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**Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms**

### Albinism worldwide

#### Note by the Secretary-General

The Secretary-General has the honour to transmit to the General Assembly the report of the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, in accordance with Human Rights Council resolution [37/5](#).

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\* [A/74/50](#).



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

### *Summary*

The present report is submitted pursuant to Human Rights Council resolution [37/5](#) concerning the mandate of the Independent Expert on the enjoyment of human rights by persons with albinism. It provides an overview of the situation of persons with albinism in different regions worldwide, summarizing legislation and policies and identifying gaps in the enjoyment of human rights, as well as best practices. In the report, the Independent Expert makes recommendations on concrete measures that can be implemented to integrate, recognize and enhance the human rights situations of persons with albinism globally. The recommendations are aligned with the Sustainable Development Goals and the pledge to leave no one behind, beginning first with the furthest behind.

## I. Introduction

### A. Methodology

1. On 29 March 2019, the Independent Expert sent a questionnaire to stakeholders, including Member States, United Nations offices, national human rights institutions, civil society organizations and individuals, including persons with albinism.<sup>1</sup> The present report is based largely on the compilation of the information received from 97 stakeholders, as well as research<sup>2</sup> and findings from the country visits of the Independent Expert.

2. The Independent Expert hopes that the report will not only shed light on the situations of persons with albinism globally, but also prompt much-needed research, data collection and discussions on issues affecting this group of people. She aims to publish a comprehensive report in the near future to reflect the extensive information received in the submissions.

3. The important issues relating to women and children are not detailed in the report given that the report of the Independent Expert to the forty-third session of the Human Rights Council will focus on those themes.

4. It is important to note that, in compiling the report, the Independent Expert placed emphasis on national and, in a few instances, regional law, policies and practices. International human rights laws and standards as they apply to the human rights of persons with albinism have not been factored in, as that topic was covered in the previous report of the Independent Expert to the General Assembly ([A/72/131](#)).

### B. Definition<sup>3</sup>

5. Albinism is a relatively rare, non-contagious, genetically inherited condition in which a person produces little to no melanin, resulting in little to no pigmentation, in the skin, hair and eyes. Albinism affects people worldwide regardless of ethnicity or gender. Persons with albinism are highly vulnerable to skin cancer and often have disabilities mainly as a result of visual impairment and attitudinal barriers owing to their appearance. They have also been recognized as persons who face racial discrimination and stigmatization on the ground of colour (see [CERD/C/ZAF/CO/4-8](#), paras. 20–21). These intersecting factors have resulted in physical attacks, including killings in eastern, western, central and southern Africa.<sup>4</sup>

## II. Eastern, Western, Southern and Central Africa

6. The majority of the submissions received were from the geographic region of Africa,<sup>5</sup> where the prevalence of persons with albinism varies from 1 person in 5,000 to 1 person in 15,000, with selected populations in Southern Africa having a

<sup>1</sup> See <https://www.ohchr.org/EN/Issues/Albinism/Pages/IEAlbinism.aspx> for the list of submissions.

<sup>2</sup> The Independent Expert expresses her appreciation to the International Human Rights Programme, Faculty of Law, University of Toronto, and to Duncan Dixon, Research Librarian, Trinity Western University, Canada.

<sup>3</sup> See [A/HRC/37/57](#) for additional information.

<sup>4</sup> See <http://albinism.ohchr.org/human-rights-dimension-of-albinism.html>.

<sup>5</sup> A total of 62 submissions were received from Angola, Benin, Burkina Faso, Burundi, Cameroon, Côte d'Ivoire, the Democratic Republic of the Congo, Eswatini, Ghana, Guinea, Kenya, Malawi, Mali, Mozambique, Namibia, the Niger, Nigeria, Senegal, Sierra Leone, South Africa, Somalia, Togo, the United Republic of Tanzania, Uganda, Zambia and Zimbabwe.

prevalence of 1 person in 1,000. Despite the relatively high prevalence of albinism in the region, official data have been compiled in only five Member States, namely, Côte d'Ivoire, Malawi, Namibia, Sierra Leone and the United Republic of Tanzania. The census conducted by the latter country in 2012 is likely the most extensive national survey on albinism to date, given that it contains relatively detailed disaggregated data.

