

Game Changer at 12 – A 4/20 Reflection

Today is April 20th; 4/20 as it is sometimes called. It is an exceptionally significant day for me. It was on this date 12 years ago that I got the phone call informing me of my diagnosis of chronic myelogenous leukemia (CML). There is no cure for CML. It is a fairly rare form of leukemia that scientists have not yet determined its cause, however they assert that it is not hereditary nor is it environmental. I call it the game changer. I have a deep, deep sense of gratitude as I mark this day. Gratitude because for the past 12 years living with CML has been mostly good news. We caught it early; so early that since then I have been on a daily oral chemo regimen which has not allowed it to progress. Gratitude because my support system, my village, is indescribably amazing. Although there is occasional sadness, my wife and children have been rock solid. My siblings and close friends allow me to sometimes forget that I am living with CML.

A few years ago, my wife Lorna asked me, “what are you going to do for cancer?” I had to really think about that. There have been a few times when I’ve spoken publicly about this journey. Responding to her question required the overlap of my personal and professional lives. It required deep thought and vulnerability. To whom much is given, more is required. I was given the gift of CML so that I could do something with it; something more than beat it. As the universe aligned, also a few years ago I was approached by then Rochester City Council member Malik Evans and current Deputy Mayor Patrick Cunningham to consider joining the advisory board of the Wilmont Cancer Institute (WCI) here in Rochester. Both were members of that board. Other than Malik, it lacked representation of people of African descent. I joined. Since then, I have been learning about many other forms of cancer and cancer data for the WCI catchment area. Through this learning I finally found out what I must do for cancer.

Some of what I have learned is astonishing to me. Rochester, NY has some of the highest instances of “lifestyle cancers” in America! Deeper still, Black people in Rochester lead this most unfortunate list. Lung cancer is the lifestyle cancer we lead in. Does everyone know this? How many families have lost loved ones prematurely to lung cancer? How many are suffering with it right now? On this 4/20, my diagnosis date, I will be sharing my reflections with my colleagues at the Wilmont Cancer Institute. I will recommend (more like demand) that WCI embarks on a massive awareness campaign to counteract the unfortunate reality. We should be discussing this everywhere our people gather. Everywhere! Smoking is a scourge on Black families. It was, and is, on mine. We can do something about this people; not just in Rochester but everywhere. Of course, not just because I say so. Addiction is real and requires treatment. That treatment begins with awareness and an acknowledgment that we have a serious challenge that requires our attention.

The intersection between my personal and professional lives looms large as the specific areas where lung cancer dominates are some of the poorest neighborhoods in Rochester. There is a direct correlation between the systemic economic marginalization of these neighborhoods and the health of the people who live there. We must do better if we truly believe in the dignity of all people; if we are committed to everyone having access to adequate and affordable health care – the kind of care that I have been receiving for 12 years from the Wilmont Cancer Institute. I am privileged to lead an organization like Action for a Better Community where our focus is to seek justice for people who have been denied it for too long. A healthier community IS a better community. I am committed to that and will use my credibility to advocate for better health outcomes for people on the margins. I continue to

learn from the professionals in the Black Physicians Network, the Black Nurses Association, and the African American Health Coalition. In collaboration with them and others we will keep pressing for health equity.

Cancer sucks! It really does. I close by once again acknowledging my gratitude for the mercies I have been given and earned via paying keen attention to my health. A strict diet, a reasonable amount of exercise and my spiritual approach are my medications (along with that chemo pill I take daily). I encourage all of us to go to the doctor and check ourselves out. Do that for your family; for the people who love and are concerned about you. Twelve years is a long time, but it is nothing when compared to the number of years we can save by making any necessary changes so that we can be more useful to our families and the communities we serve. I give thanks for life. I give thanks for love as we continue to defeat CML.

#DFTCML

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