

# THE TIE THAT BINDS

**SOUTH CAROLINA AT THE CROSSROADS: HIV/AIDS AMONG CHILDREN AND YOUTH**

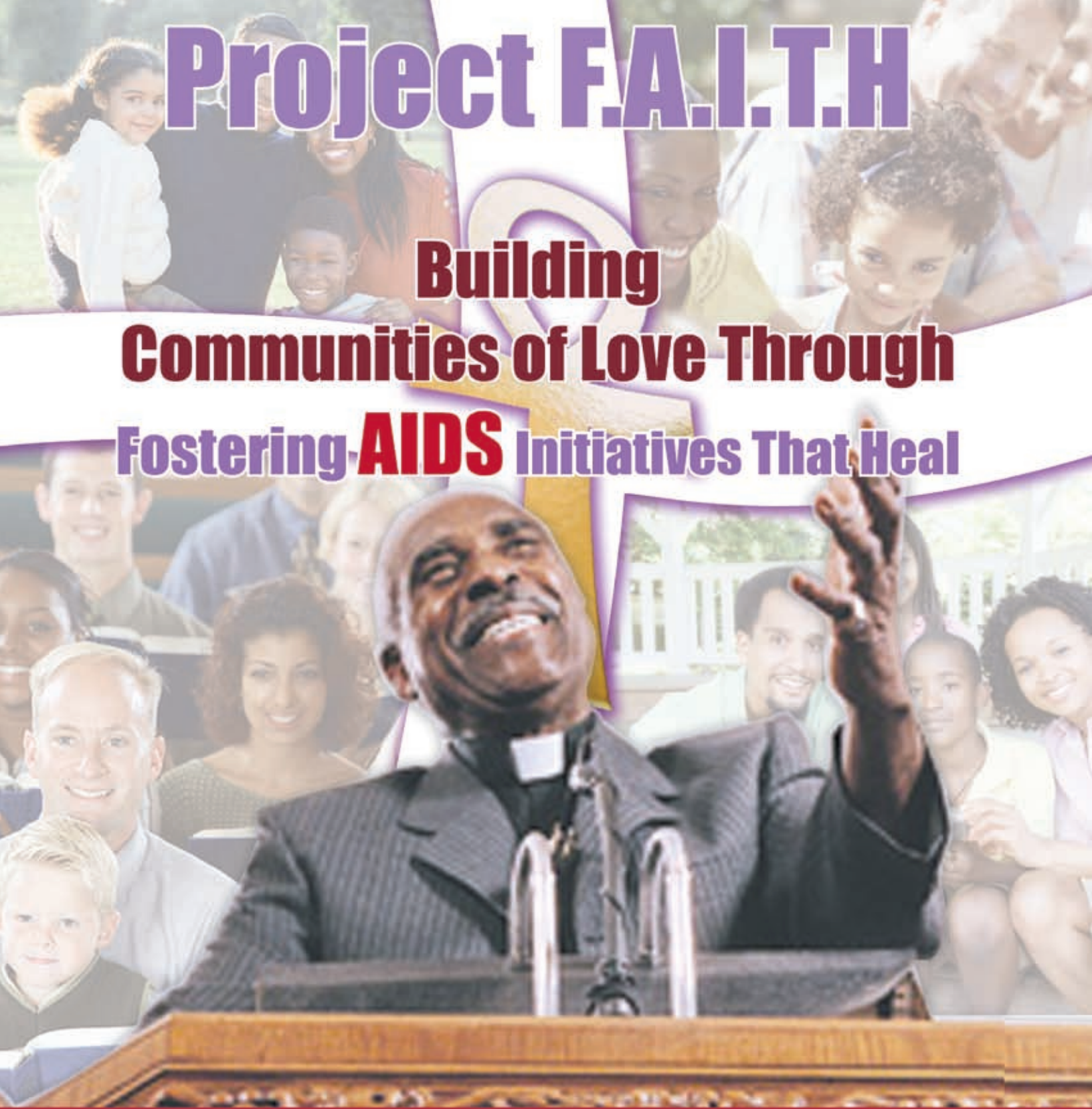
**Special Edition - May 2008**



**LINKING SOUTH CAROLINA TOGETHER ONE COMMUNITY AT A TIME**

# Project F.A.I.T.H

**Building  
Communities of Love Through  
Fostering **AIDS** Initiatives That Heal**



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# EDITORIAL

## FLEETING MOMENTS



It's almost impossible not to notice these days that young people are in a crisis state. So much of what we hear in the world focuses on the negative aspects of being young in America. We have reality television that depicts adults who struggle with discipline issues.

Family relationships are strained...we now call upon outside experts to tell us how to raise our own children.

We've called upon "The Nanny", Dr. Phil, and Judge Mathis to resolve issues that took years to create within our homes. Sometimes adults are busy working....trying to make our children's lives better than we had it....but at what cost? There is the "My Space" website, sexual predators on the loose, and technology that makes sure we create artificial "friendships" on-line.

If you think that raising a healthy, well-balanced child is hard now, imagine yourself for a moment faced with the added responsibility of raising a child born with HIV/AIDS. Just take one moment....imagine what it must be like caring for, supporting, and guiding a child or teen to adulthood. Young people living with HIV/AIDS must survive within a world of ignorance, prejudice, and peer judgment. My guess is that most of us can't even imagine it!

You should know that there are caregivers facing this reality every day in South Carolina. Many caregivers have decided not to tell their children...their grandchild.. why they are sick so often. Many caregivers think that it's best not to tell their loved ones why they must go to the doctor so often! We don't know why parents and caregivers have chosen to provide HIV/AIDS care to loved ones in secrecy. If this is the right decision or not, only time will tell.

Thanks to the AIDS Benefit Foundation of South Carolina and the SC Department of Alcohol and Other Drug Abuse Services (SCDAODAS), the Tie That Binds staff has been able to cover many compelling, and sometimes controversial topics. Creating this special edition *South Carolina at the Crossroads: HIV/AIDS Among Children and Youth* has truly been our greatest labor of love. Although it has taken some time to put it all together, it is a MUST read.

