

This article was downloaded by: [University Of Maryland]

On: 18 December 2012, At: 06:47

Publisher: Routledge

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



## Ethics & Behavior

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/heb20>

### One Voice: A Commentary on the Syphilis Study at Tuskegee by a Descendant's Daughter

Lillie Tyson Head <sup>a</sup>

<sup>a</sup> Daughter and 7th Child of Freddie Lee Tyson

Accepted author version posted online: 23 Oct 2012. Version of record first published: 28 Nov 2012.

To cite this article: Lillie Tyson Head (2012): One Voice: A Commentary on the Syphilis Study at Tuskegee by a Descendant's Daughter, *Ethics & Behavior*, 22:6, 472-474

To link to this article: <http://dx.doi.org/10.1080/10508422.2012.730004>

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## COMMENTARIES

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### One Voice: A Commentary on the Syphilis Study at Tuskegee by a Descendant's Daughter

Lillie Tyson Head

*Daughter and 7th Child of Freddie Lee Tyson*

#### PERSONAL EFFECTS AND AFFECTS

The family of Freddie Lee Tyson was in utter shock upon learning sometime in 1973 that a Syphilis Study had been conducted by the United States Public Health Service (USPHS) on African American men in Tuskegee and Macon County, Alabama, from 1932 to 1972 without their consent. Some of the 623 men in the study had syphilis and some did not have syphilis. A few weeks after learning about the study, we also learned the unthinkable, our dear father was one of these men. The most disturbing thing to all of us was the fact that Daddy did not know that this study ever existed, neither was he aware of being a participant. All eight of his children were crushed, we had many questions, but Daddy had few answers. Daddy had not been informed. For the first time, I saw pain, frustration and fear in our father's eyes. I heard anger and confusion in Daddy's voice. Even today the family still has lingering questions and some suspicion about the study and Daddy's involvement.

Freddie Lee passed away in 1988 as the result of a car accident on his way to work. His health was remarkable for a man of 82 years. He had exceptionally good health all of his life. Daddy strongly believed in a healthy diet, staying active, and maintaining a close spiritual relationship with God. Unfortunately, Daddy did not witness the 1997 Presidential Apology by President Clinton, but our mother, Johnnie Mae Neal Tyson, did watch via television. It was upsetting our family, especially his granddaughter Carmen, that her grandmother, the silent heroic partner, was not invited to this auspicious occasion by the powers in charge. Mom died in 2010 at the ripe age of 99. She lived through it all.

## LEGACY OF THE USPHS SYPHILIS STUDY

The USHPS Syphilis Study at Tuskegee is the longest and the most egregious and unethical, health and medical treatment study ever conducted in the history of the USPHS. The study today is used as a primary teaching model for Inform and Consent. According to my father, he, along with several other farmers, was approached by a group of White doctors and a Black nurse in the little Texas community of Macon County. He said they were told they had “bad blood” and they needed medical care. They needed to get tested and treated by the team doctors and a nurse from the USPHS. He said, this group of men would get medical treatment for their condition, receive a burial insurance and be provided a meal after each treatment. The most horrendous acts of this study are these inhuman treatments: (a) the men were not told they had or did not have syphilis; (b) they were not informed of the known facts about the effects on untreated syphilis on human beings; and (c) they were not aware of and denied treatment for syphilis when penicillin became the medical treatment of choice when penicillin became available in 1943. The existing oppressed and impoverished culture during these times helped influence Daddy, (I believe) to trust this medical team. Without knowing the true purpose of the study he felt confident this “treatment” for his “bad blood” was good . . . All of these 623 men were good human beings, uneducated yet wise, trusting and unsuspecting, hard working and shared a love for family and community. It is painful to realize this study was mostly racially motivated.

The profound health problems and anguish imposed on their spouses and their children is still unraveling. It is clear these men were victims of poverty and racism. Yet their desire to protect their families was evident when they chose to seek medical care after being told they had “bad blood.” Their sole intent was to improve their health status and ease the financial burden of doctor bills and burial expenses when the time came.

