled Jonathan.

Although he is aware of how HIV is transmitted he is still afraid. He avoids contact with his brother's children. "To this date, I will not hold a kid, I will not hold a

baby. I'm so scared to hold a baby," he remarked. He fears accidently causing them harm.

He has his issues about the disease and admits that he is not perfect in dealing with its affects on his life in his relationships and with his own sense of self. It took him a long time to come to this point of acceptance. He doesn't deny his need to take medication for depression, the antidepressants help just as having a good support group has helped him.



Illustration 3. Jonathan Carter. Jonathan Carter was diagnosed with AIDS in 2000.

### **Stigma Defined**

What is stigma and why is it so powerful? "Stigma in terms of HIV is something that we see affecting peoples lives on a daily basis. I would describe it as a mark that's placed on individuals by society sort of a mark of shame," said Melissa Pintor Carnagey, a social worker and intake specialist with AIDS services of Austin. Stigma affects people accessing medical care and the treatment that they need. Behaviors that are seen as bad or wrong are often times associated with the disease.

"Individuals come to us many times not in their best place and in a very vulnerable state. Stigma plays a big role in that," said Carnagey.

"People's lives could change negatively in some instances because of stigma and the way society views HIV and people living with HIV," said Carnagey. The solution in combating stigma is education she says.

"People can disassociate themselves and then see HIV as something people brought upon themselves which is not the case, said Carnagey. "HIV infects anyone and it affects us all," she added.

This external stigma is only half of the problem. People living with HIV/AIDS also face stigma from within.

Dave Martin wants people to see beyond the veil of illness. As an openly gay man who is honest about his diagnosis he encounters this ignorance.

There's a lot of ignorance driving stigma. But stigma isn't always unidirectional. Stigma also comes from within the person being stigmatized, you come to believe what everyone else is saying about you. You come to see yourself as having no value, that no one is going to want to be with you because of this thing you have and so you stigmatize yourself. You don't want to tell people that you have it because you expect them to react in an ignorant way, he said.

Hiding from this disease is a detriment. "AIDS is with you for the rest of your life so you have to face it head on," said Martin.

The topic of HIV advocacy and education is the platform for one of America's pre-eminent beauty queens. Caressa Cameron, Miss America 2010 made it her personal mission to speak up against the discrimination of PLWHA as well as promote education surrounding the oftentimes-taboo topic.

In October Cameron spoke at the 23rd annual AIDS Walk Austin, which benefitted AIDS Services of Austin. The walk is a fundraiser that gives ASA the ability to "provide direct care services to over 1,500 Central Texans and HIV prevention education to over 10,000 people," according to a press release by the organization in advance of the event. The organization estimates there are 6,000 people living with HIV and AIDS in Central Texas. This year they surpassed their goal by twenty thousand dollars raising \$160,000.

Cameron's involvement with the issue is personal. "I saw first hand what HIV and AIDS can do to a person, can do to a family because my family cared for [my uncle] in the last months of his life and he died in our home," asserted Cameron.

Throughout her reign as Miss America she has consistently brought her platform to light. In April she received prestigious Whitman-Walker Partner for Life Award for her dedication to HIV/AIDS awareness. "I knew that it was my responsibility to combat social stigmas behind this thing," she declared in an interview on the 700 Club earlier this year. <sup>10</sup>

Because HIV and AIDS is something that is 100 percent preventable and we have all of the tools necessary to make sure that people remain safe. Its my responsibility, though I may not always agree with the decisions that other people

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make for their lives, if I have life saving tools and information to pass on to them then I will do that, she added.



**Illustration 4. AIDS Walk Austin.** Caressa Cameron, Miss America 2010, walked in the AIDS Services of Austin Annual AIDS Walk in October.



**Illustration 5. AIDS Walk Austin.** The AIDS Services of Austin Annual AIDS Walk raised \$160,000 for care and support of People Living with HIV/AIDS.



**Illustration 5. AIDS Walk Austin.** An ach of red balloons on display in front of Austin City Hall in honor of the annual AIDS Walk put on by AIDS Services of Austin.

## HIV/AIDS Policy: National, Statewide and Local

Scientists did not always know how HIV was transmitted or how to prevent the spread of infection. In 1984, Ryan White, a thirteen-year-old boy from Indiana who suffered from hemophilia, underwent a blood transfusion. After that day his life was changed, he was kicked out of middle school for having contracted HIV infected through the blood supply. The young man became an activist for PLWHA. At the time the public considered the disease a gay disease and labeled it gay cancer.

A courageous young man, White fought against stigma and led the public to reexamine its mores and values in regards to the disease.

In 1990, the year White died, the federal government entered the conversation of AIDS with the passage of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. <sup>11</sup>

The RWCARE Act is the largest federal program dedicated to providing care and treatment for people living with HIV. A key component of the public health safety net, it reaches hundreds of thousands of people every year with medical care, drugs, and support services. The CARE Act has been a huge success in reducing sickness and death from HIV disease and helping people live longer, more healthy and productive lives, according to AIDS Alliance. <sup>12</sup>

AIDS advocates made an important victory with the fourth reauthorization of the Ryan White Act in 2009. White's mother, Jeanne White-Ginder, was present when President Barak Obama signed the legislation. The RWCA authorizes the federal expenditure of funds for a range of services from health care to prevention programs, education programs to awareness campaigns.