Like no other time in our state's history, it is imperative that government officials, schools, parents, and the community at large come to grips with this reality. We ask that you not only take the time to read this edition, we ask that you share it with folks in your family, church, and social network.

We should let you know that the South Carolina HIV/AIDS Council does not necessarily subscribe to all opinions shared by the authors. However, we pray that this edition will create a new sense of empathy and empowerment for all those confronted with HIV/AIDS. Only through our caring and sharing will we create communities that protect and nurture HIV positive children and young adults in need.

# BRYAN'S STORY

## The Journey of A Mother and Her Beloved Son

During 2007 South Carolina had the largest waiting list in the nation for persons living with HIV/AIDS that could not gain access to their medications. The following testimony was presented in March 2007 in Washington, DC, at the Ryan White Titles Panel. Brryan was 16 years old at the time and was accompanied by his mother Jennifer.

**BRRYAN:** In 1996, I lay dying on a hospital bed. In a matter of two (2) months I had gone from a playful, energetic, and happy five year old to a bloated, feverish and vomiting kid who could not walk. My mother struggled to carry me to numerous appointments, begging and praying for doctors to find a reason why I was appearing near death. I was tested for a large number of diseases, even rare ones that usually only exist in other countries.

But since I wasn't at risk for HIV, I wasn't tested for it. It was not until May 24th, 2 months after I became severely ill, that my mom and my doctor both asked for me to be tested for HIV. The results were devastating. I was diagnosed with AIDS, a number of other AIDS-related infections and my family was told I was not going to live long. Doctors said six months at the most, and according to the medical journals at that time, anyone in my condition had died within 3 months.

Being diagnosed with AIDS wasn't the only tragedy.

The way I got to be HIV+ was even more horrible. My own father, who was not HIV+, but worked in a blood lab was the cause of my illness. It was traced back that when I was only 11 months my father injected me with HIV tainted blood he had taken from his work. Not only was I dying but I was also the victim of a crime.

Yet, by the grace of GOD, the power of prayer, and medications, I stand before you today as a miracle wanting to tell my story to bring hope to many and knowledge to all.

I just celebrated my 16th birthday 11 days ago. A miracle indeed, but there is a down side to each birthday I celebrate. That puts me one step closer to a day when my birthday present from the government may be no health coverage and no meds.

Happy Birthday to me.... I think not! Even a bow and wrapping paper can't make that gift look pretty.

**JENNIFER** (Brryan's Mom)

You see at the present time, Brryan is covered under Title Four (now Part D), for women, children, and youth. Girls who grow up and turn into women are still covered under Title IV. But Brryan and many other boys will grow up into men and what then....,put on a waiting list or a reduced benefit formulary.

### Editor's Note:

*Gender does not affect care: Both boys and girls are moved out of Title IV/Part D created for*



*women and children and moved into Title II/Part B on their 19th birthday.*

Unfortunately, the proper term for waiting lists are death lists. No more money to the AIDS Drug Assistance Program (ADAP) could mean either Brryan dies or someone else. If not, many others have to die so Brryan could be moved up on the list to be covered. Or they could say, let's have a reduced formulary and cover all the medications that are available.

The big problem here is that the meds that a physician believes are best for his/her patient may not be available through the formulary. Therefore, people who are only HIV positive are ending up with

AIDS due to being inadequately medicated. And of course the cost to assist someone with AIDS is usually at least 10 times more than assisting someone who is HIV positive due to more and longer hospitalizations, more opportunistic infections, and more medication needed.

There is even more of a down side to his condition. Side effects from medications which can be deadly themselves under the present formularies many times are not treated. For instance, it is usually impossible to get the proper meds to treat the chronic diarrhea, the muscle atrophy or wasting syndrome, the high cholesterol, the neuropathy, the mental disorders, entire body systems shutting down, or the pain that goes hand in hand with being treated for HIV.

Yes, mental health is definitely an issue that needs to be addressed with youth and adults. Did you know that a common occurrence with HIV is something called white matter on the brain? This so-called white matter can present itself in various mental disorders such as ADD, depression, unstable mood disorders, and numerous others. One can suffer from post traumatic stress syndrome just from being diagnosed and the stress and stigma that comes along with it. Not keeping someone who is HIV positive mentally healthy only feeds the spread of the disease.

A mentally unstable person is more likely to be non-compliant with a medication routine and make poor choices involving health, nutrition, substance abuse, and sexual activity. So not only does this lead to both the HIV+ person becoming an AIDS

diagnosis, but quite possibly others getting infected. The end result no matter how you look at it is more expensive and more deadly.

One other thing you may not know. In order to qualify for Ryan White services requires poverty. How horrible! As if the diagnosis itself is not devastating enough. For instance, for Brryan to receive any service from the present care act, his family, five siblings, and myself have to remain poor. So it appears you not only punish the infected, but those affected must also suffer, endure more hardships, and have their lives controlled by the disease. A diagnosis of an HIV family member means the rights of the entire family are greatly compromised.

**BRRYAN:** The fight for all those infected and affected by HIV is different today than when Ryan White was alive. His fight was to try to stay alive until another medication that just might work was developed. My fight is having access to those meds which now exist. When the Ryan White Care Act was originally written, a diagnosis of HIV+ soon became AIDS and all too soon DEATH. But today, the medications can prolong life, reduce progression to AIDS and prevent DEATH, YET PEOPLE ARE STILL DYING. WHY? Because many refuse to see HIV and AIDS as a health issue and the government refuses to fully fund Ryan White to assist all those infected and affected by HIV in all areas of health.

