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HIV Won't Defeat Me, "And I Don't Surrender to Stigmas and Judgments!"

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Introduction

I've taken that AIDS acronym, invested in it as a trade name, and ran with it. First, there are some things I have surrendered to like, domestic violence, some drugs, liquor, and smoking. I have also surrendered to low self-esteem, depression, and slitting my wrist. After that pity party, and by the way no one showed up at that party, an older woman with HIV told me to get up and live.

My name is Miriam Whitehead-Brice. I got married in June 1997. I went to see an ENT Doctor, in February of the year of 2000, because I had a sinus infection that lasted too long. He looked in my nose and commented that I had a deviated septum. Then he said he had seen these problems in patients that are HIV positive. He asked if I ever been tested and casually kept talking. He went on saying more but, I was still stuck on that initial comment of being tested for HIV. In a daze I responded, "No". We stared at each other as if we were in a "who will blink first contest". I lost and started crying. He commented that there were worst things than

HIV, HIV, HIV, HIV, was still ringing in my ears as I walked out of the Doctors office and out to my car. Who? How? When? Why? Those words were now ringing through my brains.

I got tested and they said that it was caught in time. The Counsellor commented that I had it for about 3 to 5 years and was almost AIDS defined. I stared at her with a blank look on my face. My comment was, "guess I will have to look that phrase up, AIDS defined". The counsellor started talking about life expectancy, calls from the health department, giving me brochures, and I stood up and shouted, "STOP talking". She told me to be calm as I called my husband and told him. He drove down to the clinic. He held me and said, "Our vows say in sickness and health. I love you. I'll keep you here as long as I can". I looked at him and repeated the end of his sentence, "as long as you can!" and then went back to sobbing. I had a secret now and, I am usually an open book. I had lost weight and became paranoid. I tried to take one day at a time but, what if my time was almost over. I wanted to hide, disappear, and go back in time when HIV was on my door and I did not open it.

Paranoia had saturated my soul. I was a mess, a wreck, on edge and walking around screaming from within. My eyes darted from side to side to see if someone could hear me. My

husband went with me to the first of many clinic appointments. I stared at others in the waiting area thinking about the reason they are here. Just as I was going to burst into tears they called my name. I insisted that I be the very last patient or the very first with no one else in the waiting area. The Doctor was very pleasant and made sure that I was the very last patient from then on. She was very assertive when it came to medication adherence. I told her how I had shingles the year before and she said something about an opportunistic infection. She told me I should have gotten test then! She then talked about medicine regiments and cocktails. She told my husband to get tested again. She talked about stigmas and judgments. She asked me about disclosing to family and friends. I said yes, to my immediate family but, not to my children. She pointed out a very good support group and Psychiatrist.

At first medication adherence was a problem because, I was not used to taking medicine; let alone medicine for a lifetime. Education and communication became my focus during doctor visits. Speaking truthfully with doctors will compliment your appointments. Talking about even the smallest details can prevent destruction! Keeping up with doctor appointments was overwhelming at first but, necessity overrides overwhelming. There was a time I was given a "medicine holiday" to prevent resistance of the medication because, I would eat a meal and take my HIV medicine and just throw-up the pills. This was because emotionally I was still in denial somehow. I had to get all my faculties together to live successfully. A stable mind-set leads to good health. Adjusting your diet and exercise is also good medicine. Survival is a must and staying undetectable is an avid goal.

I kept my appointments, and all was well. I joined a support group and I cried during sessions, not from their stories; from thinking how my world was never going to be the same. I told some close friends. One family member was concerned about what others may say about me. My psychiatrist wrote me another prescription after I cried telling her about my family's discussion about me. They had a family meeting without me because, it was about me. I faced stigma and judgments head on. I asked my primary care physician "why he did not suggest that I take a HIV test when I got shingles?" He told me that I did not look like something was wrong with me. "Was that a stigma or judgment", I asked? He waved me off. That was my last time seeing him. Stigmas and judgments were attached to this

disease like an overweight caboose slowing down the journey or process to your destination. Stigmas can hinder your optimism and judgments can upset your values and self-esteem.

