

Together: We are the Solution

In early March I had the extreme delight and honor of attending the 12th Annual Positive Living Conference which was held in Ft. Walton Beach, an event that is held annually for those living with HIV. This conference though was not just educational this time around; it was also a memorial for a great advocate in the fight against AIDS, Marty Delaney. A man who dedicated his life to helping those living with HIV/AIDS, by founding Project Inform, a leading national HIV patient advocacy organization that provided information to a terrified community about the growing epidemic and any possible ways of treating AIDS. When Delaney began his organization in 1985, AIDS was a death sentence. Delaney became a leader in the movement to accelerate FDA approval of promising new therapies. His work in this area has benefited not just people with HIV, but also patients with other serious diseases, such as cancer and hepatitis C. He was a leader in bringing the industry and community together to create solutions to improve patient access to HIV treatment. Marty was a visionary, an analytical, and unafraid to ask tough questions and push for solutions that improved access for patients. At the same time he was diplomatic, and empathetic to the needs of all parties at the table. He was extremely gifted in his ability to bring groups together with opposing views and arrive at solutions agreeable to all. In the process, he built trust, understanding, and pathways for future collaborations between the community, industry, and government groups.

The National Institute of Allergy and Infectious Diseases Director Anthony S. Fauci, M.D., said, "Millions of people are now receiving life saving antiretroviral medications from a treatment pipeline that Marty Delaney played a key role in opening and expanding. Without his tireless work and vision, many more people would have perished from HIV/AIDS."

President Bill Clinton sent a letter dated March 11, 2009, and in his letter he said, "Marty stands as a shining example of the successful results that are possible when we truly commit ourselves to attaining a worthy goal. Someday, AIDS will be banished from the headlines of our newspapers and relegated to the chapters of our history books, and it will be in no small measure because of Marty Delaney."

I never got the honor to meet and speak with the man who touched so many lives. Every story that was told was unique in its own way about how Marty had personally stepped in and touched their lives. His body may not have been in that room, but his spirit was so abundant I could feel his presence in that room that he had come to year after year to speak out for those living with HIV. All his work and words now live on within us and embolden our cause to continue our fight to help those living with HIV/AIDS, to stop and prevent future HIV infections and finally come together to find a cure for AIDS.

One thing we have learned in advocating new policy in the fight against AIDS is that not everyone will be there at our side, not everyone will show their support, not everyone will write you a check. But we must never give up, and never shut up. Your going to make enemies along the way, but if anything can give us inspiration it is the story of Marty Delaney, who by the way was not HIV Positive, but a

person who cared enough about all human life to show the world that we will not set back and let this epidemic continue to claim so many lives. All 400 attendees have made that vow to carry on the torch of Martin Delaney and work together to find the cure for AIDS and fight for more federal funding for the South. Only then can we conquer the health inadequacies and disparities in the South.

According to the Southern States Manifesto : Update 2008, The Southern Region has the most people living with HIV, the highest in all four regions, yet the South ranks fourth, dead last when it comes to Federal Funding for HIV/AIDS.