7. Persons with albinism reside throughout the region, with some opting to live in urban settings where they benefit from better social services and relatively less stigmatization. In Eswatini, Namibia and Sierra Leone, the frequency of albinism appears to be higher in rural areas, whereas in South Africa, the United Republic of Tanzania and Zimbabwe, it is higher in urban settings.<sup>6</sup>

## A. Normative and policy framework

8. Few countries have specific laws, policies and measures that specifically address the human rights of persons with albinism. However, in many countries,<sup>7</sup> persons with albinism are protected by constitutional clauses on equality and non-discrimination, including on the grounds of disability, colour, gender and age. They are also often covered by disability and health legislation.

9. Owing to a combination of deep misunderstanding of the condition of albinism, inadvertent exclusion from human rights advocacy, a paucity of best practices concerning the human rights of persons with albinism, and the absence of specific measures concerning persons with albinism, the implementation of human rights norms and standards can be challenging. Consequently, some Member States have taken action to make specific reference to persons with albinism in proposed legislation. This is in line with the new Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa, which specifically references persons with albinism.<sup>8</sup> Specific mention of persons with albinism has also been proposed in Malawi's Disability Bill of 2019. Similar initiatives were reported in Guinea, Kenya and Uganda.

10. In some cases, national legislation sanctioning offences related to persons with albinism provides additional protection. For example, Malawi's Penal Code has been revised to incorporate tougher penalties for attacks against persons with albinism. Anti-trafficking laws in Mozambique cover not only the trafficking of organs but also body parts, the latter being relevant to the nature of attacks faced by persons with albinism in the region. The National Legal Aid and Awareness Policy 2015 promotes better access to justice for all, including persons with disabilities.

11. In the past decade, national action plans containing specific measures promoting the enjoyment of human rights by persons with albinism have emerged, including de facto plans and policies in Kenya, South Africa and the United Republic of Tanzania and de jure plans in Malawi, Mozambique and Nigeria. However, significant support is necessary to implement such plans effectively.

<sup>6</sup> Namibia: Lund and Roberts, "Prevalence and Population Genetics of Albinism: Surveys in Zimbabwe, Namibia and Tanzania" in *Albinism in Africa: Historical, Geographic, Medical, Genetic, and Psychosocial Aspects*, Kromberg and Manga, eds. (San Diego, California, Elsevier, 2018); South Africa: *Albinism in Africa: Historical, Geographic, Medical, Genetic and Psychosocial Aspects*, Jennifer Kromberg and Prashiela Manga, eds. (Academic Press, 2018); Eswatini (Minerva).

<sup>7</sup> Angola, Burkina Faso, Burundi, Cameroon, Ghana, Kenya, Mali, Malawi, Niger, Nigeria, United Republic of Tanzania, Uganda and Zambia.

<sup>8</sup> Uganda (African Albino Association and National Council for Disability).

## B. Main human rights issues

### 1. Non-discrimination

12. Persons with albinism face rampant discrimination and stigmatization in this geographic region, mostly on grounds of disability and colour, but also on additional grounds such as gender and age. All submissions received highlighted discrimination as a common challenge. A study in the Democratic Republic of the Congo found that 22 per cent of persons with albinism faced discrimination within their families, while 66 per cent reportedly faced discrimination in the broader community.<sup>9</sup> A survey on albinism conducted in Sierra Leone in 2018 showed that nearly 80 per cent of the persons with albinism who were surveyed faced stigma, discrimination and social exclusion in their communities.<sup>10</sup>

13. A general lack of understanding of albinism prevails in most countries.<sup>11</sup> Albinism is frequently viewed as a supernatural phenomenon: a form of evil, a “curse” or “punishment” imposed by supernatural beings. Some view persons with albinism as being contagious, possessing mystical powers, bringing luck or being sub-human or non-human. Some view them as incapable of mental and physical tasks and as unwanted foreigners in their own country owing to the colour of their skin. These misconceptions have resulted in normalized bullying, mockery, name-calling, taunts and jeers on the street. In some cases, they have led to physical attacks and killings.

