

Mandates of the Independent Expert on the enjoyment of human rights by persons with albinism; the Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

Ref.: AL NGA 3/2022
(Please use this reference in your reply)

16 May 2022

Excellency,

We have the honour to address you in our capacity as Independent Expert on the enjoyment of human rights by persons with albinism; Special Rapporteur on the rights of persons with disabilities and Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, pursuant to Human Rights Council resolutions 46/12, 44/10 and 42/16.

In this connection, we would like to bring to the attention of your Excellency's Government information we have received concerning **Comfort Paulinus**, a woman with albinism from the Akwa Ibom State who is in need of urgent medical treatment for skin cancer.

According to the information received:

Comfort Paulinus, a woman with albinism, is 32 years of age and originally from the Akwa Ibom State. She was diagnosed with skin cancer and has been living with this condition for seven years. She had received initial treatment, but the cancer became aggressive and began to spread. She visited the Nnamdi Azikiwe University teaching hospital of Nnewi in Anambra State for free excisional surgery funded by the International League of Dermatological Societies. However, she suffered a seizure after she was anaesthetized for the excision and the surgery had to be stopped. She then underwent further review and was referred to the Oncology Department of the University of Nigeria Teaching Hospital in Enugu for radiotherapy and chemotherapy to shrink the tumour so that the rest could be excised. This referral took place in November 2021, but she has yet to receive this treatment as Ms. Paulinus is unable to afford treatment, yet her lesions, which are located on her face and partially on her head and ears, continue to grow. A video of Ms. Paulinus shows her face covered with bandages and what appears to be large lesions which are impeding her vision.

On 18 January 2022, a letter was sent by a civil society organization working with persons with albinism on behalf of Ms. Paulinus to the Executive Secretary for the National Commission for Persons with Disabilities in Abuja, appealing for help for Ms. Paulinus. On 26 April 2022, Ms. Paulinus went to see a doctor in Enugu State for a consultation and was told that she needs immediate treatment as her lesions were bleeding regularly. However, she is not able to afford the treatment although the National Albinism Policy adopted by the Government in 2012 states that such treatment should be free and

accessible. As a result of the skin cancer, Ms. Paulinius is not able to continue going to school and live a normal life. She is often ostracised and discriminated against in her community not only due to her albinism condition but also due to the disfiguring impact of the lesions and tumours on her face. Her mental health has also suffered significantly due to the physical and psychological stress she has endured.

Reportedly, 10 other individuals with albinism from Akwa Ibom State are still awaiting treatment for skin cancer due to their inability to afford treatment, and it is understood that persons with albinism in other States in the country are in similar dire situations.

While we do not wish to prejudge the accuracy of these allegations, we are seriously concerned that lack of access to urgent medical care for Ms. Paulinius will result in the deterioration of her health and possibly death.

We wish to highlight that albinism as an inherited genetic condition that is characterized by a significant deficit in the production of melanin, results in the partial or complete absence of pigment in any part or all parts of a person's skin, hair and eyes. As a result, persons with albinism are highly susceptible to ultra-violet induced skin damage, in particular skin cancer. Research have shown that most persons with albinism in sub-Saharan Africa die from skin cancer between the ages of 30 and 40 years.¹ As such, skin cancer is likely to be the leading cause of death in the region for persons with albinism. Additionally, persons with albinism are also considered persons with disabilities due to the visual impairment normally associated with their condition.

While we commend your Excellency's Government for adopting its National Policy on Albinism in 2012, we wish to reiterate that this Policy calls on the authorities to implement particular strategies including the provision of "secure free, accessible qualitative treatment and rehabilitation of [persons with albinism] with skin cancer."² However, we are concerned that despite the adoption of the said National Policy, Ms. Paulinius and a number of persons with albinism continue to face significant challenges in accessing free, essential and life-saving treatment and services related to skin cancer.

We would like to reiterate that the National Policy on Albinism also aims to ensure provision of vital services for persons with albinism not only in relation to rights affecting their health, but also in relation to education, social security and legal services. We urge your Excellency's Government to ensure the provision of support and assistance to persons with albinism in line with the spirit of this Policy, which represents a best-practice initiative that many other States in the region and beyond have yet to adopt.

In connection with the above alleged facts and concerns, please refer to the **Annex on Reference to international human rights law** attached to this letter which cites international human rights instruments and standards relevant to these

¹ A/HRC/37/57

² <http://albinofoundation.org/wp-content/uploads/2017/04/National-Policy-on-Albinism.pdf>

allegations.

As it is our responsibility, under the mandates provided to us by the Human Rights Council, to seek to clarify all cases brought to our attention, we would be grateful for your observations on the following matters:

1. Please provide any additional information and any comment you may have on the above-mentioned matters.
2. Please provide information on how Ms. Paulinius can benefit from health and essential medical services needed to treat life-threatening skin cancer, as well as mental health support services.
3. Please provide further information on the implementation of strategies identified in the National Policy on Albinism, particularly in relation to health and essential medical services related to skin cancer.

We would appreciate receiving a response within 60 days. Past this delay, this communication and any response received from your Excellency's Government will be made public via the communications reporting [website](#). They will also subsequently be made available in the usual report to be presented to the Human Rights Council.

Please accept, Excellency, the assurances of our highest consideration.

Muluka-Anne Miti-Drummond
Independent Expert on the enjoyment of human rights by persons with albinism

Gerard Quinn
Special Rapporteur on the rights of persons with disabilities

Tlaleng Mofokeng
Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

Annex
Reference to international human rights law

We would like to remind your Excellency's Government that Article 25(b) of the Convention on the Rights of Persons with Disabilities which Nigeria ratified on 24 September 2010, requires States to "provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities..."

We also take the opportunity to recall Nigeria's obligations under article 12 of the International Covenant on Economic, Social and Cultural Rights, ratified in 1993 to guarantee the right of all people to the highest attainable standard of physical and mental health. In this regard, the Committee on Economic, Social and Cultural Rights considers that "[e]very human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity" and that the framework of the right to health should be around the following elements: availability, accessibility, acceptability and quality (General Comment No. 14, paras. 1 and 12).