

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

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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.

I would like to bring to the attention of your Excellency's Government some suggestions concerning two Bills pending at the Brazilian Parliament which address the enjoyment of human rights by persons with albinism. These Bills, 7523/2010, and 7762/2014, were submitted on 23 June 2010, and 2 July 2014 respectively.

Generally, I would like to stress the importance of both Bills, which have now been pending for nearly 8 and 4 years respectively. Their adoption and implementation would be positive for Brazilians with albinism as they would facilitate the full enjoyment of their human rights. Furthermore, this would concretize the overarching pledge of the Sustainable Development Goals, which is to leave no one behind, beginning with the furthest behind first.

Regarding both Bills, it is important to ensure that the different types of albinism are covered, including oculocutaneous albinism, whose main types are tyrosinase negative albinism and tyrosinase positive albinism, as well as ocular albinism, and Hermansky-Pudlak syndrome. A medical diagnosis is key to identifying whether a person is affected by albinism.

With regards to Bill 7762/2014, I support the suggestion to establish a national register in consultation with persons with albinism and civil society organisations. The data collection could be done through, for example, the insertion of a specific question in the next population census, in addition to the set of questions developed by the Washington Group on Disability Statistics. Data collection should be undertaken with the participation of persons with albinism. In advance of the next national census, other existing sources of information could be used, such as school records as well as prevalence and epidemiological studies. In addition, considering the high vulnerability of persons with albinism to skin cancer, this Bill could also recognize albinism as a public health issue under the responsibility of the Ministry of Health. Furthermore, to ensure full implementation of the law, I would suggest the elaboration and adoption of a specific, concrete and time-bound national action plan on albinism.

Measures that would complement those already identified in this Bill include training on albinism for health workers including ophthalmologists, dermatologists, and nurses (in particular, midwives), as well as training on albinism and on reasonable accommodation measures for professionals in the field of education, in particular teachers

in primary and secondary schools. In addition, it is highly important to ensure free access to sunscreen and to consider adding sunscreen to the list of essential medicines. This is key to ensure prevention of skin cancer to which persons with albinism are vulnerable. It is therefore also fundamental that treatment for skin cancer, once contracted, is of quality and that is available, accessible and affordable. To this end, and in order to facilitate access to dermatological services, mobile clinics could be considered as a means to reach out to the most remote communities. Regarding access to ophthalmic care, the Bill should consider including the distribution of vision devices as well as the facilitation of the importation of glasses and other assistive devices as a measure of reasonable accommodation.

Bill 7523/2010 complements Bill 7762/2014 with regard to the distribution of sunscreen, but would benefit from an emphasis on the specific and urgent need of sunscreen for persons with albinism. Similarly, adding a provision to ensure the adequate training of health workers about albinism and how to use sunscreen would constructively improve the current provision.

I would be grateful for your observations on the suggestions above, and I am looking forward to the continuation of the discussion on these two Bills.

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

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