14. With the exception of a few countries, including Kenya and the United Republic of Tanzania, persons with albinism are absent in key governmental positions and many are not involved in civic and political life and representation.

### 2. Right to life

15. Persons with albinism in the region generally have a lower life expectancy owing to multiple factors. These include skin cancer; HIV/AIDs, due to the myth that intercourse with persons with albinism can cure the disease; and harmful practices related to the manifestation of belief in witchcraft, including the idea that the body parts of persons with albinism can bring success and good luck.

16. As a result, hundreds of cases of attacks and other related violations such as murder, mutilation, ritual rape, infanticide and trafficking of persons, organs and body parts, as well as grave robberies, have been reported in 28 countries in the region in the past decade.<sup>12</sup> It is widely believed that such crimes increase near election periods, as has occurred in Kenya, Malawi,<sup>13</sup> Uganda and the United Republic of Tanzania.

### 3. Health

17. Skin cancer is the most prominent health issue, with a stream of deaths of persons with albinism of all age groups reported consistently to the Independent Expert and mentioned extensively in several submissions received. It is important to point out that skin cancer is a highly preventable form of cancer that generally responds well to treatment upon early detection. Yet, persons with albinism in the region, especially those in rural areas, face challenges in accessing health-care

<sup>9</sup> Democratic Republic of the Congo (Inena Gaylord).

<sup>10</sup> Sierra Leone (Sierra Leone Albinism Foundation).

<sup>11</sup> Angola, Cameroon, Democratic Republic of the Congo, Kenya, Mozambique, Nigeria, Senegal, Sierra Leone, Somalia, Uganda, United Republic of Tanzania and Zimbabwe.

<sup>12</sup> See <https://www.underthesamesun.com/content/issue>.

<sup>13</sup> See communication addressed to Malawi, available at <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gId=24323>.

products and services in general. In the United Republic of Tanzania, only an estimated 42.7 per cent of persons with albinism living in temporary holding shelters designated for their protection, including in Buhangija and Mitindo, have access to general health-care services.<sup>14</sup>

18. In many countries, access to general and specialized health-care services to prevent skin cancer is often hindered by poverty and social exclusion. Other barriers include the unavailability and unaffordability of sunscreen. Lack of government support in the integration of persons with albinism into the general health-care system also seriously impinges on the enjoyment of the right to health by persons with albinism. In the cases where skin cancer screening and treatment exist, robust monitoring by the government is needed to assess their effectiveness, an essential component to achieving the highest attainable standard of health.

19. In certain countries, there is also limited understanding of albinism among persons with albinism themselves. This is evidenced by the common belief among persons with albinism, particularly in rural areas where there is a dearth of specialists, that pre-cancerous lesions are a normal part of albinism or the result of allergies.<sup>15</sup> Consequently, many persons with albinism do not seek medical attention until they are in the advanced stages of the disease.

#### **4. Education**

20. Poverty is a major barrier to education, given that children with albinism often cannot afford the necessary assistive devices, tuition and sun-protective clothing. This, in addition to other factors detailed below, often leads to high dropout rates.

21. In some cases, parents withhold their children from school or have them start at a later age because of fear of attacks, prejudice or concerns about their child's learning ability, as well as fear of wasted investment since the future of the child remains in question in the light of societal prejudices. In Burkina Faso, some 30 per cent of girls with albinism do not finish primary school,<sup>16</sup> and in Burundi, an estimated 56 per cent reportedly drop out of school.<sup>17</sup>

22. In the classrooms, there is often little to no reasonable accommodation for students with albinism, such as assistive devices, reading material with large print and additional time during exams. In a survey conducted in Sierra Leone, 57 per cent of school-age respondents said that their schools did not provide them with the necessary support and accommodation to enable them to access education on equal terms with others.<sup>18</sup> This often leads to poor academic performance, reinforcing prejudices about the learning capacities of persons with albinism, which further contributes to low self-esteem and diminished ambition.