I guess we can blame this all on the heat, but here are the facts. The South comprises 36.4% of the total US population. Of the top 20 areas with the highest AIDS case rates in 2006, 11 states (55%) are in the south. The South has the highest number of adults/adolescents living with AIDS in the U.S. The number of persons living with AIDS has increased from 1993 to 2005 at a greater rate in the south than in any other region of the U.S. The South has the highest number of people dying from AIDS in the U.S. The number of persons who died from AIDS related deaths increased from 2001 to 2005 at a greater rate in the South, than in any other region of the country. Of the 20 metropolitan areas with the highest AIDS cases rates in 2006, 16 of those 20 states, (80%) are in the South. The southern states also have a higher percentage of new AIDS cases among persons living in non-metropolitan areas than any other region of the country. That's just the stats on Advanced HIV cases. Of the 20 states with the highest rates of persons living with HIV (not AIDS) in 2006, 11 states (55%) are in the south. Of the 15 states with the highest rates of new HIV diagnosis, 9 States (60%) are in the South. And yes, Georgia is included in every one. Prevention and treatment, or should I say lack thereof, for HIV/AIDS is further complicated in the South by the high prevalence of HIV-infected individuals living in rural areas. Southern States comprise 65% of all AIDS cases among rural populations. According to the CDC from 2001 to 2006, The south lost 197,209 Americans to AIDS and this nation as a whole lost 545,806 Americans to AIDS. But lets talk about Georgia for a moment. In 2005 we had 1,267 new HIV diagnosis and 932 new AIDS diagnosis. I wanted to first point out to the continuing disparaging numbers of the African American Community who comprised 1,005 (79%) of new HIV cases and 989 (80%) of new AIDS cases. But the number that crippled me when I read this report was that there were 9 children under the age of 13 in 2005 and 11 children in 2006 that were newly diagnosed with HIV. Less than 13 years of age. This is a travesty. But then I looked to the next line and saw children aged 13 – 19 years had 58 in 2005 and 75 in 2006 newly diagnosed HIV cases. I know your probably like stop with the numbers. Buts that's just it, that's the problem. These numbers just go on and on and they continue to grow. These young people's lives are being burdened by an awesome force before they are even given a chance to begin. Already this year our own health department has had over 5 new cases of HIV in 19 year olds and just this past week one new 16 year old.

Plain and simple more people are living and dying with AIDS in the South than in any other region of the country. So what can we do to change this?

Earlier this year we petitioned President Obama for more resources for the south, to sign a Clean Needles Act and to re-instate the Ryan White fund that is due to sunset on September 30, 2009. These are two pieces of legislation that literally save lives. We are calling for a change in distribution

methodology so that funding follows the epidemic; a \$70 Million Increase for Title II Base; Increased set-aside ADAP supplemental from 3% to 5%; Counting of those living with HIV to be included in the numbers of AIDS cases so that we can finally get real accurate information; Capping of administration expenses; inclusion of hepatitis co-infection; increase in coordination and accountability; Establishment of core services; Codification of the Minority AIDS Initiative; “Severity of Need Index” to be developed and finally create the first National Strategy to Combat AIDS, one that isn’t only taught through abstinence education which is not working. And on May 07th, President Obama answered our call personally with a conference call to the HIV community before he released his proposed Federal Budget to the press or public detailing to us the contents of his new budget. The President’s budget includes desperately needed budget increases for most parts of the Ryan White HIV/AIDS Modernization Act, and the AIDS Drug Assistance Program (ADAP). However, the increases were relatively small, and Part D (funds and services for women and children) and SPNS were flat funded.

These increased appropriations, while modest, will expand access to care and treatment for un- or underinsured Americans living with HIV/AIDS. For the first time in a long time, the Ryan White funded dental program got a closer budgeted increase to our requests than the remaining portions of the HIV/AIDS Treatment Modernization Act.

HRSA - Ryan White total increase		AIDSWatch 2009 Congressional Asks
+\$54 million		
Part A	+\$8 mil	+103 mil
Part B base	+\$10 mil	+105,4 mil
ADAP	+\$20 mil	+268.6 mil
Part C	+\$10 mil	+66.4 mil
Part D	0	+57.7 mil
Dental	+\$2 mil	+5.6 mil
AETC	+\$4 mil	+15.6 mil

The budget also includes a \$53 Million increase for the Centers of Disease Control and Prevention to expand HIV prevention efforts. This appreciated increase is a long way off of what hundreds of AIDS advocates asked Congress and the Administration for during AIDSWATCH, this past April. The HIV community still remains apprehensive about how the CDC can respond to the apparent need with such a small increase.

Sadly, the language which preserves the unjustified ban on using Federal dollars for syringe exchange programs is still present in the budget. Many HIV prevention advocacy organizations including the Better Way Foundation have issued strongly worded statements of disappointment over the missed opportunity to show leadership by eliminating the syringe exchange ban as a part of the budget process. As we have seen with failed Abstinence Only programs, kids are going to have sex, we see the same failure to help with prevention efforts by continuing the syringe exchange ban, injecting drug users who can’t get access to clean needles, will find a way, including sharing of needles which leads us further to the spread of Hepatitis, HIV and AIDS.