In refusing to see the truth and by not completely

funding the necessary care and medications for all those infected, those in government are willing to allow people to die. Even if they say that they support fully funding Ryan White at its present level, what they really mean is we are choosing to kill millions of people with HIV and AIDS by not providing them with care and medication although it is available. Therefore, they are choosing who lives and who dies. More people are diagnosed every year, more people are living longer with this disease, yet no more money is set aside to help them.

**Editor's Note:**

*When the funding remains the same but more people need to use it, then either each person's share gets smaller or some people cannot be covered at all.*

It's like you have thrown us a bowl of mashed potatoes and told us to feed the world. Our prayer for you today is that you will find the courage to win the war against AIDS by choosing to save lives and fully fund the Ryan White Care Act at the necessary level.

**JENNIFER:** We can remember Ryan and all the others who have died of AIDS by saving Brryan and many more people.

**BRRYAN:** HIV to me stands for HOPE IS VITAL. So stand strong and pass it on. Thank you and God Bless!

Sponsored by TIICAN The Ryan White CARE Act, Title II, Community AIDS National Network, Inc.-Washington, DC

# IT'S ALL ABOUT FAMILY

BY DAYSHAL DICKS



Dear South Carolina HIV/ AIDS Council,

I have had HIV for 12 years. I was born with HIV ....but it's not worrying me at all. My name is Dayshal Dicks and I am in the 7th grade. I got a lot of friends.

My real mother had me living in a car until my grandma got me from her. I haven't seen her since then and my father has nine other kids. I haven't seen or heard from him but I don't cry no more. I use to cry myself to sleep at night, but now I got a family. I've got my sister, brother, cousins, and friends who like me as I am, not for what I got.

If it wasn't for the Lord and my grandma...for taking care of all of us, I don't think we could have made it this far in life. I now can make it if Magic Johnson did. Me and my grandma went to see him in North Carolina. He was saying you always must take your meds like he does. I do most of the time....or if I forget my grandma reminds me to get them all the time.

That's why I love my family so much. They care about me so much and I don't forget their birthdays. But they never get me nothing....but that's OK! I don't care that the only one who gets me something is my grandma. Every time I try to get her something she says no or she just takes it back and gives me my money. I don't take the money or I just go put some gas in her cars for taking us to school.

That's my story about me!  
Love  
Dayshal

## Working with HIV+ Youth and Teenagers In South Carolina One Social Worker's Perspective

Wanda Gardner, MSW

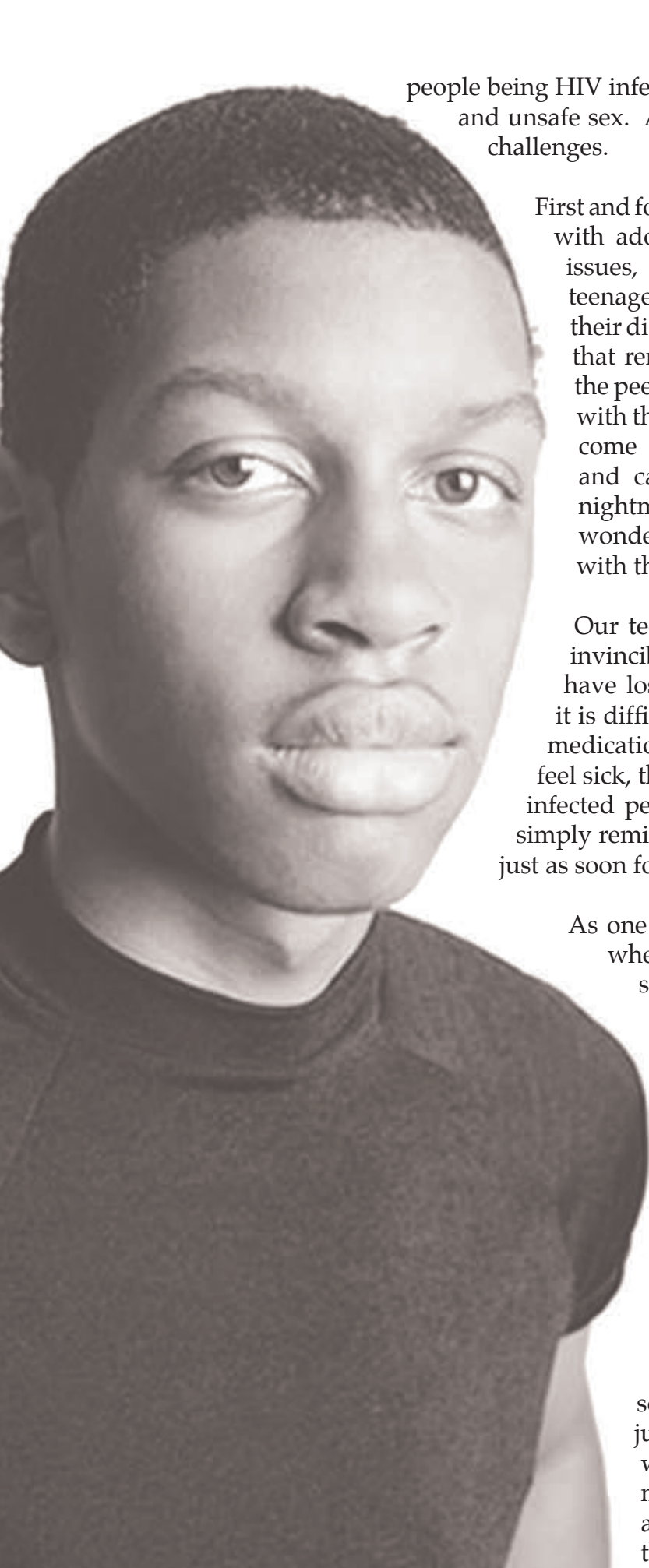
An image of an infant, an elementary school student or a teenage athlete probably does not come to mind when you think about someone living with HIV in South Carolina. However, there are approximately 640 youth and teenagers ages 0 – 19 infected with HIV living in South Carolina. Most of these youth receive their medical care in one of three facilities in South Carolina.