23. Teachers are often unaware, unable or unwilling to provide for the needs of students with albinism or do not invest the time necessary to help with basic accommodations that cost little to nothing, such as allowing students to copy from their notes.

24. Children in school also face bullying, teasing, discrimination and stigmatization from their peers and teachers alike. Other students may refuse to play with children with albinism, sometimes on the orders of their parents or fuelled by pre-existing social prejudices.

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<sup>14</sup> United Republic of Tanzania (Karagwe Community-based Rehabilitation Centre).

<sup>15</sup> Mozambique (Shade Tree Project).

<sup>16</sup> Burkina Faso (Association of Burkina Faso for the Integration of Persons with Albinism).

<sup>17</sup> Burundi (Association des femmes albinos espoir du Burundi).

<sup>18</sup> Sierra Leone Albinism Foundation.

## 5. Employment and adequate standard of living

25. Access to employment is a challenge for persons with albinism in the region. Barriers to education often result in a lack of qualification for indoor jobs. Many persons with albinism work outdoors on farms or sell their wares in markets, where they suffer from sun exposure and increase their risk of skin cancer. Lack of reasonable accommodation at work can also be hazardous, for example, where there is no flexibility around night shifts, which increases vulnerability to attacks in some countries.

26. Moreover, employers or potential employers often discriminate against persons with albinism, stigmatizing them as inferior or incompetent or as persons whose physical presence may scare potential customers away.

27. In other instances, particularly in private enterprises, employees with albinism of all sexes are vulnerable to sexual harassment and ritual rape by employers due to the belief that such acts bring wealth and good luck in business.

28. Persons with albinism who have their own businesses also face discrimination because potential clients do not wish to buy from someone with albinism. Owing to prevailing unemployment, persons with albinism have difficulties accessing loans. They also miss crucial opportunities to earn capital in situations in which they are disinherited by family members because of their condition.

29. Many persons with albinism therefore live in extreme poverty. In Uganda, persons with albinism were found to be generally poorer than those in rural areas. Where critical socioeconomic schemes or services exist, knowledge on how to access them is lacking among persons with albinism, including social security benefits on the basis of disability.

## 6. Access to justice and legal remedy

30. Barriers to access to justice include a culture of silence related to a manifestation of belief in witchcraft, financial barriers and a fear of reprisals from relatives and community members when an attack has been perpetrated by a family member or a respected member of the community. There are also barriers attributed to lack of legal literacy among persons with albinism, including lack of understanding of legal processes, and lack of access to information, education and training. Underreporting and low levels of monitoring and follow-up by both State and non-State actors are also significant challenges (see [A/HRC/40/62](#)).

## C. Best practices

31. Successful awareness-raising at the national level, including through public condemnation of attacks against persons with albinism by politicians, as well as the platform of International Albinism Awareness Day marked annually on June 13, as adopted by the General Assembly in 2014, has facilitated public education on albinism in the region. More than half of the countries in the region have reported celebrating this day, with a wide range of both traditional and innovative approaches. These campaigns have reportedly contributed to a decline in reported cases of attacks in certain countries, including Cameroon, Côte d'Ivoire and the United Republic of Tanzania.

32. The innovative use of beauty pageants popularly known as “Mr. and Miss Albinism” has spread across the continent as a popular tool for awareness-raising.

33. On employment, several countries, including, Kenya, South Africa, the United Republic of Tanzania and Zimbabwe, have affirmative action programmes for the

hiring of persons with disabilities, including persons with albinism. Persons with albinism have been appointed to high-level government and public positions in Kenya, Malawi, South Africa and the United Republic of Tanzania.

34. Since 2013, the Government of Kenya has specifically allocated an annual budgeted fund of 100 million Kenya schillings (nearly \$1 million) for persons with albinism. In Côte d'Ivoire, the State policy on socio-professional integration has led to the recruitment of 18 persons with albinism to public service.