<sup>&</sup>lt;sup>11</sup> Ryan White HIV/AIDS Treatment Extension Act of 2009. S. 1793, 111th Cong., Library of Congress 19 (2009) (enacted). Print.

<sup>&</sup>lt;sup>12</sup> "Ryan White CARE Act." *AIDS Alliance Home Page*. Web. 28 Nov. 2010. <a href="http://www.aids-alliance.org/policy/ryanwhite/">http://www.aids-alliance.org/policy/ryanwhite/</a>.

President Obama also rolled out the first National HIV/AIDS Strategy in July of 2010. This strategy has three main goals:

- 1. reducing the number of people who become infected with HIV;
- 2. increasing access to care and improving health outcomes for people living with HIV; and,
- 3. reducing HIV-related health disparities." <sup>13</sup>

The vision for the strategy reads,

The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination <sup>14</sup>

The strategy's aim is respectable but it cannot be effective without community support and continued efforts to raise awareness. "Success will require the commitment of all parts of society, including State, tribal and local governments, businesses, faith communities, philanthropy, the scientific and medical communities, educational institutions, people living with HIV, and others." <sup>15</sup>

The strategy is meant to be a roadmap to the nation's response to the HIV epidemic in this country by indentifying priorities and strategic action to produce measurable outcomes.

Today our National AIDS Strategy in conjunction with state policy is sending a clear message that PLWHA will not drop through the cracks. The Ryan White CARE Act

<sup>13</sup> United States. Government. Office of the President. *National HIV/AIDS Strategy for the United States*. Web. 29 Nov. 2010. <a href="http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf">http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf</a>.

<sup>14</sup> United States. Government. Office of the President. *National HIV/AIDS Strategy for the United States*. Web. 29 Nov. 2010. <a href="http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf">http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf</a>.

<sup>15</sup> United States. Government. Office of the President. *National HIV/AIDS Strategy for the United States*. Web. 29 Nov. 2010. <a href="http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf">http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf</a>.

authorizes federal spending on the issue of HIV/AIDS ranging from treatment to testing. The annual budget is over \$2.1 billion dollars. For people who don't have access to antiretroviral medication the RWCA is a last resort source of funding.

Part of the \$2.1 billion dollars goes to treat people living here in Central Texas.

The strategy was met with mixed emotions. There were some things in it that were on point with realizing and understanding and reiterating the fact that people of color are being disproportionately affected. That we needed to do something about the number of people who didn't know their status who weren't getting tested.... The strategy itself cannot be implemented without community support, said Tim Bailey.

Bailey is an enthusiastic warrior for the cause of advocacy for PLWHA. He serves as vice chair of the Austin Area Comprehensive HIV Planning Council, which is funded by the RWCA. The council tries to determine local needs by reviewing data, as well as listening to clients and providers.

Diagnosed with the disease in 2004 when he was 24-years-old Bailey manages his disease with antiretroviral medication. His positive diagnosis changed not only his life, but his career path too. About being HIV positive he says, "It doesn't have to define who you are. It becomes a part of who you are."

Once I began to process my diagnosis, about two years into it, I took that first step of volunteering at an AIDS service organization. I began to see what a gift it was to be positive. I began to see the faces of those people that I was helping by serving this agency.

When he volunteered at Doug's House, a local AIDS hospice he said, "I realized that day when I saw those faces that it was crucial for me to be involved and be engaged." Bailey is overflowing with energy and passion when he talks about the service he provides to the area as a volunteer. "I couldn't get enough of the volunteer opportunities, but the reason I couldn't is because it was life giving. When I stop and think about why I'm doing it and who it benefits from my energy I am revived and in a

moment to know that at the end of the day I can feel satisfied in knowing that I've been part of providing services for people and giving hope to others who feel like there's nothing to hope for."



**Illustration 6. Tim Bailey.** Tim Bailey is Master's student in the School of Social Work at the University of Texas at Austin. Diagnosed with HIV at 24-years-old Bailey works with many local groups surrounding the issue of HIV/AIDS.

For this champion of the cause of HIV & AIDS, Tim Bailey continues his work with vigor. His empathy towards PLWHA and understanding of the epidemic is an asset to the local planning council. He has had to help many friends through their first steps in learning of their positive diagnosis. "You may have ended up in this situation because

you made choices. We all make risky decisions every single day. The consequences are what differ. You have to give yourself grace in those moments," Bailey said.



**Illustration 7. Tim Bailey.** Tim Bailey manages his condition with antiretroviral medications.

I can't imagine taking this journey alone and I'm glad to say that I don't have to but I realize that other people don't have that privilege. That is what makes it more important for warriors to be out there to champion the rights of people living with HIV and AIDS and helping to end stigma, not just reduce it but end the fact that harassment and discrimination and rejection happens just because of the fact that people are diagnosed HIV positive. This is not something that people should die with, its something that people should live with. It is tangible and it is attainable. What keeps it from happening is a society that chooses to be silent on the issues and that is something that we cannot allow anymore, said Bailey.