These facilities utilize a multi-disciplinary team approach in treating HIV+ youth and teenagers. Many of the patients

that we see were infected at birth after being born to an HIV+ mother (peri-na-tal transmission). Perinatal transmission occurs much less today because of the development of new drugs available to pregnant HIV+ women. Initially, few people expected these children to live long but today many of these children reach their teen and adult years and continue to do well because of better treatment options.

Unfortunately though, we are seeing greater numbers of young





people being HIV infected through risky behaviors such as unprotected and unsafe sex. As a result, HIV+ youth and teenagers face many challenges.

First and foremost, they face the normal challenges associated with adolescence such as peer pressure, sexual identity issues, and the desire for independence. Youth and teenagers living with HIV also face challenges unique to their disease. Challenges like taking multiple medications that remind them each day that they are different from the peers that they so much want to be like. Combine this with the fact that some of the medicines taste unpleasant, come in pill sizes that would make most adults gag and can cause side effects such as nausea, diarrhea, nightmares and discoloration of the eyes, it is no small wonder that medication adherence is a major challenge with the youth we serve.

Our teenagers, like most teenagers, think that they are invincible. Despite the fact that many of these children have lost one or both parents to HIV/AIDS, sometimes it is difficult to convey to our teenagers the importance of medication adherence in treating their disease. They don't feel sick, they are doing the same activities as their non-HIV infected peers... so why bother to take medicines that will simply remind them that they have a disease that they would just as soon forget?

As one teenager once told me, "I only think about HIV when I have to come here" referring to our clinic. I sometimes wonder if a teenager really has the ability to internalize the message, "Take your medicine and live; don't take your medicine and die."

HIV+ youth also struggle with disclosing or telling others about their HIV+ status. Do they tell anyone? Can they trust their best friend? How will they deal with dating? Who will want to date them once they find out about the HIV? Will they find someone to marry? Will they ever have children of their own?

These are questions that HIV+ youth ask but sometimes it is just easier to pretend that the HIV just doesn't exist. No matter how many times we describe HIV as a chronic illness that can be managed like other chronic illnesses, there remains a certain stigma around HIV. Our youth discover this stigma early in their lives from messages they



receive from the media, the community and their families. They know that they will not get the same response as someone disclosing that they have diabetes or cancer.

Realizing the stigma associated with HIV, many youth guard their HIV+ status very closely. Issues of disclosure and sexuality are discussed during clinic visits. The risk of passing the virus to others is emphasized. Teenagers are educated about the law which states that before they have sex, they must disclose their HIV+ status to their partner. Condom use is discussed. But some youth and their families want to pretend that they are not having sex.

The issues of poverty also affect our HIV+ youth and teenagers. If a family is facing eviction or termination of their electric service, a child not taking his medication is secondary at that point and time to that family. They have a more pressing immediate need from their standpoint. It is difficult to follow a medication regimen that requires you to take your medicine with food if there is no food in the house. Although these poverty challenges are not just unique to HIV + youth and teenagers, they do compound the already difficult circumstances that these kids face on a daily basis.

Yet we still must introduce to these youth and teenagers the need to keep moving forward in spite of their circumstances. We must stress to them that they must plan for the future and believe that this future is obtainable. Knowing these facts, it is even more urgent that we deliver the message home to these youth and teenagers of adherence, education and prevention. Although there are challenges involved in working with HIV+ youth and teenagers, we also have the opportunity to share in celebrations. There are honor roll certificates, sports accolades, successful adherence stories, high school graduations, college acceptances and job opportunities.