35. In Malawi, subsidies are provided to secure homes of persons with albinism as a protection measure. In the United Republic of Tanzania, the decrease in the reported number of attacks has been attributed to the transfer of persons with albinism to temporary holding shelters, although careful reintegration into the community is now necessary.

36. In Malawi and Namibia, sunscreen products are on the Ministry of Health's list of essential drugs, and free sunscreen is provided in public hospitals in South Africa. A skin cancer production and distribution programme is run by civil society groups in the United Republic of Tanzania in collaboration with the government. In Ghana, the abundance of local shea butter is used to produce sunscreen.

37. In an attempt to combat harmful practices linked to a manifestation of belief in witchcraft, the United Republic of Tanzania has mandated the registration of all practitioners of traditional and alternative medicine (see [A/HRC/37/57/Add.1](#)).

### III. Asia and the Pacific

38. The Independent Expert noted a serious lack of data concerning the human rights of persons with albinism in the Asia and the Pacific region. She received three submissions, from Australia, Japan and New Zealand, which, along with her findings from her country visit to Fiji in 2017 (see [A/HRC/40/62/Add.1](#)) and other research, has provided the information below on this region.

39. The reported prevalence of albinism varies in both Asia and the Pacific. In Japan, it stands at between 1 person in 7,900 to 1 person in 27,000.<sup>19</sup> Australia does not have official data, but a civil society organization estimates that there is approximately 1 person in 700 persons with albinism living in the country.<sup>20</sup> New Zealand reports a prevalence rate of 1 person in 16,000.<sup>21</sup>

40. During the visit by the Independent Expert to Fiji in 2017, she learned that the Pacific region potentially has one of the highest prevalences of albinism in the world, at around 1 person in 700 for oculocutaneous albinism type 2 alone.

41. In the absence of official data, the United Nations Information Centre for India and Bhutan estimates that in India, there are approximately 150,000 persons with albinism.<sup>22</sup> In China, a documentary produced with the support of the Chinese Organization for Albinism put the number of persons with albinism at 90,000, with 1 person in 65, or 20 million persons, estimated to carry the gene.

42. The submissions received indicated that persons with albinism were scattered throughout the various countries, with no clear urban-rural distribution. In Fiji,

<sup>19</sup> Japan (Japanese Albinism Network).

<sup>20</sup> Australia (Albinism Fellowship of Australia).

<sup>21</sup> New Zealand (Albinism Trust).

<sup>22</sup> United Nations Information Centre for India and Bhutan, International Albinism Awareness Day, 9 June 2016.

certain parts of the country appeared to have a greater prevalence of albinism within their communities, namely, Bua in Vanua Levu, Kadavu Navosa, Rewa and Savusavu.

## A. Legislative and policy framework

43. The human rights of persons with albinism are generally protected through constitutions guaranteeing equality and access for those with disabilities as well as specific legislation on disability, health, employment, building codes and access to the legal system.<sup>23</sup> For example, persons with albinism are protected under the Australian Disability Discrimination Act of 1992 and the Rights of Persons with Disabilities Act 2018 of Fiji.

## B. Main human rights issues

### 1. Non-discrimination

44. In China, there appears to be a lack of awareness about persons with albinism, particularly in rural areas, where they are exposed to prejudice and discrimination owing to their appearance.

45. Testimonies received from Mumbai, India, indicate that persons with albinism tend to be viewed as a curse, and in Japan, they reportedly suffer from prejudice and stereotypes. In some cases, they have been mistaken for foreigners or considered “punks”.<sup>24</sup> Moreover, they have reportedly been told by authorities, at school and in the workplace, to dye their hair black to conform to perceived norms of what a Japanese person ought to look like.<sup>25</sup>

46. In Australia, albinism is viewed in a relatively positive light, as people tend to be curious and want to know more about the condition. Furthermore, some persons with albinism do not stand out because there is a relatively large number of persons with fairly low pigmentation or fair skin in the country. Nevertheless, sometimes, children endure bullying owing to their physical appearance and are excluded from social activities including sports, because of their low vision.<sup>26</sup>