## THE APOLOGY

After the exposure of the USPHS Syphilis Study in 1972 at Tuskegee, a class action lawsuit was filed on behalf of the 623 African American subjects in 1973. Because of the extreme unethical research protocol, medical abuses and health care disparities that caused grave embarrassment. Anguish screams and cries called out for answers and apologies. Thankfully, the racial climate and living conditions had improved in the United States. Civil rights and equal social justice had evoked the conscience of the nation. Because of the outrage felt by some dedicated and concerned bioethical medical researchers and health professionals, an Apology Commission was formed. They were driven to seek an apology for the physical and moral harm inflicted upon these men, their families and the Tuskegee Community. The USPHS and the government needed to be held accountable for allowing such horrific treatment to its citizens. In 1997, then President William Jefferson Clinton apologized nationally to the living survivors and their families of the Study on behalf of the U.S. government. Indeed, this apology was well received and an exemplary gesture. Along with the apology there were monetary settlements for the men, the establishment of The National Center for Bioethics in Research and Health Care at Tuskegee University, and the expansion of stronger Institution Review Boards that include National Bioethics Advisory Commissions.

The apology heightened the awareness about health disparities, unfair health treatment within the African American community, and the need for culturally sensitive medical and health research. It also changed research protocol and authorized stricter Informed and Consent policies. Then, too, it provided another gateway for African Americans to become visible and strong advocates for health care reform. Today with the Annual Commemoration of the Presidential Apology, the opportunity exists for the descendents of USPHS Syphilis Study to tell their fathers' and grandparents' stories. It is the obligation of the families to become vigilant in speaking out against health disparities and the unfair health treatment to the poor and needy. We also must remember the inhuman treatment as we remain steadfast in asking our questions, seeking answers and the truth about the USPHS Syphilis Study at Tuskegee.

### CAN IT HAPPEN AGAIN?

Because we are better educated than our fathers and most laws and research procedures have changed, it is doubtful that a study like the USPHS Syphilis Study at Tuskegee will happen in the African American community again. To ensure that it doesn't, we must become the Voices of Our Fathers, and for every man, woman, and child impacted by the USPHS Syphilis Study in Tuskegee and Macon County, Alabama. I am hopeful that this unethical research study and the medical nontreatment of human beings with a curable health problem will never be allowed on anyone, anywhere ever again. With the National Center for Bioethics in Research and Health Care at Tuskegee University, and other Bioethics Centers around the country, the Institution Review Board and the National Bioethics Advisory Commission in place today that oversees and monitors all medical research, hopefully there will never be a repeat of this study. However, due to the growing number of people today without adequate health care and the high unemployment rate, there are increased risks of prolonging and creating serious health issues. There is vulnerability among those in most need of health care and medical treatment.

I was once premature in thinking the USPHS Syphilis Study would discourage participation in medical research by African Americans. To the contrary, I have read recent research that indicates this is not true. African Americans are responsible contributors to medical research. They willingly participate in research today. More African Americans are well-informed participants, and more are joining the ranks as health professionals and administrators.

### LESSONS LEARNED

The harsh lessons learned from the USPHS Syphilis Study at Tuskegee are providing all health and medical professionals with wisdom and guidance every day while conducting their research. Those charged with these tasks have learned to treat participants in their studies with dignity, compassion, and respect regardless of age, race, sex, or socioeconomic status. Health research is crucial and necessary for medical cures and improving the quality and longevity of life. Research is justifiable, is meaningful, and should accurately predict what is expected, but only when done ethically. On the positive side, the USPHS Syphilis Study at Tuskegee will ultimately pave a smoother road to better health care research and stand as a transformed legacy to the men in the Study who suffered so much. I voice this in tribute to my beloved father, Freddie Lee Tyson.