As a member of the planning council he says, "We work hard to try to ensure that the needs of clients in our area are met. We can do that because of the funds of the Ryan White CARE Act."

The Austin HIV Planning Council has allocated millions of dollars for the "treatment, care, and support of HIV/AIDS clients." Its mission "is to develop and coordinate an effective and comprehensive community-wide response to the HIV/AIDS epidemic." <sup>16</sup>

In Travis county over 6,000 people are living with HIV/AIDS while 20 percent of them are unaware of their HIV status. <sup>17</sup> That 20 percent of the population is a risk for spreading the infection.

In July of 2009 Texas Democratic Senator Rodney Ellis of Houston and Representative Yvonne Davis of Dallas filed Senate Bill 877. <sup>18</sup> This bill would require doctors to offer HIV screenings at regular office visits. Patients would have the opportunity to opt-out of the screening. Their hope is to capture a part of the population that would not normally seek testing.

Under Former President Ronald Regan the Ryan White CARE Act contained a provision that criminalized nondisclosure of HIV status. It is one unspoken reason why people avoid testing. The law has since shifted that burden from the federal government to individual states. Many states nationwide have enacted laws that can be used to punish sexual behaviors that pose a risk of HIV transmission. In about half the states, the law is

<sup>&</sup>lt;sup>16</sup> Austin Area Comprehensive HIV Planning Council. HIV Planning Council Hosts Public Forum Series to Share Comprehensive Needs Assessment Finding. 21 July 2010. Web.

<sup>&</sup>lt;sup>17</sup> Texas, United States. City Council of the City of Austin. City Mananager. *RESOLUTION NO*. 20090924-069. September 24, 2009. Print.

<sup>&</sup>lt;sup>18</sup> Texas, United States. Texas Legislature. S.B. No. 877. By Rodney Ellis and Yvonne Davis. Print.

HIV-specific. A person knowing their HIV positive status who commits the unconscionable action of maliciously spreading the disease is prosecutable under the law. How effective those laws are varies.

In Texas "HIV transmission cases have been brought to court under aggravated assault laws whereby a person 'intentionally, knowingly, or recklessly... uses or exhibits a deadly weapon as part of an assault'. Saliva is considered a deadly weapon," according to Avert.org an international HIV & AIDS charity.<sup>19</sup>

Some states punish those convicted of offences such as prostitution or rape more severely if the person knows they have HIV. Spitting or emitting HIV-infected bodily fluids at another person while in prison is also an offence in some states. At least nine HIV-positive individuals in the US have been sentenced for spitting with sentences ranging from 90 days to 25 years, according to Avert.org. <sup>20</sup>

In Alabama, for example, transmitting HIV or other sexually transmitted diseases is punishable by a class C misdemeanor, whereas in Texas nondisclosure of HIV status has been prosecuted as assault with a deadly weapon.

<sup>&</sup>lt;sup>19</sup> "Criminal Transmission of HIV." *AIDS & HIV Information from the AIDS Charity AVERT*. Web. 28 Nov. 2010. <a href="http://www.avert.org/criminal-transmission.htm">http://www.avert.org/criminal-transmission.htm</a>.

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## **Conclusion: Going Forward**

The reality for people living with HIV/AIDS is no longer as harsh as it was when the disease first came to light. It is not a death sentence though there is a shroud of shame, silence and stigma surrounding the disease.

Although medications exist to counteract the effects of the virus they are expensive and have harsh side effects. A broader problem with the stigma is that it has negative affects on a person's willingness to get tested and to seek treatment. Stigma also produces a negative affect on relationships and quality of life.

With diagnosis and proper treatment, HIV is a manageable disease like other chronic illnesses. PLWHA are living full and healthy lives.

It has been 30 years – countless deaths – and still no cure, no vaccine. While scientists are making strides in researching and developing a preventative method, hundreds upon thousands of people are carriers of the disease. Advocates blame silence.

In response to this silence President Barak Obama rolled out the nation's first National AIDS Strategy. It is the hope of his administration that this strategy will produce measurable results by reducing infection rates, providing adequate housing, care and treatment for PLWHA as well as educate all members of society about the epidemic and its consequences.

In our lifetime a viable vaccine to prevent the transmission of HIV may be found, although a vaccine won't help those already infected. For this to happen changes in public policy continued public awareness must be addressed. Continued research to maintain the lives of those already infected is also necessary.

HIV/AIDS affects all groups; there is no way to put it in a category as our society has done, gay white male, black intravenous drug user, sex worker, promiscuity – these ideas are not only false, they perpetuate the idea of "it can't happen to me."

In summary the stigma associated with HIV/AIDS has a direct impact on people seeking testing and treatment. If we work to reduce stigma surrounding the disease we can better help people to seek out the proper medical care they need as well increase testing rates.

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