COMMENTARY

"You Can't Let Go" – A Black Community Leader's Perspective on Engagement and Advocacy

« Vous ne pouvez pas laisser tomber » – Point de vue d'une dirigeante de la communauté noire sur la mobilisation et le plaidoyer

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Abstract

Lanre Tunji-Ajayi is president and CEO of the Sickle Cell Awareness Group of Ontario (SCAGO). This charitable organization focuses on ameliorating the lives of those living with sickle cell disease by providing evidence-based support to patients and supporting clinical and psychosocial research, health promotion and the development of best practice guidelines. Lanre's passion for this work is personal. Following the death of her brother Sunday Afolabi from preventable and treatable complications of sickle cell disease, Lanre immersed herself in advocacy for community health and quality patient care. In this oral history narrative, Lanre reflects on her decades-long journey advocating for those living with sickle cell disease – a disease which disproportionately affects Black people. Her reflections focus acutely on the challenges she has faced in raising awareness and visibility, including through formal public engagement policy processes. Lanre also speaks to the personal costs she has encountered engaging in this advocacy work and the subtle and institutionalized forms of anti-Black racism that have punctuated this already difficult effort to bring about change.

Résumé

Lanre Tunji-Ajayi est présidente et chef de la direction du Groupe de sensibilisation à la drépanocytose de l'Ontario (SCAGO). Cet organisme de bienfaisance vise à améliorer la vie des personnes atteintes de drépanocytose en offrant un soutien fondé sur les données probantes aux patients et en appuyant la recherche clinique et psychosociale, la promotion de la santé et l'élaboration de lignes directrices sur les pratiques exemplaires. La passion de Lanre pour ce travail prend racine dans sa vie personnelle. Après le décès de son frère Sunday Afolabi, à la suite de complications évitables et traitables de la drépanocytose, Lanre s'est engagée dans la défense des droits de la communauté en matière de santé et de soins aux patients. Dans ce récit, Lanre réfléchit sur son parcours de plusieurs décennies en faveur des personnes atteintes de drépanocytose - une maladie qui touche les personnes noires de façon disproportionnée. Ses réflexions portent essentiellement sur les défis qu'elle a dû relever pour sensibiliser et accroître sa visibilité, notamment par le biais des processus officiels des politiques de mobilisation du public. Lanre parle également des coûts personnels qu'elle a dû supporter en s'engageant dans ce travail et des formes subtiles et institutionnalisées de racisme anti-Noir qui ont ponctué l'effort déjà difficile pour amener le changement.

Engaging with Policy Makers: Be Persistent and Proactive

The intersection of race and chronic disease, that Is where we are.

The government is not going to come and say, "Oh, we know there's sickle cell somewhere, we want to help you." We have to be proactive; we have to go and knock on their door. We have been knocking on this door for years. Most of the time you find that the needs of the community fall on sympathetic ears, but that does not mean that they are going to do anything about it. So, it calls for intense advocacy. It calls for persistent advocacy to ensure that the patients and families will have access to care similar to that of all the people in the province who may not be of their race or who may not have sickle cell disease. I have held advocacy meetings at the seats of power in Toronto, Saskatoon and Ottawa to get policy makers to understand that we are not leaving. I always say persistence in advocacy is the key to success.

However, the happenings in 2020 with the killing of George Floyd brought to light the racism that is deeply rooted in the western world, and that helped us in a way. As sad as it is, it had some positives because it helped people wake up and realize that there are things we need to look at in our own environment in Canada. There is racism, and we need to address it. I think that opened a new way of looking at things for everybody, even at the ministry level. We continue to proactively knock on policy doors; as one goal is achieved, we need to work on the next one, and the next one.

They want to brush you off because there are so many people who are coming at them and they are thinking, "Well, it's very small, this population, money should be going to this and that," and that's why you have to be more proactive. Sickle cell only affects about 6,500 people across the country, with about 3,500 in Ontario. So, it may make logical sense to a politician to think, "Why am I putting money here when I could put money in something that affects way more people?" But then why is the funding trajectory for cystic fibrosis and hemophilia very different even though there are fewer people with those diseases than with sickle cell disease? Cystic fibrosis affects a total of 4,200 hundred people in Canada and the annual budget is close to 20 million. Until recently, there has been no sickle cell organization with an annual budget of more than $200,000 in the country.