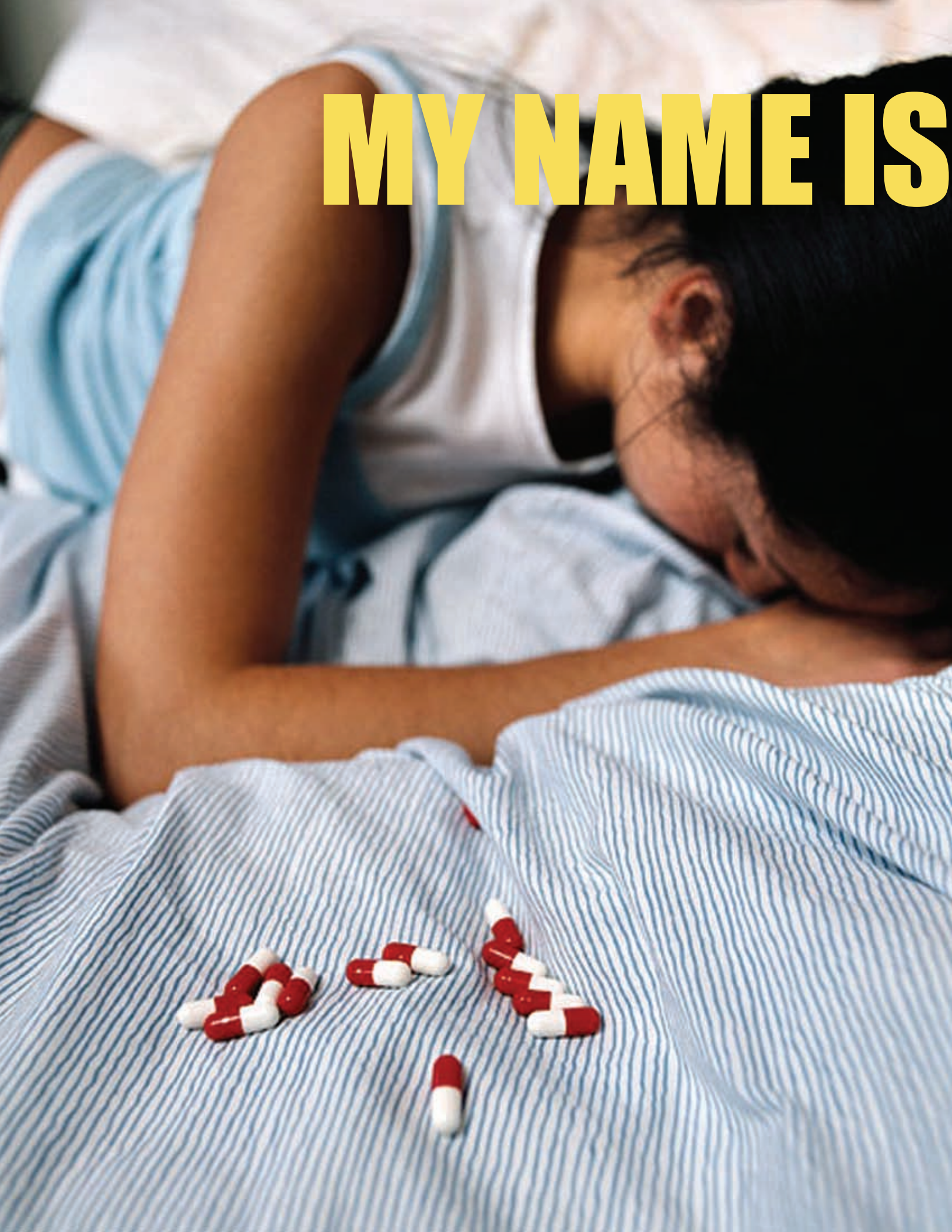
I recently received a phone call from

one of our former patients who is now being followed through adult services. This patient was followed in our clinic for several years and faced the challenges of medication adherence, stigma, poverty stricken home life, and she dropped out of school before earning her high school diploma. However, before she left our clinic she finally got the message of medication adherence and took control of her illness. She contacted me recently to say that she is living independently and recently earned her GED. This same teenager now wants to be an advocate and share her challenges and her triumphs. She stated, "I have a story to tell and I think others should hear it." I totally agree that her story is worth telling!

As we see the increase in the number of young people infected with HIV through risky behaviors, it is important that we strengthen our prevention and education efforts with this population. Youth and teenagers must also take responsibility for their actions and strengthen their resolve within to eliminate or minimize at-risk behaviors. We as a community must work together to reduce the stigma associated with HIV and embrace the fight against HIV as if it were a part of us, because truly it is a part of us.



**MY NAME IS**



# SAVANNAH

By C.M.

This story is about my family and myself-although I know that it's supposed to be about me and my true feelings about my sickness. I am a teenager that lives in South Carolina...I have been living with HIV / AIDS for 16 years, and I'm still trying to cope with the illness.

I am very blessed to be here in spite of the illness. When I was born, I had some difficulties breathing. My mom said I was born a "blue baby", which means I wasn't getting enough oxygen to my lungs. She almost lost me three (3) times during her pregnancy. But thank God I'm here!

My mom explained to me when I was 13 years old how I got infected, but I don't blame her because she was infected by her first husband. She started to tell me all about it but I told her, "No"...I already knew how much she was hurting.

Sometimes I get angry about what he did to my mother and me because without this illness, I could have had a normal life. I also feel cheated.

It goes back to when I was 3 months old and I started having surgeries. I had a thyroglossal duct cyst (thy-ro-glossal-duct-cyst--- that means they removed a cyst from my thyroid in my throat). Shortly after that I had pneumocystic carinii pneumonia (PCP-a special lung disease only HIV positive people get). I kept getting them to the point where it damaged my lungs and left scar tissue which made it even more difficult to breathe.

So every 2-3 months I have to go into the hospital for a "tune-up" which means that they put me on antibiotics and breathing treatments to help clear my lungs. My mom says that she can tell when my lungs are getting worse because I use more oxygen from my tank. She says that my energy level gets lower, I'm tired quicker, and I am very sleepy.

You know, at one time I didn't have to use my oxygen so much, but now I have to use it constantly. I feel trapped having to wear a canula (A flexible tube that is inserted into a body cavity, duct, or vessel to drain fluid or administer a substance such as a medication) everywhere I go -- to bed, the grocery store, even shopping. If I didn't have it with me, I get bad headaches and my heart starts to race from lack of oxygen.

My mom tries to educate me as much as possible when it comes to this illness. She always stays on me about my medicine and I STAY ON HER. It gets tough sometimes, but we make our way through it. We make excellent team partners, even though my Mom has been on dialysis for six (6) years and carries the virus. She's a strong woman and an excellent role model when she's tired....she still pushes on!

My mother and father have always said that I have my mother's ways. I am always pushing myself even when I need to rest. My father never wanted to see me angry or sad so he would buy me anything and also gave me money. I had two beautiful parents and now I only have my mother. My father died two years ago on Labor Day (September 5, 2005).

Sometimes I really miss my father and I can't believe he's gone. I also have three siblings total but my oldest brother Michael is deceased. The eldest girl is 26 and she has three children. Last, but not least, the youngest brother is 21 and he helps my Mom and me as much as he can. He sometimes has plans with his friends and girlfriend but cancels them if anything comes up with my Mom and me. He's very caring, even though sometimes he gets on my nerves. I love him and I ask God for nothing else to happen to my family, any of my family members.

# ANOTHER REFLECTION

## "Living With AIDS Without Shame"

by DAYSHAL DICKS



I sent this to Ms. Bambi because I need you to know something else.....

I think that HIV/AIDS is not dangerous to me. I guess because I had it for 13 years. The only thing I am wondering is about the kids that are 4 years and older that are living with it and if their mothers and fathers are giving them the care they need.

At first, I was scared to talk about it. Now, I am not because it is on me. I did not like MaMa because now she is missing and I sometimes think about her. I wish I could find her by myself. I am going through something because when I had a boyfriend, I was in love with him. By the third week, I told him that I had HIV, he said, "It is over".

I said O.K. then he started to talk about me behind my back. I told him that I have HIV and it is not anything you can say about it. I told him what he said will not hurt or break me. I am going to be the same person I was before I met him.