One day at my former job, they had a type of Fair. Different vendors were available to help the employees. I did not have life insurance, so I filled out an application. I was truthful in answering the questions. I handed it to the person behind the table. I then moved to another table with jewellery on it. The Insurance Representative jumped up from behind the table yelling my whole name. Her voice was high, excited, and loud as she exclaimed, *"You made a mistake on the application"*. She was out of breath and noticeable. *"You checked that you are HIV positive and you are not!"* The room suddenly got quiet and the listeners were listening, and the busy bodies were watching! I said back to her in a semi loud voice that I apologized, and the Representative scratched it off. I immediately went to a phone and called the insurance company and told them what happened and said their representative needed more training. They took money for the Insurance out of my checks for about a couple of months and then sent it back as a refund and a notice of not being qualified for that life insurance.

Every three months or so, I had to get blood work done. This was for an update to see if the medicines were working and to make sure other things in my body were okay. It was a little chilly that day so, I had on long sleeves. After my name was called, I went back to get my blood drawn. I watched the phlebotomist pick up her orders. This woman, this so-called medical professional, started huffing and puffing, sighing loudly, and slamming vials and paperwork around! I knew at that moment the phlebotomist assumed I had contracted HIV intravenously. She thought finding a vein might be difficult. Quietly, I rolled up my sleeves to reveal gorgeous, thick, and visible veins. Then a sigh of relief was heard from this phlebotomist. I am known to be witty and quick to respond. My intentional and tactful responses showed no signs of filters, at times. This time wisdom took a hold of me and I just blurted out that I became HIV positive from unprotected sex. It was hard for me not to say anything else. The woman thanked me without an apology. She told me that she needed to hear that. I turned my head and held back the tears. I realized that my purpose should override the pain but, my courage and faith went missing!

At another medical facility, while I signed in, the receptionist read my paper work with an attitude. I watched as she read my diagnosis and passed it to the other women working in the reception area. They started pointing and giggling. Later, all the other patients that came into the office after me had been seen and left. I noticed that a different group was now with me waiting to be seen. I also realized more than an hour and a half had gone by. I questioned the receptionist and the other women smiled and smirked. Anger boiled up in me as I blatantly stood up beside the receptionist desk and stared at her until she became uncomfortable. Thoughts of violence raced through my mind along with hurt and discouragement. The doctor came out and I got very loud and my words were not pleasing. The doctor made an excuse for their actions at the front of the office. I left with my head held high and my esteem buried beneath embarrassment and disgust. I was on psychotropic medicines

and wondered why I was having these angry and depressed feelings.

Why didn't the medicine kick in? Seroquel, doxepin, trazadone, abilify, and lithium, where are you? I really needed them to cover me at that time. I should have politely spoken to the doctor. Sometimes it's gets hard dealing with stigmas and judgments. I could have educated them on HIV/AIDS; missed that window!

Depression got a hold of me and it would not let me go. I became great at masking my affections and moods. I slit my wrist one evening. It was like looking at a bystander cut my lower arm two inches up and down. After realizing what I did, I drove myself to the hospital. I served three days in a mental facility. I know I wanted to live but, confusion wrapped around me like a blanket in cold weather. My family was deeply concerned. My husband did not know how to react! After coming home from the hospital, I decided to talk to my children. Their response was phenomenal. My middle child said, *"Ma, you can do this. You were made for this"* the other two said, *"Is that all? We love you and we knew you were keeping a secret but, no one would tell us."* They made the difference in my life. I pressed pass the hurt to live for them.