You cannot let it go. You cannot relax.

Even though we have some promises from ministries for funding, I'm still consistently asking, "Where are we on it? Who is reviewing it now?" You have got to be on top of it, you cannot sit aside. Otherwise, another election will come by and they will say, "Oh yeah, that's gone with the election. Let's move on." We do not know who is going to be in the next government and if they are going to support us.

You cannot waste time while people are dying and suffering. And so, working with policy makers is something that you must be persistent about and that you cannot let go of – you know, you cannot lose sight of them. There is a way to do policy advocacy, which I had to learn. It was not taught to me, but I learned from working in advocacy over the last 19 years that persistence is the key to the win.

Strategic Engagement and Purposeful Collaboration: The Art of Bringing People Together

One of the things we have done is create the Patient Advisory Advocacy Council within the Sickle Cell Awareness Group of Ontario (SCAGO). This is a nine-member council comprising individuals with sickle cell disease, their caregivers, family members, a medical doctor and myself as CEO as an *ex-officio* member. The members of the council sit on hospital working groups and provide advice for protocols for care. We are empowering and bringing the voice of sickle cell disease across the hospital. We are shifting the conversation to bring visibility to the patients as spokespeople and researchers in their own disease areas because no one knows their disease more than them.

We are seeing a shift in that we are engaged from the get-go more than ever, and we also initiate engagement on an as-needed basis. Based on what we need to accomplish, we will engage with the right people who will make it happen. So that is strictly how we have been working. If I want the hospital to do something for a program in the hospital, I reach out to the administrators of the hospital. If I want to do something that has to do with newborns, I reach out to Newborn Screening Ontario. I strategically pick who I need to reach out to and who I need to speak with based on the work that we are trying to do. We will reach out to policy makers at different levels who will help to ensure that we are successful in our aspirations and can make the impact that is needed. In addition, collaboration, collaboration, collaboration! Collaboration is important. We have to look for collaborators who will help us advance what we want – so you have to call the Black Health Alliance to the table, you have to call Council of Agencies Serving South Asians to the table, you have to look for the appropriate collaborators and engage and work with them to achieve your goal.

"Sickle Cell Disease is a Family Affair": The Personal Motivations and Sacrifices of Advocacy Work

The sickle cell work is a lot. I work from 5:00 am in the morning until 7:00, 8:00 pm, minimum, and it is all sickle cell. That is my schedule most days. So there has to be passion. I am not salaried, so it has to be passion. My passion for this work is rooted in my family. I am a sibling of individuals that have sickle cell disease, but I am not a parent and I do not have the trait myself. So, if you ask me, "Why do you put so much energy and time into this when you're not directly affected by the disease?" then I am going to say, "it's [the] love of siblings," and I always say sickle cell disease is a family affair. Being a sibling is what is pushing me and propelling me to keep going because I know how much my brother suffered before he died and I'm grateful to God my sister is still alive. I know what it could be living with sickle cell disease, and I want to ensure that we do not have to lose another young person to preventable complications.

Sometimes it gets to be too much because I'm so overwhelmed and have so much to do, and I'm like, "OK. Hold on. Let's put this in perspective, why am I doing this?" When it gets like that, it is funny sometimes, somebody will send me a text to say, "Ms. Lanre, I just want to appreciate you for all you do." Or sometimes it is somebody in need in the hospital and I think, "Well, this is why I'm doing what I'm doing." Somebody has to speak on their behalf. So that is why I do what I do. It is not because I have enough funding and resources, because there is little of that. I sometimes use my own money to support this work at the Ontario or global level. But when a 20-year-old says to me, "I don't want to live. I want to die. It's more peaceful. It's better for me. I'm in pain all the time. I don't want to be here anymore," that is deep. That is deep. That is deep. These people are what keep me going. Everything we do is to bring visibility to sickle cell disease and amplify the voices of the people and families living with this disease.

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