Cameroon Townhall for Healthcare Professionals

Meeting Minutes, June 19, 2021

Host: Cameroon Townhall for Healthcare Professionals

Date: June 19, 2021

Chair: Dr. Munoh Kenne Foma

Co-Moderators: Elvis Ndansi (lead moderator), Dr. Christelle Jouego Tagne (French-language co-moderator)

Guest Speakers: Dr. Munoh Kenne Foma, MD, MPH, Chair of the Town Hall; haematologist and oncologist, New York (at the time); Arrey Echi, Sickle cell advocate and writer, Founder, Joy2Endure Foundation, Cameroon; Dr. Ferdinand Ndum, MD; medical doctor living with sickle cell disease, in residency, Germany (trained at the University of Buea)

Distinguished Guests: A general practitioner in the US, a medical school friend of Dr. Ndum, A physician and drug regulator who formerly practised in The Gambia and Cameroon, A researcher on sickle cell disease in Cameroon, A participant who spoke on prevention, A Nigerian pharmacist and doctor

Title: Sickle Cell Disease in Cameroon: Science, Lived Experience and Care (World Sickle Cell Day)

Agenda Items:

1. Welcome and opening remarks
2. Presentation by Dr. Munoh Kenne Foma on the science and management of sickle cell disease
3. Testimony by Arrey Echi, sickle cell advocate and founder of Joy2Endure Foundation
4. Testimony by Dr. Ferdinand Ndum on growing up with sickle cell disease in Cameroon and care in Germany
5. Discussion and Q&A
6. Closing remarks and next meeting

Opening Remarks:

- The session was held on World Sickle Cell Day and brought together clinical teaching, a patient advocate's testimony and a doctor's own experience of the disease.
- Elvis Ndansi moderated with Dr. Christelle Jouego Tagne, who summarised in French. Louisa Viban, Dr. Bryan Tegomoh and another co-moderator sent apologies.

Presentation Points:

Presentation by Dr. Munoh Kenne Foma: "Sickle Cell Disease: From Pathophysiology to Care in Cameroon"

1. History and stigma:

Dr. Foma explained that sickle cell disease was present in Africa for centuries, where children who repeatedly died young were thought to be cursed (the Nigerian 'ogbanje', a child who comes and goes). It was first described about a hundred years ago in a dental student from Grenada in Chicago, although Africans had lived in America for centuries without a diagnosis, which he presented as a sign that health is also political.

2. Genetics and the link with malaria:

The disease results from a single amino acid change (glutamic acid replaced by valine) in the beta globin gene on chromosome 11. Carriers (AS) are protected from severe malaria, which explains why the trait persists where malaria is common; he put trait prevalence in Cameroon at about 18.2 percent. He explained inheritance risks for couples and noted that haplotypes differ (Benin, Bantu, Senegal, Cameroon, Arab-Indian), with the Bantu type producing the least fetal haemoglobin and the most severe disease.

3. Burden and survival:

Africa carries about 80 to 90 percent of patients, and WHO reports about 300,000 affected births a year. He said the median age at death is about 18 years in Cameroon, 21 in Nigeria and 48 in the United States, and that most children in Africa die before their fifth birthday if untreated. Acute chest syndrome and infection are the main causes of death.

4. Complications and gaps in care:

Sickle cell affects every organ: pain crises, acute chest syndrome, splenic sequestration, stroke, gallstones, kidney failure, priapism and eye disease. He listed gaps in Cameroon: no routine screening of pregnant women or newborns,

unreliable blood supply (families paying 5,000 FCFA and finding donors), no exchange transfusion, limited X-ray and opioid access, and no adult haematologists in most hospitals. He advised half normal saline for hydration and pulse oximetry to detect acute chest syndrome.

5. Treatment options:

Hydroxyurea, used for over 30 years, reduces crises by about 50 percent and should be offered to patients with more than three crises a year, from age two, with blood count monitoring; he noted the first large African trial came only in 2019. Newer drugs (L-glutamine, crizanlizumab, voxelotor) are largely unavailable in Cameroon. Bone marrow transplant from a sibling can cure young patients, and gene therapy, including CRISPR-based editing, has shown early success.