I took a HIV/AIDS Teacher and Instructor Course, I was more mentally sound. I wanted to find out more about what I was going through. If you are planted on a firm foundation of confidence and a seeker of endurance you will survive. Only for a moment can petty influences abruptly idle your position. If you cannot move from that initial diagnosis I urge you to go to a support group. Just listening will help with some healing.

There is a difference between being set apart and being alone. I choose to believe I am set apart. With that mentality you move forward and let others know you can live, function, and enjoy life. It's okay to cry. Keep in mind; either you are going to be a victim or victor; a catastrophe or a catalyst to help another. That can set the tone for a day by day mind-set. Informed education helps when speaking to family members and friends. Understanding how to accept rejection is important. Yes, rejection, stigma, and judgments can leave a sunken feeling in the pit of your stomach. If your heart beats to an optimistic beat, you shake the dust off and keep it moving. At times the dust can get muddy but, that can come off too! *"This is where my faith and courage collide! Someone needs me more than I need to hide!"*

I had my first book signing. The book contained some spiritual poetry and needed editing but, the content was inspiring. More than sixty people showed up. I told the audience that since 2000 the doctors also diagnosed me with lupus, fibromyalgia, asthma and phlebitis. I needed a completely new right knee. They also said I had Trigeminal neuralgia, Also, and six screws and rods were surgically placed in my lower spine from degenerative disc disease. In addition, I was Bipolar with anxiety issues and had a history of an attempted suicide, OCD, HPV (some cancer cells frozen), a torn rotator cuff and cataracts in both eyes. Endometriosis, bursitis, three cysts on my left kneecap and osteoporosis, peripheral autonomic neuralgia, Raynaud's syndrome, sinus problems, and acid reflux are all in this one

body. I now have a new right knee; my left shoulder and right shoulder have been repaired again, four screws and two latches placed in her upper neck (spine), and four toes repaired. My thirteenth surgery was in October 2017. During July 2018, the lupus “butterfly-rash” appeared and so did vasculitis. I’m a walking miracle and battle at the same time.

I came out of the proverbial “HIV closet” The clinic that I attended HIV group therapy with, asked me about working there. I went from client to co-worker. I learned about Planning councils, Ryan White Funding and more.

It took about five years to get to that point in my life where tears would not fall for pity’s sake; and a couple more years of Psychiatric therapy, group therapy, and keeping it a secret therapy. As people found out, the word rejection became like a callus on a construction workers hand. I got used to it and continued to build. There is a certain level of comfort when you understand your purpose. That, “why me” place has been demolished by “why not me” I understand now, I’m supposed to accept and make lemonade with these lemons placed on my table.

My husband and family pray for me and participate in my health also. They go with me to some support groups. At first, they were very concerned. Now since I’m out in the open they ask me to speak at their jobs. My mother and sister are Professors with Doctorate’s in Theology. I speak to their classes about HIV/AIDS and behaviour change. My family prays when I cry and laughs when I laugh! They are a big part of my support system. Some family members and doctors are still shocked that I’m alive and well. They’ve had friends and loved ones pass away from the complications of HIV/AIDS. They look at me with loud thoughts of, still hanging in there, type gestures! Some choose not to be around me. A person asked me if she could interview me because, I had no shame. I went to respond negatively but, the look in her eyes was sincere. She was not aware of what she said. My cousin always announces that, “Miriam is a miracle.” People will be people!

My appearance is always neat. You do not know what I am going through unless I tell you and then you would think me a liar. Currently I’m a Published Author, Wife, Mom, Grandma, Poetically inspiring speaker, Minister, and HIV/AIDS Activist. I volunteer at Food pantries and I’m a Volunteer Chaplain with Baltimore City’s Police Department’s Chaplaincy Program. Yes, I wear many hats, but I keep the baggage low. I cannot afford to be stressed out. I’m HIV positive so, I might as well have a positive outlook on life.

