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# Living the Life

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## **Abstract**

This is a presentation which tells the story of an African American gay male and how he deals with living with HIV for the last 6 years of his life. The presentation highlights the challenges, struggles, and difficult conversations around stigma, as well as the journey of different business as well as personal relationships. The lines of how mental health and physical health played a vital role in his overcoming the challenges of medication adherence. The new information regarding PrEP (Pre-Exposure Prophylaxis) and how its impact regarding his sexual behavior. The oral presentation will be the first hand account of working in HIV prevention, through diagnosis, to what life is like for this young man today.

#### Communication

Communication is how we share information in this field and it is vital to the way it is perceived by the general public and for me for those closest to me. I became an advocate in the field of HIV/AIDS prevention over 10 years ago. However, my introduction to the disease was long before that as a teenager when I sang at a funeral of an extended family member who died a mysterious death. At family gatherings, I saw how his skin changed complexions to very dark, his hair grew thin, and he became tired very quickly doing mundane tasks. When he passed away no one talked about what he died from, no one spoke of how long he had been sick, and no one mentioned him in family conversation. It was then I learned the damaging effects this disease could have on even the way we coexisted in family dynamics. I knew even at that age if there were ever going to be someone who wanted to ensure that young man's life meant something or even worth mentioning again...it had to be me.

Through that experience, I learned how to shut down and stop communicating those things I never wanted anyone to know. I learned how to quickly deflect a conversation when approached with an uncomfortable topic and became quite good at it. However, I also learned over time that if I were going to get anywhere in life I had to communicate and do so effectively to be clearly understood. Speaking publicly came easily to me as I have been a musical director for most of my life and was able to teach vocal workshops around the world. Now a new topic had peaked my interest. There was something now that was not only worth singing about but now there were many who were going to end up like that young man in my extended family if I did not open up and communicate about what was going on!

# Change

Although I thought I'd mastered effective communication, I had no clue of how to go about changing the mindset of people I shared time, space, childhood memories, or even the same DNA but something had to be done. In 2009, I became fortunate enough to gain employment at the Centers for Disease Control in the Division of HIV Prevention. I was opened to a whole new world of education and cutting edge breakthroughs in the fight against HIV. During my time I had learned about PrEP and PeP (Post-Exposure Prophylaxis) and its effects against the transmission

of this virus that had affected so many of my friends' lives changing the landscape of prevention. Although change is inevitable in order for it to be effective, we must recognize the benefits of it. Changing the way we speak about the virus and relay the information to newly infected persons in clinical and non-clinical settings will ultimately provide new ways to educate those in close proximity to those infected. Modern technology has found new ways to potentially stop the transmission of the virus. However, the fight against the stigma associated with HIV is still ongoing.

There are persons across multiple communities, more prevalently in Men who have sex with Men who now use PrEP as their only form of contraception and not as an addition to safer sex practices thereby choosing to engage in natural sex with partners who are most times unaware of their HIV-status. We have to find more ways of changing the behaviors for those who are at the highest risk of contracting the virus. In order to do so, we have to change the way people who are living with the virus are treated in society. Change has to happen at the grassroots level. It has to start in our churches, our health department, in our schools, and yes, even our homes. I believe the reason for new incidents are high is because of the lack of counseling and education for those diagnosed with HIV and how to deal with the challenges they face on a daily basis. Whether its access to adequate healthcare, which should include mental wellness, or if it is changing the socio-economic effects of those who have not been linked to care because they are simply trying to survive day to day. At some point, we have to change our messaging to include learning how to take care of the whole person and not just treat the virus.

## Connection

It's about finding a way to connect with people who are just trying to live life the best they can. Not everyone is fortunate to have the educational tools we have nor can they comprehend them at the same level. It's our connection to each other across all walks of life that will renew our passion as we look for ways towards the best quality of life possible for all people.

A few years ago there was a connection made between two guys, myself being one, who found each other through a joint business venture. Through long hours of conversation we decided to go to dinner and meet to discuss the project we would be potentially working on together. It was sitting there at dinner that I recognized this other guy was meant to be more than just an acquaintance. The connection between us was so strong



that I never wanted dinner to end! Towards the end of the evening the news was shared... I'm HIV Positive. Whenever I share this story people always ask well...what did you do with that information? Did you find a way to bow out gracefully? Did you tell them that you work in public health and that it would be okay to date him? To share something so personal had to be hard for him to share with you. It's always interesting because they never assume that the person sharing the information was me instead of the person receiving the information.

To answer those questions... no he didn't bow out gracefully and although I shared with him much more than my resume of accomplishments in music as well as public health, he found ways to get further educated by speaking with his own primary care physician and continues to find ways to stay connected to me. Together we share our story of hope, healing, and education to promote awareness and prevention of HIV/AIDS. In life, business, and in love we find ways of assisting others on how to begin the

conversation surrounding HIV/AIDS. He continues to support me and pushes me to be the best me I can be.

In conclusion, it is our commitment to effective communication that we are able to help others learn ways of reducing the stigma attached to the virus. We continuously seek ways that we can change the mindsets of individuals infected and affected on how they can live their best lives beyond the diagnosis. We are also liaisons who are known for providing ways of connecting those youth living with HIV in underserved populations find adequate healthcare. Our videos promote healthy relationships on YouTube under the handle David Johnny. When speaking to people in the community I never wanted to be seen or viewed as the "face" of HIV/AIDS. I want to be most noted for living the life of one who was diagnosed and continues to stay in treatment through the advocacy and sharing my story can be part of the "history changers" continuing the fight to eradicate this virus.