

Mandate of the Independent Expert on the enjoyment of human rights by persons with albinism

REFERENCE:
OL BRA 16/2019

29 November 2019

Excellency,

I have the honour to address you in my capacity as Independent Expert on the enjoyment of human rights by persons with albinism, pursuant to Human Rights Council resolution 37/5.

During my recent official visit to Brazil, I had the occasion to meet with Members of the Commission on Human Rights of the House of Representatives and the Federal Senate, as well as members of the Commission for Constitution and Justice and Citizenship (CCJC). In response to the invitation from the latter to submit my recommendations on draft bill 7762/2014 (Projeto de lei N.º 7.762-B, de 2014), and in addition to my observations made in a previous letter sent to Your Excellency's Government on 20 June 2018 (document number OL 8/2018), I make the following recommendations to draft bill 7762/2014:

1. Include sunscreen on the list of essential medicines

Rationale: Access to sunscreen is strongly related to the right to life of persons with albinism. Given that sunscreen protects the person with albinism from early contraction of skin cancer, which can be fatal, sunscreen for people with albinism are analogous to antiretroviral for people living with HIV or insulin for people with diabetes. As of today, persons with albinism in Brazil, particularly those in the North and others from low socio-economic background, face the same risk of developing skin cancer as their counterparts in many parts of Africa, which is estimated at 1,000 times the risk of persons without albinism. Sunscreens for body, face, lip and corollary after-sun products are essential in the lives of people with albinism, particularly those living in the tropics. Distribution of sun protection kits containing a comprehensive pack of sunscreens – which are considered essential medicines – is a best practice in other countries with tropical climates.

2. Priority access to the public health network especially in the areas of dermatology, ophthalmology, oncology and genetic counselling, in order to ensure fulfilment of the right to life, health, education, and employment

Rationale: There are often lengthy delays in seeing specialists and yet access to these specialized services is strongly related to the right to life of persons with albinism. Therefore, priority access ought to be included in this bill. Access to dermatology services can prevent advancing skin cancer and premature death. It can also give access to early intervention and other prevention measures. Access to ophthalmological services facilitates access to education, leads to employment indoors and away the sun. Regarding genetic counselling, some types of albinism are syndromic, for example hermannsky pudlak syndrome (HPS) which can seriously affect the lungs and bowels, as well as life expectancy.

3. Equal access to *all* benefits for persons with disability, including assistive devices and social security

Rationale: It is important to definitively bring persons with albinism under the disability regime and guarantee access to all enjoyment of rights and privileges set out for persons with disabilities in Brazil.

Integrating this recommendation would settle the ongoing debate about whether persons with albinism have disabilities. A debate which has cost many persons with albinism access to those rights and privileges for which they should have qualified.

Many people with albinism have been barred from access to the social security benefit: Benefício de Prestação Continuada (BPC) program on the basis that they do not meet the impairment test for the BPC. Yet most persons with albinism – over 90 percent - have very low vision requiring assistive and adaptive devices to study, work and carry out daily living activities. Even where there is no low vision, there is often a skin impairment or vulnerability. Overall, for the purposes of meeting the impairment test of the BPC, albinism per se (in nearly all its forms) is an impairment causing multiple disabilities: low vision and skin vulnerability.

I would be grateful if you could share this letter with the relevant Commissions of the House of Representatives and the Federal Senate for integration of the above recommendations into draft Bill 7762/2014. I consider the adoption and implementation of Bill 7762 as a life-changing step for many persons with albinism in Brazil. It would also be decisive towards the establishment of federal, state and municipal public policy programs contributing significantly to the ending of discrimination against persons with albinism.

As it is my responsibility, under the mandate provided to me by the Human Rights Council, to seek to clarify all cases brought to my attention, I would therefore be grateful for your observations on the following matters:

1. Please provide any additional information and/or comment(s) you may have on the above-mentioned recommendations and please share any information on progress made in terms of adoption of the bill at Congress.

This communication, as a comment on pending or recently adopted legislation, regulations or policies, and any response received from your Excellency's Government will be made public via the communications reporting [website](#) within 48 hours. 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 my highest consideration.

Ikponwosa Ero
Independent Expert on the enjoyment of human rights by persons with albinism