6. Research neglect:

He contrasted about 28 approved HIV drugs in 40 years with four for sickle cell disease, three of them less than four years old, and said the American Society of Hematology had only recently made the disease a priority. He also described stigma in the US, where patients are labelled as seeking pain medication.

7. Arrey Echi: an advocate's view:

Arrey Echi said community attitudes and hospital care remain poor, that even referral hospitals lack essentials, and that some general practitioners show little commitment to patients in crisis. She said hydroxyurea costs about 12,000 FCFA in Cameroon, out of reach for most. Her foundation began a medicines programme the previous year that had reached about 200 warriors, with another 200 planned that June.

8. Dr. Ferdinand Ndum: living with the disease:

Dr. Ndum, 31, described pain as his first memory, giving up football at age 10, and the burden on his family. He avoided hospitals during crises because of long waits and indifferent staff, did not receive effective pain treatment until about 15 or 16, and believed he would not live past 22. After moving to Germany in January 2016, health insurance, a cholecystectomy, hydroxyurea with regular monitoring and later monthly crizanlizumab infusions transformed his health. He called for treating patients as normal people, attention to mental health and depression, and role models, and recalled being subjected to an exorcism as a teenager.

Discussions and Q&A Session:

- **Comment from a researcher on sickle cell disease in Cameroon** She said patients in Cameroon lack basics such as paracetamol and oxygen, that some doctors

caring for sickle cell patients have given up, and urged participants to help fund drugs and vaccines.

- **Comment from a physician and drug regulator** She said staff attitudes in Cameroon drive patients to traditional healers, that customer care should be taught in medical, nursing and pharmacy schools, and that curricula should prioritise common African diseases such as sickle cell disease. She argued that funds spent on one official vehicle could buy a year of hydroxyurea for about 50 patients and that generic supply could be negotiated, as was done for HIV drugs.
- **What are the barriers to premarital and prenatal screening in Cameroon? (a participant who spoke on prevention)** The Chair said the disease is not treated as a health priority, so neither training nor screening follows. He noted Ghana screens all pregnant women, that PCR capacity built for COVID-19 could be used, and that hydroxyurea, a generic, could be placed on the essential medicines list. He favoured informed choice over mandatory premarital testing. Elvis Ndansi proposed that mayors counsel couples to test during the 30-day marriage registration period, through the councils.
- **Is hydroxyurea available in Cameroon? (chat)** The Chair said it is sold in specialty pharmacies at an unstable price of about 12,000 to 20,000 FCFA a month, and that some patients stretch a pack over fewer days. He said manufacturers can be approached for donations of newer drugs.
- **If you were Minister of Public Health, what three things would you do? (Elvis Ndansi to Dr. Ndum)** Dr. Ndum named population-wide sensitisation, funding and subsidies so that every patient can get medicines, and specialised sickle cell clinics that would also train students.
- **Comment from a participant on pain management** He said colleagues in Cameroon hesitate to give adequate doses of pain medication and that analgesics run out of stock, and saw universal health coverage as the main long-term solution.
- **Is there an organisation through which people can support patients? (participant)** Elvis Ndansi pointed to Arrey Echi's Joy2Endure Foundation. Arrey Echi, by typed answers, listed three projects needing support: buying folic acid and other supplies for warriors, school sensitisation in September, and screening in remote communities.

Call to Action and Closing:

- Elvis Ndansi thanked the Chair for the presentation and invited those wanting the slides to contact him.

- He thanked Dr. Ndum and Arrey Echi and encouraged members to support her foundation's projects.
- The next session was announced for two weeks later.

Next Meeting

In two weeks (July 3, 2021): Customer Care in Healthcare Facilities in Cameroon.

Recording: https://www.youtube.com/watch?v=cMDZNw0lbes

Submitted by: Co-Moderators, Cameroon Townhall for Healthcare Professionals