After twenty-one years of marriage, my husband and I still like each other. I found out that I’m in a “Serodiscordant relationship.” I’m positive and my husband is negative. I wrote a book of my memoirs entitled, “And I Don’t Surrender, to Stigma and Judgments” and a children’s book called “My Grandma is HIV Positive” coming soon!

I joined an organization called “O.W.E.L. (Older Women Embracing Life)”.

We meet the first Wednesday of the month. We are a group of women that are mostly fifty and older infected or affected

with HIV/AIDS. We talk, share stories and testimonies, love, laugh, and learn about how to better manage are bodies and communities. So far, it’s the only older women’s group of its kind. I joined and became one of the four Spokes models for the “HIV STOP WITH ME Campaign” for the state of Maryland. I was on buses, billboards, the radios, and signed autographs. People wanted my autograph on a picture advocating HIV/AIDS, Wow! I am also a member of “20/20 Leading Women Society”. Women that are infected with HIV/AIDS are recognized as leading women because of their works in communities. They are making an impact on the lives of others whether infected or affected.

“Could I do more,” is what I asked myself? I started a non-profit organization, which in its grassroots stage called, “The S.Y.S.T.E.M (Share Your Story To Empower Many)”. That woman who told me to get up and live had passed away without me knowing or telling her how she changed my life. If she was there at my initial diagnosis maybe I would not have gone through so many changes, let stigmas get to me, and hear the silent stares of judgment. I took some grant classes and learned how to write up a business plan and just like that I found myself being the Founder of an organization.

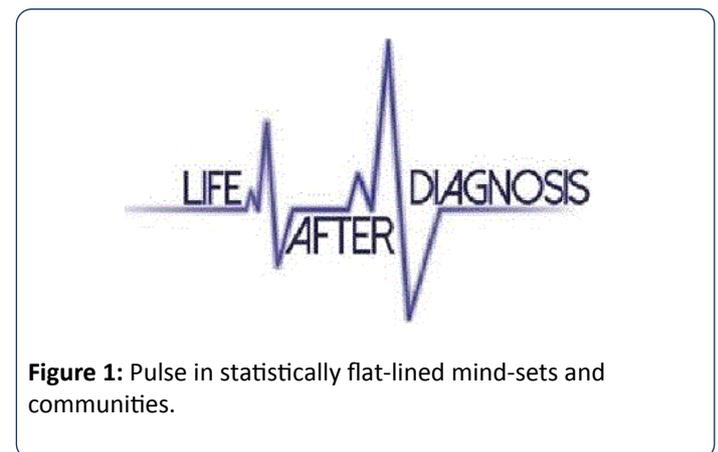


Figure 1: Pulse in statistically flat-lined mind-sets and communities.

The S.Y.S.T.E.M promotes “Life After Diagnosis” (Figure 1). We promote life after any diagnosis. What you go through in life should not shut down your assignment. It should enhance it, qualify it, and be deemed necessary to share. After almost a decade I chose to tell the world that I’m HIV positive with an undetectable status. From the United States to England’s TruthLoader.com I’ve shouted, “move over world and make room for me”. I’ve spoken in a lot of arenas to the young and old about HIV. I say, “Have that relationship! Write that book! Be a positive and functioning member in your communities and workplaces!” Yes, you will face adversities, fears, stigmas and judgments. Someone is waiting to hear your story, so they can be hopeful and want to live.

Yes, that initial diagnosis can be life changing. At first my thoughts went through a spiraling kaleidoscope. When facing stigma, I understand, they are not educated. When I walk into a room, and people know about me being HIV positive, I think that I make them uncomfortable and wonder about their unprotected sexual practices. When people attempt to judge me, they are forgetting what they have done this “high horse mentality” can be disturbing; then I realize that there is “no

horse” they come from a place of hurt. I choose life. *“And I Don’t Surrender to Stigmas and Judgments”.*

“I seek to create a pulse in statistically flat-lined mindsets and communities”

Be a part of The S.Y.S.T.E.M. (Share Your Story To Empower Many)