When he told me that it was over, I now know how my MaMa felt when the men let her down. I know I was not going to let him put me down because I am a Black strong female that has a lot going for her. If someone in his family wants to know, I will tell them. His aunt died with the same thing I have. He is trying to put me down and it is not going to happen. This is the end of my story. I hope that you like it.

Sincerely,  
Dayshal Dicks

# LIVING A LIFE OF AIDS WITHOUT SHAME

## "A Grandmother's Story"

by Wilhemina Dixon

Dayshal came to live with us when she was two months old. When Dayshal came to live with us we let everyone in the neighborhood know she was HIV positive. Although the community knew about Dayshal's disease, they made no difference in her and the way that she was treated.

When Dayshal was four years old, I tried to enroll her in Headstart where I explained to the teacher that she had AIDS. The teacher began to

cry. I informed her that it is O. K. to be afraid because I once was, but I would want Dayshal to be treated like everyone else.

When Dayshal was five years old, she was involved in a car wreck. Dayshal let the nurse know that she took AZT. If she did not tell them, they may have wrongly diagnosed her and given her the wrong medication or some medicine she wasn't supposed to have.

When Dayshal was six years old, she started to school and I did not know what to expect. So I told her that you are going to school to learn and not necessarily to make friends. One day I picked her up from school and she told me that I have something to tell you. "Ma, I have 200 friends". It caused me to turn my head with tears in my eyes.

My husband took Dayshal to the Doctor. They refused treatment because she was not on her father's private policy. What if I had been killed in a car wreck? Would my child never get to see a Doctor again? I understand the laws. We drove from Williston, South Carolina, to Columbia, South Carolina, and were sent home without my child being seen by a doctor that day.

Dayshal is now 13 years old. We are talking to her about condoms and birth control. Telling her how she needs to be careful because of her sickness. That she would not want to bring a sick child into the world. How important it is for her to be honest with her mate about her condition.

The reason why it is important to tell children early is because as they go through school, they establish friendships and bonds. If they wait until the child is in Junior High school, they have to explain to their friends at that time ...then their friends may walk away because they are scared.

My focus is to reach out to the youth and AIDS and to let them know that you do not have to be scared. We need to stress the importance of educating the children that this disease is not just a sexual disease. There are other ways of contracting the disease.

Tell them to speak out because it is nothing to be ashamed of, because it is no different than a person having cancer. Despite what they may have, the sky is the limit. One speaking out could help a whole nation.



# LIVING WITH HIV AND CONQUERING IT

BY  
CRYSTAL HILTON

I am a young, black, single, independent woman. I am also HIV positive. I have lived with this virus for 20 years. I was born with this virus and have lived with it my entire life.

It all began in the year of 1987. My grandma said I was a very sick baby and the doctors didn't think I was going to live. Not only was I an infected baby, I was born with drugs in my system as well. My mother was a drug addict, so there were different types of drugs in my system.

The doctors first gave a few months to a year to live once they saw how sick I was. My grandma took me in as a foster child at 5 months. I was always sick and crying and my grandmother said when I cried there was nothing she could do to make the pain go away. She said the doctors still tried to predict my future and told her I wouldn't last long. They told her I would not live to see the age of 3.

My grandmother adopted me when I was 5 years old as her daughter. My grandma and I

then moved to Florida from New York. We had some ups and downs, some good days, and some bad days with my health. My grandma also had diabetes and I know it wasn't easy for her.

A year later she moved my sister with us from New York. My sister helped out a lot with me. She would do my hair, make sure I took my baths and give me my medicine. I knew my grandma was happy cause she got a break at the same time.

After a year with my sister, she moved back to New York to live with our mother. I didn't really get to know my mother. We didn't have that mother-daughter kind of relationship. We looked just alike with the same personality and everything. I just didn't get the chance to really know my mother. During 1998 my grandma got a phone call that my mother had died. I was sad, I was hurt. Although I didn't really know her I still loved her so very much.

My grandma told me we were moving from Florida to South

Carolina. She said she didn't want to move back to New York with her getting older and everything. I never wanted to move to South Carolina, I just knew it was a bad idea.

My first year was OKAY, and then I started making friends at school in the 8th grade. Things slowly tried to get crazy. All of a sudden I had one friend and another and another, but this one girl stood out. She stood out because she gave me the most trouble.

I noticed the students whispering every time I entered the room, but I didn't give it a second thought! The girl that stood out, the girl that was supposed to be my friend, started asking me questions and the next thing I knew she started picking on me saying, "That I Had AIDS".

It seemed like ever since then my life just spun out of control. The girl I thought was my friend was never my friend. I don't know what she told people....but it seemed like everyone just had to know was it true. I would get phone calls, some late at night...





"Is it true?" "Do you really have AIDS?"

I would say no or just hang up. There is a difference between AIDS and HIV, but even if they would have asked me if I had HIV, I still would have said, "NO"! Back then I was embarrassed. I didn't want them judging me. Plus, it was none of their business! I was a very private person and that to me was definitely private. Too private!

It just felt like it was the end of my life because it was the talk of the town. The girl and I (who I thought was my friend) had a couple of classes together. Sometimes she would make sly remarks, or comments with

me and the word AIDS and the students would laugh and pick on me. This went on from the 8th grade until now.


That's right, it's still going on til this day. It's not as bad now as it was then. The town I live in... the majority of the people are ignorant when it comes to HIV/ AIDS. They have no idea how they almost destroyed me. Some adults and teenagers tormented me in school.

I feel that the school robbed me in my education. I never got to finish high school. I was scared to go to school and face another day of torture, being teased and tormented because of my illness. I finally found out the truth of why they kicked me out

of school. They didn't think the other students were safe with me there. My grandma told me more than once, but I didn't believe her because I thought she was just saying that so I would take my medicine because sometimes I didn't want to take my medicine.

