Who Makes up the MWCCS Participants? An Introduction to Selected Study Participants

By Martha Williams, MWCCS Study Participant from UAB Jackson

Like a diamond, the MWCCS participants come from different facets of life. The cohort is made up of vastly different individuals from different walks of life. In this article, we introduce some of the faces of some study participants.

One particular facet is a 47-year-old mother of 3 who credits the study for saving her life. After gaining a few pounds, she was experiencing shortness of breath and difficulty walking. While participating in the studies echocardiogram (ECHO) sub-study, she realized why. She found her symptoms were due to significant blockage of arteries in the heart. Within one week of her study visit, she had open heart surgery to save her life. She said if it wasn't for the study and the need for the money to pay her cell phone bill; she wouldn't be alive today.

Another facet of this cohort is a 61-year-old mother of 3 handsome sons. She thought the devastation of finding out she was HIV positive equaled to a death sentence and a life alone. She thought who would want to be with a woman with 3 kids, HIV positive and fighting to make ends meet. Her sole motivation for joining the study was to help her make those ends meet. However, she found a staff that was always welcoming her with open arms, eager to listen to all the stories about her sons' achievements and see all the pictures of her adorable grandchildren. She would always say, "I am getting paid to go see my second family". Through years of rebuilding her life as a woman who happens to have HIV, she found love again. And the first people she could not wait to share her good news with was the MWCCS study staff.

As the Southern sites started recruiting new study participants, new facets of the MWCCS diamond emerged. For example, one study participant, a 33-year-old gay man, has a story that he is sure many have heard and can relate. He was born in a small town in Central/East Alabama and has lived there his entire life. He had a pretty normal childhood with both parents and an older sister. As the baby of the family, he really didn't experience any trauma. However, as he started to develop, he felt quite different from the rest of the young men in his small town. Around age 12, he started to have feelings towards the same sex, however, growing up Southern Baptist in the "Bible Belt", he was not only looked down upon, but was considered the greatest "sin". Fast forward to late high school/early college years, he started meeting others with the same feelings and during college, he experienced many firsts, but one of the most prominent was his first "gay experience". Although it felt right, his upbringing made him feel wrong. Then the struggle began. After his feelings were awaken, and in the mist of struggling with his desires for members of the same sex, he knew he could not go back to the small town he grew up in. Instead, he moved to the "big city" of Birmingham. As he now had the opportunity to have more firsts and meet new and exciting people, he also ended up finding meth and started a relationship with it. The next few years had its ups and downs. The highs were high, and the lows even lower than he could have ever imagined. After years of active addiction, he decided to make a change and after revealing his drug addition to the important people in his life, he entered into a treatment facility. After three long months, he graduated from the program and started to put the pieces of his life together. Then he was faced with the reality of an HIV positive diagnosis. He felt everything from anger to feeling like he had just been dealt a death sentence. After some time, he realized he was very wrong. To his surprise he found a sense of peace and empowerment all at the same time, and had taken back control of his life. He has since educated himself of his diagnosis, enjoyed being a part of studies to help fight this epidemic, and has meet some great people. Today he chooses to fight, and not allow his past to define him. He is proud to stand tall and tell his story, hoping to inspire others, and to help those who have lost all hope.

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My own facet started with youthful mistakes. I started exploring drugs in college and by the time the dust settled, I was completely unaware that I was addicted. Years, opportunities, & experiences were a blur. I came across Narcotics Anonymous and began my first of many attempts to get clean. In 1996, after my seventh treatment center, and now the mother of four children, I began to put my life back together. Years of unprotected sex and numerous sextual partners left me with a fear of being HIV positive. Every time I was tested for HIV in each treatment center, my stomach would hurt for hours. I just thought I would one day hear those words, "you have HIV". I knew it was only by God's grace that I never heard those words. As part of my gratitude, I am committed to help others who have heard those words. This gratitude led me to participate in the WIHS study in the Summer of 2014. I consider it a privilege to allow others to know HIV doesn't have a particular race, sex or gender it can happen to and almost happens to anybody.