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IN RESPONSE TO THE RARE-X DEIP ANNOUNCEMENT

An important message on behalf of the rare disease community of color

On January 21, 2021, it was brought to the attention of the [Rare Black Lives Matter Too](#) RAM Collaboration that the nonprofit organization, RARE-X, decided to launch the Diversity, **Equality**, and Inclusion Program (DEIP), a program funded through a grant from Genentech and Travele Therapeutics.

Upon thorough review and consideration, the *Rare Black Lives Matter Too* RAM Collaboration has concluded that RARE-X is not only seeking to duplicate the [Rare Disease Cures Accelerator-Data and Analytics Platform \(RDCA-DAP\)](#), but has also announced the RARE-X DEIP effort in deliberate contrast to the [“Our Lives Matter” Diversity, Equity, Inclusion \(DEI\) Initiative](#), a [Rare Advocacy Movement Collaboration](#) (RAM).

The RARE-X announcement, publicly promoted on January 21, 2021 to the rare disease advocacy landscape via email subscription, one day after the inauguration of President Joseph Biden and Vice President Kamala Harris, is an ill-timed blatant disregard for the sensitive community-based dynamics of the currently racially siloed rare disease advocacy community.

As racial tensions peaked in June of 2020 and continued to soar with the rise of white supremacy, police brutality and the exposure of racial health disparities during the COVID-19 pandemic, RAM’s “Our Lives Matter” DEI Initiative stepped up when no other rare disease advocacy group would and became a safe haven for the global diverse people of the rare disease community, especially rare disease people of color. As all rare disease umbrella groups remained quiet, and thus complacent, as the former American Presidential administration encouraged prejudiced biases and acts of discrimination against various groups of non-white people, RAM’s “Our Lives Matter” DEI Initiative organized to develop authentic, sustainable DEI solutions designed to build authentic trust between the diverse people of the rare community, the biopharmaceutical industry and the various stakeholder groups that currently dominate the rare disease advocacy landscape.

The “Our Lives Matter” DEI solutions became available to the rare disease landscape during the month of September, 2020 and have remained available ever since. Unlike RARE-X and the sponsors of DEIP, RAM’s “Our Lives Matter” DEI Initiative did not need to wait for a



humanitarian focused Presidential administration to be inaugurated in order to establish DEI programs that are meaningful to the real world people of the rare disease community.

As a result, the RARE-X DEIP announcement has been received as an extremely disrespectful message to not only rare disease people of color, but to the entire community-based advocacy network that collaborated and contributed to the development of RAM's "Our Lives Matter" DEI Initiative.

It is the position of *Rare Black Lives Matter Too* that RARE-X and each sponsor of this program issue a conscious public apology to the global rare disease community in order to begin the process of rectifying this injustice.

RARE-X has taken the unfortunate position of promoting the development of a rare disease-focused DEI program without the expertise or input of a DEI rare disease expert of color. Instead, RARE-X chose the path of tokenism.

What is **tokenism**? Tokenism is the practice of making only a perfunctory or symbolic effort to give the appearance of being inclusive to members of non-white, heterosexual groups, especially by recruiting men of color or women of color in order to give the appearance of racial and/or sexual **equality** within an organization and to ultimately deflect accusations of discrimination. In the face of racial segregation, tokenism emerged as a solution that, though at times have been earnest in effort, has only acknowledged an issue without actually solving it.

While tokenism is a practice developed and managed by the dominant institution, it requires the willing participant of at least one person of color. In the case of RARE-X, [Teneasha Washington, PhD, MPH](#) has accepted this position as [DEIP lead](#) for RARE-X. Regardless of having absolutely no experience as a rare disease community-based advocate within the dynamic, ever-evolving landscape of the complex rare disease advocacy ecosystem, Dr. Washington is now publicly tasked with labeling herself as an instant community-based advocate kicking-off a "scoping project" to explore the rare disease community, under the guidance of her white rare disease advocacy colleagues that have historically participated in maintaining the current racially siloed advocacy ecosystem.