Turns out my grandma was telling the truth. I knew my grandma wouldn't lie to me. I guess in a way it kind of hurt me to hear that people were actually scared of me because of my HIV. I think my grandma probably knew a little bit of what was going on because she would ask me was something going on at school?

But how could I tell her that I



cried myself to sleep at night. How could I tell her that I hated going to school? How could I tell her that the students were tormenting and teasing me because of my illness? How could I tell her that I hated what I saw in the mirror? How could I tell her the HIV was ruining my life?

I didn't think I was going to be able to tell her but I told her. I told her the kids at school didn't like me and were picking on me because of my illness. My grandma told me to ignore them, then once she seen how it was really bothering me, she asked me if I wanted her to talk to the principal? I said no because I knew it would make it worse. I just wanted all the teasing to go away.

I was expelled from high school in year 2003. My grandma found out she was diagnosed with colon cancer and passed away in the summer of 2004. My grandma was my mother, my father, my best friend, my everything! We didn't always see eye to eye, but we were very close. She was the most beautiful, wonderful, loving, giving, unselfish, kindest, and caring woman I knew. She was so strong and amazing, she was the perfect grandmother. She was the greatest mother.

For years I've been ashamed and embarrassed by my illness. I knew it wasn't my fault, but at the same time it was nothing to be proud of. I didn't know how to be open or comfortable about it until now. It took years....but I know my grandma wanted me to be safe, that's why she didn't want me telling anyone because she knew the people wouldn't understand or know how to act. She was trying to protect me and it took me years to see that.

I got my GED in 2007. People have tried to put me down, doctors have tried to predict my future, and some of my family said I wouldn't be anything. But I've noticed something...I have been proving people wrong all of my life.

I have conquered and accomplished so much in my life to be proud of. I've got my health under control. I've gotten my education and I've taken back control of my life. I am in control. I am going to control this virus. I'm not going to let it control me.



# **CARING WITH CONFIDENTIALITY A PEDIATRICIAN'S PERSPECTIVE**

**Tracy Macpherson, M.D.  
Pediatric Clinic  
Orangeburg, South Carolina**

Imagine you are a 16 year old male. You begin with a fever, muscle aches, and have a strange rash that comes and goes. Your mother reassures you, "It's just the flu, don't worry". But you do. You know that you had a sexual relationship with a man that ended three months ago. In an attempt to subdue your fears, you refer to the internet. You educate yourself about the early symptoms of HIV, and your fear only grows larger. As the fevers and aches continue, you go to your doctor without telling your parents. You only want to hear that "you just have the flu" from your doctor.

During the exam, your fever is confirmed, the rash has reoccurred, and the doctor finds some concerning enlarged lymph nodes. Privately and unexpectedly, you are asked, "Have you had unprotected sex?" You confess but are conflicted...do you admit to the complete truth? You fear the possible diagnosis, you fear possible exposure of your sexuality, and you fear your parents' response.

Imagine now you are this young man's doctor. HIV and other STDs are among a long list of possible diagnoses. You have ethical and legal issues to tackle in order to make a diagnosis, and in turn, initiate treatment. Providing confidential medical care for adolescents fills you with conflicts too. You have concerns about all the possible diagnoses and that he may not want to involve his parents.

#### **Editor's Note:**

***Optimal care for adolescents and young adults requires an open and honest relationship; confidentiality is an essential ingredient.***

Caring for adolescents, whether HIV positive or not, can be complicated. Adolescents at the age of eighteen as well as emancipated minors are legally capable to consent to their own medical care. The care is completely confidential. That's simple. While state laws vary, mature minors are considered fourteen and older. They may consent to medical care (but not surgery or other risky procedures) if the health care provider believes they possess the intelligence and maturity to give informed consent to the care.

This may include, but is not limited to, seek-

ing contraception, the diagnosis and treatment of sexually transmitted diseases, or obtaining outpatient mental health services. However, ethically, the clinician should only break confidentiality and involve the parents if the young man's immediate medical health is in danger, he is threatening the life of another, or if the clinician judges it to be in the best interest of the patient. That's not so simple.

Referring back to our scenario: While relatively minor illnesses like mono, or more serious illnesses like cancer, lupus, or juvenile arthritis can all cause these symptoms, missing an early diagnosis of HIV could be devastating. The doctor can most certainly initiate the evaluation of a patient without initially involving his parents or revealing his sexuality.

What if the diagnosis is cancer? No one would disagree that the parents need to be immediately involved and treatment started as soon as possible; this is in the best interest of the patient. While our young man must be privately counseled on the importance of protected intercourse, what if the evaluation reveals a positive HIV test result? What are each of our responsibilities as doctor, parent, and patient?

The doctor's role is to discuss the policies on confidentiality with both the adolescent and their parents long before help is actually "needed". All must recognize that confidential health care is essential in teen care but acknowledge that confidentiality may need to be broken in certain situations.

The parents' role is to maintain routine health care visits. These appointments serve many functions including preventive care, anticipatory guidance, and maintenance of the doctor-patient trust/relationship. The parents must respect their child's need to have a medical confidant (a doctor or nurse they trust). Finally, the patient must be honest with his doctor; difficult and sensitive issues may not otherwise be resolved. The teen must trust that his doctor will act in his best interest. Likewise, it is important for teens to communicate and pursue support from their parents.

Medical care for adolescents can be ethically and legally complex but can also be exceedingly rewarding. Confidentiality is the cornerstone to its success!



# **"HAD I ONLY LISTENED"**

**A SIXTEEN YEAR OLD YOUNG MAN'S JOURNEY**

I am a 16 year old male and I live in Richland County. On August 21, 2007, I found out that I was exposed to HIV and I know how I got it. When I was 15 years old I met a person that I thought I was deeply in love with. I would have done anything for them because I thought they were honest.

But me falling so deep into our so called, "relationship", I never thought they would be the one who would change my whole life upside down. I never had a thought in my head about them giving me anything. Even though my Mom said no, I moved in with them at 15 and I loved everyday of it. But I always had doubts in my head, because everything seemed so perfect.