And with regards to the Abstinence Only funding, we are very pleased to report that the money is being redirected to effective programs and innovation. 75% of “Abstinence Only” monies are being reallocated to evidence based and promising teen programs. The remaining 25% of “Abstinence Only” funding will fund the development and evaluation of new ideas to decrease teen pregnancy and protect the health of school aged youth. While this movement is in the right direction towards eliminating failed abstinence only programs, the decision to solely focus on teen pregnancy prevention misses an important opportunity to include STD prevention programs as part of a comprehensive strategy. The inclusion of STD Prevention is critical for culturally appropriate and comprehensive health education that is relevant to all populations at high-risk.

Finally, in spite of an epidemic housing crisis and proven effectiveness regarding the prevention benefits of providing housing for poor or low income people living with HIV/AIDS, the Housing Opportunities for People with AIDS program was flat-funded. HIV advocates were hoping the program would also see a modest increase in funding in an effort to respond to the clear and present need. Housing is one of the top issues facing people living with HIV/AIDS.

The AIDS community understands that the United States is experiencing one of the most tragic economic collapses in recent history and resources are scarce. However, to weather these tough times and return stronger and more competitive in the future, we must make investments to protect our most valuable resource, the American people. HIV/AIDS programs prevent thousands of HIV infections and prolong and save the lives of over a million people living with HIV/AIDS here in the United States each year. We are grateful to have a President who fully understands the reality facing many Americans living with and at-risk for HIV. This Administration and Congress must act now to direct resources to combat the raging domestic AIDS epidemic. All of our lives depend on it.

We know what the next year holds and we stand ready to help pick up the slack.

In our continuing commitment in the War Against HIV and AIDS, The Better Way Foundation in partnership with the Southern AIDS Coalition have set forth what we feel are eight worthy and attainable goals.

1. Reduce new HIV infections by 25% in five years while increasing the outreach and access to HIV counseling, testing, and screening in every State and territory;
2. Reduce all late-term AIDS diagnosis by 25% within 5 years.
3. Implement the CDC opt-out testing recommendations across each of the Southern AIDS Coalition jurisdictions within three years;
4. Increase the number of persons aware of their HIV, STD, or hepatitis infections who enter and make optimal and sustained use of care and treatment;
5. Improve health outcomes for people with HIV/AIDS as indicated by clinical and other indicators (CD4, Viral Loads, etc.);
6. Increase age appropriate, science driven education for prevention of all sexually transmitted diseases;

7. Advocate for increased State Funding for prevention, treatment, care, housing, and services for people living with or at risk of HIV/AIDS, STD's and hepatitis; and
8. Continue to advocate for increased Federal funding for prevention treatments, care, housing, and services for people living with or at risk of HIV/AIDS, STD's, and hepatitis that is based on and allocated by the growth of the epidemics and the needs of people living with these diseases throughout the United States.

As our community prepares for the inevitable changes ahead, The Better Way Foundation has created several partnerships with organizations across America including the NAPWA (National Association of People Living With AIDS), Southern AIDS Coalition, Local Ryan White Consortium, National Prevention Information Network, and the Global Health Council. Together we are the solution. We extend our dedicated support and strong interest in all efforts that bring the people of our nation together to achieve our collective goals. We offer this view into the South as a way to substantiate the dire needs of people in our region. We will champion the needs of any person with or at risk of HIV, hepatitis, or other STD's wherever they live in the State of Georgia, Across Our Nation, or around the world and will collaborate with any willing partners. We are united in the desire to meet these goals and to live in a South, a nation, and a world without STD's, HIV, and AIDS. We invite each and every one of you to join us in this quest.