Since the murder of George Floyd, a surge of biopharmaceutical companies and nonprofit advocacy organizations made public statements in solidarity of Black Lives Matter. While some believe their statements in solidarity of Black Lives Matter is sufficient without action, others have chosen to deploy a "DEI-branded" program created and facilitated by the white collective, effectively reinforcing the stigmatized structures of the current therapeutic development industry. What groups like RARE-X fail to recognize is that a person's skin tone alone does not equate to their capability of accurately understanding and interpreting the non-white rare disease experience.



Rare Black Lives Matter Too does not diminish Dr. Washington's potential to one day learn enough about the rare disease community to eventually become an effective ally. However, the actions of RARE-X and their respective sponsors in the blatant development of a Diversity, **Equality** and Inclusion Program, has communicated their complete disregard for real world community-based rare disease experts that have dedicated their time, energy and hearts into the development of sustainable DEI solutions designed for the rare disease advocacy landscape.

Even though the [press release](#) and subsequently paired [blog article](#) is a classic example of tokenism organized by a group of white executives with the desire to control every aspect of diversification and equitable unification efforts that take place within their target markets, the “Our Lives Matter” DEI Initiative felt a duty to educate both the rare disease community and rare disease industry executives considering which DEI programs to support.

EQUALITY VS. EQUITY

We would like to bring your attention to the letter “E”. The letter “E” in RARE-X’s DEIP stands for “equality.” In contrast, the letter “E” in the “Our Lives Matter” DEI Initiative stands for “equity.” For those who may not have yet learned the difference between the terms equality and equity, you’ll soon learn that there is a big difference, especially as it relates to rare diseases.

Here is a super common visual representation of equality (left image) vs. equity (right image).



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Equality involves ensuring everyone has access to the same exact resources and opportunities, whereas equity involves distributing resources based on the unique needs of the recipients. Equality can only work if everyone starts from the same place and needs the same things. Those familiar with the rare disease experience understand that each rare disease person has different circumstances that vary at different stages of disease progression. As a result, rare disease people require the allocation of different resources and opportunities, aka equity. In fact, the growing understanding of medical equity needs gave rise to the field of precision medicine during [President Obama's Administration](#).

COMMUNITY-BASED PROGRAMS

The term “community-based” references any initiative, program and/or effort that originates from the people of a community in which the initiative, program and/or effort is developed to serve. RARE-X’s press release describes the RARE-X DEIP as being a “community-based” effort in an attempt to appear authentic. However, a more accurate description of the RARE-X DEIP would be to replace the term “community-based” with the term “community-focused”.

Upon correcting the term, however, the question then arises as to which community is RARE-X focusing its efforts on serving the best interests of? Given RARE-X has not yet engaged or sought the expertise of a rare disease DEI expert of color from within the rare disease advocacy community, the only assumption that can be made, at this point in time, is that RARE-X is clearly not focused on serving the best interests of rare disease people of color. This assumption, then creates another question: why use the term diversity, equality and inclusion?

Unfortunately, *Rare Black Lives Matter Too* has been forced to conclude that the use of the abbreviation “DEI” was RARE-X’s distasteful attempt at a glorified PR-stunt, at the expense of the diverse people of the rare disease community.

MINORITIES VS PEOPLE OF COLOR

RARE-X mentions that they have a focus on improving “trust issues within **minority** communities.” One of the most obvious tells that a “diversity-focused” program has been developed by the white collective and filtered through the white lens is the casual use of the word “minority” to describe people of color.

Why is the casual use of the term “minority” inappropriate when no reference is made to which population is being cross-referenced? For those of you who may have missed it, during the Trump Administration, the U.S. Census Bureau publicly released their [“Projecting Majority - Minority”](#) graphic. This graphic effectively showed the power of data and socially-influenced statistics because the white collective became enraged over the idea that white Americans may soon no longer be the majority racial category, as defined by the Census Bureau.