47. In New Zealand, albinism is viewed as a genetic condition, and there are no reported situations of stigmatization or discrimination. However, there can be a cycle of shame, blame and guilt associated with the diagnosis of albinism.<sup>27</sup>

48. In India and China, discrimination and stigmatization emanate from a lack of knowledge and widespread misconceptions about albinism. Such misconceptions are fuelled by the hypervisibility of persons with albinism because of their colouring and appearance relative to the majority of the population, who have more pigmentation. There are also reported cases of child abandonment and divorce as a result of the birth of children with albinism.

49. In Fiji, persons with albinism often feel isolated from society. For some, walking around their communities and participating in social activities is a difficult endeavour because they are frequently taunted and teased. For those living in rural areas and villages, even wearing hats and sunglasses as sun protection measures can be seen as inappropriate social behaviour owing to existing customary practices (see [A/HRC/40/62/Add.1](#)). In Japan, exclusion and discrimination cause persons with

<sup>23</sup> Australia (Albinism Fellowship of Australia); see [A/HRC/40/62/Add.1](#).

<sup>24</sup> Japan (Japanese Albinism Network).

<sup>25</sup> Ibid.

<sup>26</sup> Ibid.

<sup>27</sup> New Zealand (Albinism Trust).

albinism to sometimes accept certain undesirable situations that they would otherwise not accept because of a lack of options, including in the context of education, employment and marriage.

## **2. Health**

50. Vision and skin care services are generally accessible and affordable in countries such as Australia and New Zealand (ibid.). This is generally not the case in the Pacific Islands, where public services are often in dire need of resources and support. Moreover, in the Pacific Islands, as well as in Japan, there are few to no specialists with expert knowledge on albinism, including in ophthalmic and dermatological care.

51. In Australia, there are sometimes financial and geographical barriers to accessing dermatological and ophthalmological care. In Fiji, geography, information and availability of services are additional barriers to health care for persons with albinism. There is also an absence of psychosocial support aimed at building self-confidence and empowerment, which are cornerstones for self-advocacy and knowledge of human rights for persons with albinism.

52. A study on the Bhatti tribe in Pakistan shows that persons with albinism are continuously exposed to high ultraviolet radiation in temperatures that can be as high as 50 degrees Celsius. This results in severe sunburn in almost all cases, a first step in the development of skin cancer. In addition, most of them are poor and cannot afford to buy sunscreen or sun-protection clothing.<sup>28</sup>

53. In Japan, persons with albinism who have high visual acuity are often not recognized as having a disability. Approximately 60 per cent of infants with albinism are not able to obtain a disability certificate from the Government.<sup>29</sup>

## **3. Education**

54. In Fiji, there is a lack of reasonable accommodation for students with albinism in most school settings, leading to early school dropouts.<sup>30</sup> In Japan, there are insufficient teachers trained in supporting low vision and photophobia, normally associated with albinism. In Australia and New Zealand, schools are often provided with funds for the reasonable accommodation of students with disabilities.

## **4. Employment and adequate standard of living**

55. In all submissions, it was noted that persons with albinism face employment discrimination on the basis of visual impairment and a lack of reasonable accommodation in the workplace. Persons with albinism in Japan have reportedly failed job interviews because of their colouring and are often forced by the employer to dye their hair black.

56. In Fiji, persons with albinism face discrimination in gaining access to and maintaining employment, although there are also stories of inclusion and professional success. Women with albinism are reportedly neglected by their families and their local communities, finding themselves in particularly vulnerable situations, experiencing prejudice from the community, dealing with health challenges owing to their condition and trying to attain a livelihood to provide for themselves and their children.

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<sup>28</sup> Azam Jah Samdani and Bahram Khan Khoso, "A unique albino village of Bhatti tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: An epidemiological study", *Iranian Journal of Dermatology*, vol. 12, No. 2 (48), (Summer, 2009).