Currently, here locally, the Better Way Foundation is working with the Muscogee County School District and the Parent Teacher Association to step up prevention efforts. We honor a parent's right to teach their children about sex, STD's and prevention methods. But parents, if you want this right, then you best teach your kids about safe sex. And the one word not allowed to be uttered in schools should be our most valuable asset in the War against AIDS, Condoms! Say it with me Parents. When you talk to your kids about sex, talk to your kids about AIDS, talk to your kids about condoms and the importance of safe sex. But in order for parents to teach their kids properly, Parents must be educated themselves and learn these techniques to teaching and approaching their children with these topic discussions. The Better Way Foundation is working to help parents by providing them with study sessions, materials, and yes even Condoms. Open the doors of communication at home, at school, and at Church. The current social stigma of ignoring the issue, has only multiplied the new infection rates. State AIDS Directors, community advocates, members of Congress, and people living with HIV are all put at a disadvantage, due to perceptions of community, faith, corporate, and social leaders who believe that knowledge of how to have safe sex with anyone encourages the act itself. There is no data anywhere that can be found to substantiate this claim. And regardless of what the Pope said to a continent plagued with AIDS, Condoms Do Prevent AIDS and Condoms Do Save Lives. Teach your kids to always be prepared.

With growing recognition that the virus does not discriminate by age, race, gender, ethnicity, sexual orientation, or socio-economic status, that everyone is susceptible, starting next school year, The Better Way Foundation will be working with the arts department of each high school to create the first School approved HIV Awareness Poster and at the same time be promoting HIV awareness through art. Beginning next school year we will be sponsoring an art contest and we will take the best picture that promotes HIV and AIDS Awareness and that students picture will be reproduced to poster

size. Once approved by the School Board it shall be placed in every High School to ensure every time a student walks through the halls to a class, they will be reminded of HIV and AIDS and hopefully somewhere down the road when that situation arises that student will remember that poster and quite possibly protect not just themselves but also protect others.

Later this year, On September 19th, The Better Way Foundation will be hosting the First Annual HIV/AIDS Walk/Run For the Cure event that will be held at our very own beautiful Columbus Riverwalk. This events purpose is to raise funds for our organization to help further our work with people already living with HIV and AIDS and to help teach and fund prevention efforts throughout the community. I do hope you will go to our website and sign up to participate in this event. Even if you don't care to walk or run, come out and hear the testimonials from people living with HIV and AIDS and hear from doctors and medicinal experts and become informed. We will also be offering Free Confidential HIV OraSure Tests at the event to show people the importance of getting tested regularly, especially to woman and yes, even if they are married. Just because you are married doesn't mean you're safe from HIV/AIDS. So many women have come to groups and told us the horror stories that their husbands had cheated and not protected themselves and brought HIV and AIDS home to them. Now some people want to say when you hit your 50's your sex life is over. Well that's definitely not the case. But just because you're older and wiser doesn't mean your exempt. In 2006 in the State of Georgia, we had 5600 new cases of HIV and AIDS for people over the age of 50 and sadly those numbers continue to grow. So the rules still apply to you as well.

Women have been hit the hardest by HIV and AIDS, especially those who are African American. Around the world, women and girls are at high risk of HIV infection. In 2006, UNAIDS reported that new infections increased most rapidly among young women, aged 15 – 24.² Women and girls now comprise 50 percent, or 15.4 million, of the 33.2 million people living with HIV/AIDS.³ HIV/AIDS was the leading cause of death for African American women ages 25 – 44 in 2004. 66% of women in the U.S. diagnosed with AIDS are African American. Programs to stem the rise of new infections among women and girls are especially needed: keeping girls in school, providing for economic independence through vocational training and micro-credit, assuring that youth have accurate information and access to services, and addressing sexual coercion and gender-based violence. We have with us tonight a group of women who are doing just that. The New Horizons COMPAS Program SISTA (Sisters Informing Sisters About Topic on AIDS). The SISTA Project is a peer led social skills training intervention for African American women and girls with the primary aim to reduce HIV sexual risk behavior. This new program is setting the way for educating African American women and children about HIV, ethnic and gender pride, safe sex practices, communication with their partners and teach them the tools to ensure they are protected. Ladies will you please stand up? I thank you all from the bottom of my heart and every person in Columbus should be honored and proud of this wonderful Intervention program that these wonderful women have started. Ladies and gentlemen please join me in applauding these ladies who are working tirelessly to help stop the AIDS epidemic in the African American community.