In a nation preoccupied by racial classifications, the moment when white Americans will make up less than half the country's population has now become one of the basis for fear-based rhetoric. For white nationalists, it signifies a kind of doomsday clock counting down to the end of racial and cultural dominance, a rhetoric that united the [Trump colt](#) and encouraged the violent attack against the U.S. Capital on January 6, 2021.

In America, the white collective has utilized its majority status as a marker of dominance. The idea of losing this marker of dominance and being referred to as the minority racial group has established a wave of tokenism practices across various industries and communities in an effort to give the appearance that diversity, equity and inclusion ideologies are valued, without any authentic intention to take meaningful action to change institutionalized racial structures. Unfortunately, the rare disease ecosystem is no stranger to this dynamic.

The white collective's negative response to the Census Bureau's projection that the white American racial population will be in the minority within 25 years to people of color, has effectively exposed the term "minority" as being a negative and offensive identity when referring to a collective group of people, without a cross-reference. As a result, it is inappropriate and disrespectful to refer to people of color as "minorities" or "minority groups" without clear reference to a majority group and the year in which the reference is being made. Had RARE-X and the DEIP sponsors chosen to authentically pursue the development of a diversity, equity and inclusion program for the RARE-X platform, they would have acquired this community-based knowledge prior to publishing such offensive articles of misinformation.

ADDRESSING TRUST ISSUES

"Just because you say you want to establish trust with people of color, doesn't mean trust is going to automatically manifest itself like a magical genie in a bottle because you wished it into fruition." - an "Our Lives Matter" contributor

As of May, 2020, there were no rare disease-focused DEI efforts deployed to specifically address the trust that is required to diversify rare disease clinical trials and make advocacy initiatives equitably inclusive. For this reason, *Rare Black Lives Matter Too* developed various customizable community-based programs through the "Our Lives Matter" DEI Initiative. The first set of "Our Lives Matter" DEI programs were made available to the rare disease advocacy environment and the drug development industry in September of 2020. As a result, the "Our Lives Matter" DEI Initiative has become a well-known option for rare disease stakeholders interested in authentically integrating diversity, equity and inclusion into their governing structure.



To obtain community-based trust one must know the diverse people of the community. In order to maintain the gift of community-based trust, one must RESPECT the diverse perspectives and experiences of the community's diverse people.

Too many companies are making the same bad decisions that RARE-X has made. Hiring an individual that racially classifies as black with absolutely no experience within the target community, in this case the rare disease advocacy community, is disrespectful to the global experiences of the communities of interest.

The unwise choices that rare disease-focused organizations and companies are continuously making have dire consequences. Hiring one black professional from outside the field of expertise and slapping a diversity title to his/her/their name, to satisfy the diversity and inclusion PR check-box, impacts the sustainability of meaningful DEI programs designed to actuate viable change to the institutional structures that reinforce racialized oppression.

The responsibility of diversifying in an equitably inclusive manner cannot fall on one person. The idea that dedicating one black person to the task of ensuring a corporate structure, a project or an initiative is sufficient to address the real world issues that impact all varieties of people of color, is unrealistic, out-of-touch and tokenistic. Every single employee, regardless of their racial classification, should be required to undergo authentic DEI training, the same way HR requires every single employee to undergo on-boarding to effectively perform their position's responsibilities.

AUTHENTIC DEI TRAINING PROGRAMS

Rare Black Lives Matter Too, a collective organization of rare disease people of color developed the "Our Lives Matter" DEI Initiative, in an effort to unify neglected rare disease advocates of color with allies of the dominant rare disease advocacy landscape to effectively diversify the drug development ecosystem and do the hard work of repairing historical injustices that have perpetuated mistrust through generations of rare disease people of color. As a result, the "Our Lives Matter" DEI Initiative encompasses several authentic community-based diversity, equity, inclusion (DEI) programs, the most popular being the unLearning program.

