

IMAGINE IF:

Being a Middle Aged Black Male Anomaly with Cystic Fibrosis



By: Terry Gene Wright

“Imagine If” you were born a healthy-looking black baby boy who is alert, bubbly, and full of energy. A bundle of joy who is proudly held by his mother who expects nothing less for her youngest child but a life filled with hope, promise, success, and good health. Well, this appeared to be the narrative as my parents Rose and James Wright took me home to begin what they expected would be a life for the better. But things quickly and unexpectedly shifted.

“Imagine If” you woke up as a child, moaning and groaning early in the a.m. because of indescribable pain in your gut. And you are just barely able to make it to your mother’s bedside, where she urgently picks you up to comfort you, despite not knowing what’s wrong.

“Imagine If” your mother does finally take you to the local children’s hospital, only for them to tell her that her son appears to have a stomach virus and ulcers. I was admitted to the hospital, where I was not only treated for this medical episode, but where I continued to spend a significant portion of my childhood, thus eventually becoming my second home.

“Imagine If” you continued to suffer, regardless of the countless hospital visits, up to and throughout grade school, with no changes as far as diagnosis or prognosis. I was repeatedly sent back to the hospital for the doctors to say, yet again, it was just a virus.

“Imagine If” you suddenly developed a love for outside sports and physical activity. And instead of running to your mother’s bedside, you are now running track and field as a top-performing preteen athlete. I proceeded full speed ahead and excelled greatly in not only track and field, but baseball and cycling. But, for a moment in time, with my newfound energy and intense level of athleticism, I felt unstoppable.

“Imagine If” you are a young adult who is now in the best physical condition of your life, but your medical issues significantly persist, and the reality sits in that you are not unstoppable. You are stopped right in your tracks from a bodily attack of unknown cause. And to make matters worse, this mysterious stomach virus is now joined by an array of other unforeseen medical issues, including regular bouts of pancreatitis, pneumonia, sinusitis, bronchitis, persistent migraines, and other adverse events.

“Imagine If” you are now an adult who has finally reached your breaking point with the reality that you are dreadfully losing the battle, and the end sadly appears inevitable. Also imagine the toll on your mental, physical, and emotional well-being. This devastating battle caused deep depression and hopelessness and continued to haunt and torment my body, mind, and soul. And, unless a miracle from God quickly happened, I was more than ready to give up.

“Imagine If” out the blue, a mutual friend sets you up with your first blind date. And though you were told how beautiful, kind, and wise she is, you are still cautiously curious. On November 1, 1999 at the age of 37, I finally had the chance to meet Michele Wise, who I called “Butterbean” the moment I met her. I knew we were destined to be together—she immediately brought a newfound hope into my life. My Butterbean and I instantly became inseparable, happily becoming Mr. and Mrs. Terry Wright on November 4, 2000.

“Imagine If” finally finding your soulmate changed your life for the better, but your health continued to decline rapidly. Still, I continued increasing my physical activity, which included running marathons, climbing steep mountains, and competing in 100-mile road bike races. Unfortunately, I still experienced a variety of unprecedented health issues. Fortunately, I had my wife by my side to help me focus on life for the better. Her pharmaceutical background proved remarkably invaluable.

“Imagine If”, over the next twenty years, you continue to endure an array of weekly emergency room visits, hospitalizations, specialists, treatments, and surgeries including gall bladder and an eight-hour pancreaticojejunostomy, only to continue experiencing relentless bouts of chronic bronchitis, sinusitis, and pneumonia. Finally, enough was enough. Michele frantically reached out to the University of Arkansas for Medical Sciences (UAMS) Infectious Diseases Division. To our shocking surprise and relief, the dots were finally connected—a diagnosis of cystic fibrosis.

“Imagine If” you have a genetic disorder affecting 1 in 17,000 African-American births and you are now officially diagnosed and counted among the rare statistics of African Americans with CF.

Well, imagine no further. In early 2017, cystic fibrosis became my surprised diagnosis at the age of 54 and my new reality. Nonetheless, this was a welcomed answer to my painstaking journey. Ultimately, my prognosis allowed me to finally receive the correct treatment regimen that I so desperately needed to start improving my quality of life.

Furthermore, my very late-stage diagnosis inspired Dr. Wright and me to establish the National Organization of African Americans with Cystic Fibrosis (NOAACF), with a mission to engage,

educate, and raise CF awareness in the African-American community to help bring valuable resources, knowledge, empowerment, and support to CF patients, families, healthcare professionals, and the community.

Now, “**Imagine If**” you joined and supported our cause! Stop imagining and together let’s make a difference through connecting resources and raising CF Awareness in the African-American community and beyond.



Terry Wright is the President and Co-Founder of the National Organization of African-Americans with Cystic Fibrosis (NOAACF), an organization with a mission to connect, help build diverse communities, and raise CF Awareness in the African-American Community and beyond through its national platform. He is an Arkansas dual-certified Master Gardener and Master Naturalist. He was elected the 2016 Pulaski County Master Gardener of the Year Award winner and a finalist for the 2017 Arkansas Master Gardener of the Year. He completed the standard curriculum in Permaculture Design in 2018. He has also been honored to formerly serve on the North Little Rock Green Committee and Commission on Environmental Efficiency. He has an impressive 36-plus year career as a Certified Personal Fitness Trainer (CPFT). Terry lives in North Little Rock, Arkansas with his wife and Butterbean, Dr. Michele R. Wright.