There is one more vital voice we need in our fight and that is the voices of those living with HIV and AIDS. This is your life, and unless your Shirley McClain, you only get one. This is your disease. For

years now we have depended upon others to fight our battles for us while we hid in the shadows afraid to come forth because of the stigmas we face together. We must overcome this fear and stand forth together, united, and put a face to this disease. AIDS is a disease that has killed over 25 million people. It is a disease that is living inside some 33 million people worldwide. AIDS can no longer continue to be a faceless disease. This disease has affected or touched every family in this country in some sort of way. Enough innocent blood has been shed. I issue a call to you today. Just as Harvey Milk recruited, I am recruiting you to come forward about your illness. It's time you bring forth the truth about your illness to your families, your friends, your work place, and let them know, that everyone, anyone, your brother, your sister, your mother, your father could be infected with HIV/AIDS. We must put a face to AIDS. No longer can HIV/AIDS patients be a statistic or race or number, but should be treated as individuals and human beings. Ease your burden upon your soul and stand up and tell your story. But in order for those living to come forth, our society must educate themselves with proper and factual information regarding the illness. The moral compass of the nation and the South's specific cultural underpinnings include fundamentalist beliefs, such as blaming those who are diagnosed with HIV disease due to sinful behaviors, such as MSM and/or those who use or abuse drugs. The New Era Baptist Church located in Birmingham Alabama posted the following on their reader board "AIDS is God's Curse on a Homosexual Life". This message remained on the reader board for more than a year. While the congregation did divide over the words on the sign, the pastor continued to espouse his beliefs and judge others all in the name of God. The fact that the sign stood for over a year and did not bring a larger outcry from other areas of the community also speaks to the acceptability of a conservative environment that is not welcoming to the range of diversity found in the community overall. These ideologies have created an environment that is indifferent at best and hostile at worst to the plight of men, women, and children alike, regardless of how they contracted the disease. Ignorance is AIDS biggest ally and mankind's worst enemy. Those reckless words on that sign increased the stigma that AIDS is a gay disease. If that pastor would have done some research on AIDS he would have found out the truth about worldwide HIV infections, he would have found that 85% of all sexually transmitted cases were through heterosexual sex, less than five percent were through MSM infections, the other ten percent were through blood transmission which includes mother to child, injecting drug users, and medical procedures.

Despite the ignorance that this one pastor portrayed, many faith based entities have become educated, have started or enhanced AIDS ministries, and have shown support for persons living with HIV/AIDS. Those who are living with HIV disease, whether or not they are aware of their status, continue to be influenced by the stigmas that exist in their cultures. The shame connected with HIV, even if one identifies as heterosexual or bisexual can still cost primary relationships, employment, housing, and other social disconnects from needed support systems. Shame and Fear of the stigmatizing reactions of others may lead to reluctance to seek testing and treatment for HIV or other STD's. Too many people are still in the dark about how widespread HIV/AIDS is in the U.S. Every hour, approximately 6 new cases of HIV/AIDS are diagnosed in our nation. And what's even sadder is that 300,000 Americans are infected with HIV/AIDS and don't even know it. We can no longer afford to live in the dark, we can no longer live in the shadows, don't let another hour go by. Even if you're not infected, it doesn't mean your not affected. Stand up and be heard. Answer my call and stand up

and tell your friends, your mother, your father, your minister, your families that HIV is in me. Be not afraid, and fear not for I will be there for you every step of the way.

The hardest thing I ever had to tell my family was that I had AIDS. But today, I tell everyone I meet that shows a sign of love in their heart and compassion to helping others and even those who don't. Because I want them to know, AIDS is everywhere, in every family, in every sector of this country, in every sector of this world, people you work along side with every day, or perhaps even a child you raised. And when they answer my call and tell you about their disease, find out the facts and lend your helping hand. When you portray social ignorance about the disease and refuse to become informed and make your own children informed, then you could quite possibly be signing their death sentence. People need their families during this crisis, we need each other to work together to help bring an end to this epidemic once and for all.

