

# Culture and Access to Services



**Azeez Butali, D.D.S, Ph.D**

*Dentist, Assistant Professor,  
Geneticist, Director of AfriCRAN and  
CEO of Healthcare Trends*

**“Access to care is as important as information about care. Some families may have limited access to care due to socio-economic situations or location (with little or no means of commuting).**

**“...the economic situation and cost of treatment will be deciding factors and in most cases jeopardize the chances of the child getting continuous care.**

**“[For my family] the cost of multiple admissions in the hospital, medications, time she missed school and other family lost hours was higher than the cost of a BMT [bone marrow transplant].”**



**You work with families who have difficulty understanding and accessing medical care for their children. What is your advice about how to improve communication and access to care throughout different cultures?**

Communication and information are important for families to continue treatment or care. This is even more important for families who speak a minority language. For instance if a family feels they do not understand the need for continuous care due to a lack of communication, they may decide to ignore future appointments especially when the importance of such visit has not been understood.

Access to care is as important as information about care. Some families may have limited access to care due to socio- economic situations or location (with little or no means of commuting).

Again, regardless of whether the care or treatment is important, the economic situation and cost of treatment will be deciding factors and in most cases jeopardize the chances of the child getting continuous care.

**Your family has experience with an inherited condition and Newborn Screening. What can you share about the treatment and your experience?**

As a parent of a child who had sickle cell disease and received a bone marrow transplant (BMT) treatment 17 months ago, I can confidently state that it was a game changer. The treatment for sickle cell disease is the same as the treatment for X-ALD and MPS-I. It is a stem cell or bone marrow transplant.

My daughter is now looking healthier, her lungs and kidney that showed signs of damage are rapidly getting better, and her blood/oxygen levels are improving. She now breathes well and does physical activities that had been impossible for her before the transplant.

She has not been hospitalized since the transplant. This is a significant change for our family. She was diagnosed at 1 year old and was admitted to the hospital over 30 times from when she was 1 until she had the BMT. Hospital stays go from a few days to about 3 weeks each time. She was on multiple medications. Her quality of life was below average since she missed school and was limited as to the type of physical activities she could do. She was also prone to catching any infection around (survived swine flu in 2009).

Overall, the cost of multiple admissions in the hospital; medications, time she missed school and other family lost hours is higher than the cost of a BMT.

Where BMT is an option, I will opt for it. With growing scientific discoveries like CRISPR and others; the cost of treatment as well as BMT will be within reach.

**Do you think it is important to add new conditions to the Newborn Screening Panel?**

The decision to screen or not to screen depends on our need to learn and act towards preventing future children from being born with the diseases. When we screen, we are able to detect new cases and understand the pathogenesis of the diseases. The knowledge gained from the clinical presentations will drive research towards cheaper treatment and prevention, despite the fact that some of the conditions are late onset.

As a human geneticist, I view every opportunity for sample collection / screening as an opportunity to learn and drive science of discovery towards healthy population.

How do we educate parents if we do not know enough about it?

Will screening stop the child from living? The answer is “NO”

Will the parents be well informed of the likely course of child’s growth, development and quality of life?  
“Yes”

Will the information affect their lives? “Yes”

While the argument to only screen for conditions for which we have treatment for appears to make economic sense, it also limits our drive for scientific discoveries that will promote cheaper treatment and interventions.