Into the first six months that we were together they started to

change. They started to lie and cheat. I never got upset with them and I would always forgive them every time they would lie. I would just sit around and ignore it because I loved them and thought they could do no wrong. Then one day while I was home alone their aunt came over and sat me down. She asked me had I been told they were HIV positive. I just stared at her in shock because I never thought they would do anything like that to me.

That same day I called my Mom and told her that they knew they had HIV two years and never told me for all of the months we were dating. So I stayed at the house until they got off work. I asked them did they have anything to tell me. They said, "No". I asked them again

and they still said "No". I asked them, "Are you HIV positive?" They asked, how did I know?... in an aggravated tone. I couldn't do anything but cry. It seemed as if they didn't even care at all.

The next day, I went to the clinic and got tested for HIV. I was so nervous. The clinic told me to come back in three weeks. Everyday I would call to ask the clinic if they had my results back. They always told me, "No".

Then I called the third week and the clinic said to come up there. The person who exposed me to HIV took me to the clinic as if they really cared. It finally hit me...it was just a game! When we arrived, a doctor came up to me and told me to follow him. The whole time I was scared and couldn't do anything but shake



and bite my nails. Then the doctor told me that I was HIV positive.

I cried right in front of him. Then he asked me did I know how I got it. I told him, "Yes". I was afraid to get my partner in trouble so I brought my self-esteem down by saying that I contracted HIV by sleeping with plenty other people. I said it knowing that I was not that type of person. I wanted to tell him that I had only been with one person in my whole life...that I thought I loved them.

When we left, my partner took me to their house and left. I was angry wondering where they were going. I found out the next week that they were having relations with other people. They had been with more than four (4) different people without

telling them their HIV status either. That just didn't seem fair to me..... so I told them I was leaving and wanted to go back to my mother's house.

The next day I went to school and it felt like hell because everyone knew what had happened. I haven't found out yet how they knew about it. But on January 1, 2008, I stayed up all night praying and asking God to help me get back to the way I was.

I wanted to be happier like I use to be. That same night a song came on the radio by Jill Scott called "Come To The Light". As I listened to the words it touched me to a point where I called my partner. I told them that we are over and it was then that they told me they had moved to Atlanta with their sister. It was then that I was happy for in that

moment I knew that everything my Mom told me came true. She told me not to trust him. She told me not to leave the house. She told me not to have unprotected sex. But I had to be hard-headed! I knew I caused all of this on myself. But I also learned that the only people that care about me are the people who have not left my side yet! They were also the ones that while I was so caught up — I treated them the worst.

Living my life now with HIV is actually not as bad. Now I am more aware than I was before I found out I was HIV positive. I am happier because I finally got my old life back. People now seem to ignore the so-called "rumors" and treat me the same again!

## "TO WHOM IT MAY CONCERN"

By Crystal Hilton

Tall, short, fat, skinny,  
black, white, man, woman,  
straight, or gay  
I don't care who you are,  
what you are,  
or what color you are.  
I don't discriminate  
against anyone  
The bad thing about it,  
I come with no warning  
No Love.

I'm indestructible, fearless  
I know no name.  
I have no mercy.  
I'm careless and heartless.  
I can take your loved one.  
I can take your friend.  
I can take your neighbor.  
I will take your children.  
I don't know good from bad,  
nor wrong from right  
I'm very dangerous and can

change your life  
I can control you, hurt you  
Destroy you  
Harm you  
And anything else I want to you  
But Only if you let Me  
If you are not smart  
And Play It Safe  
You Can Rest Assured  
I will be out to get you next.

Sincerely Yours,  
HIV

# A CONFUSED AND HURT MOTHER

I am a confused woman who has a lot of pain. Who would have thought that I, a young mother, would be trying to focus on keeping my son alive and healthy instead of thinking about what college he wants to go to, or how many kids he would want to have when he is of age, or what will he be when he's grown.

Instead we have to focus on him being HIV positive because he did not listen. He had a partner who just didn't care. Now my son's whole life has changed.

He has to go to many doctor appointments and I must go with him. I have to take off from work a lot. Thank GOD for a wonderful boss because if she was nasty, I would get in trouble, if not FIRED!

When you have HIV in the family, people treat you different. In school and your family and it's because they don't understand. My family has turned their backs on my son and it hurts.....but that's my child and I will be there until GOD calls me home.

Now that my son is HIV positive he gets NO male support. No support from his father (NONE), his stepfather (NONE) or his so-called friends (NONE). It's just ME now! I sometimes wonder why?

He's my child, but why not? I feel so alone. I hurt so bad sometimes. I want to give up--but my son needs me! I sometimes look at him and cry inside because he doesn't have a teenager's life.

If he ever gets serious with someone again, he will have to tell them and they may or may not stay. He really has a lot of pain and very little joy at this time! That's why I am a confused and hurt mother with a lot of pain!

Please pray for me!



## CHILDREN'S CORNER

### Out of the Mouth of Babes

## "WHO ARE THE PARENTS"

By Nyheme Sumpter

5th Grade

Lexington Intermediate School

Who are the parents?

Do they have no self esteem?

Well.... Probably...

If they have sex unprotected do they care for their children?

Maybe not!

If they did.....wouldn't they use condoms or test their self and their partner?

Those having HIV / AIDS could affect their children's lives!

So help your children!

Parents should be a good role model for children.

One way to help them is to tell your partner to use a condom.

Another way is to not have sex till you are married.

If you or your child has HIV / AIDS let them know.

Tell your children the truth.

So listen to these ways

and your children can be saved!

**"YOU ARE THE PARENTS!"**

# SOUTH CAROLINA HIV/AIDS COUNCIL

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  - ▼ **Syphilis Elimination Community Intervention**
  - ▼ **HIV/AIDS/STI Program Development and Capacity Building Services**
  - ▼ **Mental Health Counseling**
  - ▼ **Group Level Interventions**
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