Two years ago, before I ever even knew the name Marty Delaney, I was starting my own advocacy here in Columbus towards better policy for those living with HIV/AIDS and to help improve the education regarding prevention. This has become my life's work. The Better Way Foundation is a Positive Led Organization that helps those living with HIV/AIDS by providing Support groups, relaxation therapy classes, activities, exercise, and medicine awareness. I made the choice to take charge of AIDS in my community because I have seen the failures that lie within, the lack of information, the lack of funding, the lack of help, the lack of tolerance, the abundance of ignorance, the lack of empathy and most importantly the lack of participation of those living with HIV and AIDS. I offer my hand to those who are living with HIV and AIDS. I will walk along side with you and help you in every way I can. I will work non stop to ensure you are treated fairly and are given the best treatment possible. Don't let fear keep you from getting the help you and your disease require. Medicines are only a small part of the equation. Living life with HIV will be one of the most difficult tasks you'll ever have to endure but know that we will be there for you every step of the way. Don't go it alone. There are so many people living with HIV that need to hear your stories. People that need your support. We can learn from each other based on our personal experiences of living with this disease.

I have three letters here that were sent to me and I think it is very important that I read them to you, so you can see the pain, the frustration, the fear, and the strength to go and help others along the way.

Read Both Letters

Number 1.

I stayed alive so that my Mom would not have to lose a child. I have seen how painful that is for a parent.. Now she is gone. I am free to go if i choose. I ve lost too many friends to aids. Where im at is im about to turn 55 yrs, am unemployable, in debt, alone and unwell healthwise. So if i choose to let go, (to say to GOD.) im tired and its okay if i die now,(if its okay with him i will get to go AND I DO BELIEVE IT WOULD BE OKAY

WITH GOD) how dare anyone judge me. If it be Gods will , i will go, if not then i will find inspiration to go on. That is what i hope for from support groups. Not so much to be hit by lightning and go "oh that's

it'.... but to be helped by others who have been there or are seeking answers....and to hear and share ideas and propogate that willingness to go on. and to meet one who is where im at and maybe say "we can stay here for awhile on earth but MOST IMPORTANTLY TO BE OF HELP TO SOMEONE WHO IS HURTING and say its okay.....lets find some purpose and joy and serenity together

Letter 2

Hallow,

My name is Oliva Ndanshau, I am in my second year education at one of the institute in our country(Tanzania) taking Business Management.

I used to work in one of the NGO(Non Government Organization) in our country called Kinshai, which deals with HIV/AIDS. What made me write is this,

I heard my boss talking about your foundation and I was interested by the work that you are doing, infact the place were I am leaving there is no such thing as NGO, people are having very poor knowledge concerning HIV/AIDS and every day hundreds of people are dieing including small born babies.

I want to start the organization which will help to give information and educate people about HIV/AIDS and giving them hope to live and not giving up because many families are suffering by the loss we get from the death of the beloved ones.

Letter 3

I found your website on google search. I've just moved to Columbus and I'm laying here in bed listening to relaxing music. Everything except my mind is relaxing.

I've been positive for just 4 months now and I found your website inspirational. I've been living in the shadows as you beautifully put it. I lay awake every night for hours wondering if I'll ever be happy. When will I die? Will I let this get the best of me?

I want to make a difference in someones life. I feel if I'm able to help someone else, in turn, that satisfaction helps me get through my tough times. I want to live. I want be strong.

END LETTERS

All throughout history progress has been made through collaboration and unification, and today we all can be part of the solution. We must unite and fight to end this disease once and for all. Together, We Are The Solution.

Red, Yellow, Black and White

We All Are Equal in this Fight

For over 25 million who've lost this Fight

By Candlelight We Honor Them Tonight.

Thank You.