Authentic DEI training programs look very different to the PR-checkbox DEI programs that have been predominantly embraced by rare disease industry and community-focused stakeholders.

PR-checkbox DEI programs developed as "feel good" efforts only benefit the black individual being hired to authenticate the DEI program, also known as the tokenized professional. In reference to the rare disease space, these tokenized professionals are then placed in the position to rely on the guidance of their white colleagues that have, whether intentionally or not, maintained the racial silos of the rare disease advocacy environment to date. As a result, no



meaningful changes are made to effectively diversify clinical trials. No meaningful efforts are made to equitably distribute patient assistance programs and other resources. Most importantly, nothing changes for the collective community of rare disease people of color. PR-checkbox DEI programs are unacceptable and should not be funded.

RARE-X, like a majority of the rare disease advocacy-focused stakeholders, are historically disconnected organized groups of people that have not done the vital work to establish and maintain the trust of the greater rare disease community, especially those of color. As a result, the overall rare disease advocacy environment has become racially siloed and does not reflect the real world diversity of the rare disease population. While several rare disease advocacy-focused organizations have participated in the community-based solutions developed by the “Our Lives Matter” DEI Initiative, too many have chosen either inaction or the path of tokenism.

RARE-X does not appear to be interested in acquiring robust diverse perspectives required to authentically address diversity, equity and inclusion. In fact, as stated in a quote by Ms. Washington [found here](#), RARE-X hopes “to expand the traditional definition of diversity.” This is literally the definition of “white-washing.” What diversity looks like, should be defined by the real-world rare disease community.

As if the announcement of the RARE-X DEIP was not enough of a blatant disregard for the hard work of the rare disease community of color, RARE-X chose to drive their point home by capitalizing the word “ALL” at the end of their [press release](#). The decision to capitalize the word “ALL” is a blatant reference to the rebuttal statement - “All Lives Matter.” If you are unsure why this is significant, perhaps [CBS News](#) can help you understand. Or perhaps, [ABC10 anchor Chris Thomas](#) can explain it effectively. Or perhaps a [compilation of diverse people](#) may be enough to help drive this extremely important point finally home, to your front door, where you actually begin to feel inspired to take meaningful actions in support of humanity.

The act of supporting the RARE-X DEIP is equivalent to [not taking meaningful action](#). The rare disease community of color has gone through enough historically and in the present day. After watching white supremacists and their sympathizers storm the U.S. Capital building on January 6, 2021, the rare disease community of color bore witness to all of the biopharmaceutical companies and nonprofit advocacy organizations that chose to quote Dr. Martin Luther King Jr. on January 18, 2021, regardless of not yet taking any meaningful action to diversify their constituency.

On January 20, 2021, a breath of relief was felt on a global scale amongst all people actively in support of humanity during the inauguration of President Biden and Vice President Harris. However, on January 21, 2021, the diverse people of the rare disease community were reminded that there are several organizations and institutions are choosing to ignore the call to



action and instead continue to waste funds on developing and promoting PR-checkbox DEI programs, like RARE-X DEIP.

Because *Rare Black Lives Matter Too* has vowed to not only stand in solidarity but also in action, with the global rare disease community, the responsibility to issue this press release landed on our shoulders, in response to the RARE-X DEIP announcement. As the developers of the “Our Lives Matter” DEI Initiative, *Rare Black Lives Matter Too* will continue to take meaningful action and to work with authentic allies in support of the diversification of the rare disease advocacy landscape and the improvement of global rare disease lives.

About “Our Lives Matter”: “Our Lives Matter” is a humanitarian call-to-action from the diverse people of the rare disease community. “Our Lives Matter” represents a unified international effort by a diverse group of rare disease people that have organized to develop meaningful solutions to begin the diversification process of the currently siloed rare disease advocacy environment. The [“Our Lives Matter” Diversity, Equity, Inclusion \(DEI\) Initiative](#) is the first and only comprehensive set of practical, sustainable DEI solutions designed by rare disease community-based experts of color and allied contributors.

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