<sup>29</sup> Japan (Japanese Albinism Network).

<sup>30</sup> See country visit report of the Independent Expert (A/HRC/40/62/Add.1).

## 5. Access to justice and legal remedy

57. Although there are legislative protections in place, persons with albinism sometimes lack information and understanding on processes within the justice system as well as information on remedies when human rights violations occur. Normalized disenfranchisement, as well as stigma, discrimination and negative attitudes on the part of others may be disempowering and prevent them from pursuing complaints or initiating cases when their rights have been violated.

## C. Best practices

58. The adoption of International Albinism Awareness Day has helped civil society in Australia to gain traction in the media in raising awareness and sharing stories about persons with albinism.<sup>31</sup> Albinism Trust in New Zealand raises awareness about albinism through literature, dialogue and peer support.<sup>32</sup>

59. The Pacific Disability Forum in Fiji brings together some 65 regional partners and is instrumental in raising awareness on the human rights of persons with albinism, including by commemorating International Albinism Awareness Day.

60. In Australia and New Zealand, there are measures in place to assist persons with albinism with reasonable accommodation in the workplace.<sup>33</sup>

61. In Japan, collaborative learning is being encouraged. Each school must promote interaction with children with and without disability. In addition, a significant amount of practical and academic research on albinism is being conducted in Japan, as well as training of teachers for children with visual impairment.<sup>34</sup>

62. In Fiji, 32 public health professionals in Nadi conduct regular outreach interventions and “zone visits” to local communities, providing an opportunity for public education on albinism.<sup>35</sup> In New Zealand, Albinism Trust has created a list of appropriate sun lotions, noting that not all lotions with high sun protection factor (SPF) provide the necessary sun protection.<sup>36</sup>

63. Civil society organizations in New Zealand and Australia often collaborate with other non-governmental organizations serving persons with visual impairment.<sup>37</sup>

## IV. Europe

64. While there is a sizeable amount of scientific research on albinism in Europe, there is a significant scarcity of information relating to the human rights situation of persons with albinism. The Independent Expert has provided the following information on the basis of 13 submissions from stakeholders in 12 countries<sup>38</sup> in the region.

65. In Europe, persons with albinism live within a population that largely has relatively low pigmentation, which means that albinism is often undetected or less visible. A significant number of people across Europe, particularly in Northern

<sup>31</sup> Albinism Fellowship of Australia.

<sup>32</sup> New Zealand (Albinism Trust).

<sup>33</sup> Albinism Fellowship of Australia and Albinism Trust.

<sup>34</sup> Japan (Albinism Network).

<sup>35</sup> See country visit report of the Independent Expert ([A/HRC/40/62/Add.1](#)).

<sup>36</sup> New Zealand (Albinism Trust).

<sup>37</sup> Ibid.

<sup>38</sup> Azerbaijan, Belgium, Denmark, Finland, France, Germany, Netherlands, Norway, Slovenia, Spain, Turkey and United Kingdom of Great Britain and Northern Ireland.

Europe, are reportedly unaware that they have albinism or are diagnosed by ophthalmologists only in adulthood. Therefore, there is an existential risk that reported data and prevalence rates in the region are underestimated.<sup>39</sup> This is supported by scientific findings. For example, contrary to regional prevalence in past studies that indicate an estimated prevalence of 1 person in 17,000 to 1 person in 20,000 in the region, recent studies indicate a higher prevalence rate in some countries such as the Netherlands, where it is reported to be at least 1 person in 12,000.<sup>40</sup> In Northern Ireland, the prevalence is reported at around 1 person in 4,500, with some areas in the country having a prevalence of 1 person in 6,600.<sup>41</sup>

66. Depending on the type of albinism, in most countries in the European region, the condition is perceived as a “mild” to general disability, largely owing to the related visual impairment.

67. In several submissions, it is indicated that most persons with albinism live in urban areas because they have more developed public transportation systems, the majority of persons with albinism being unable to obtain a driver’s licence as a result of vision impairment.<sup>42</sup>

## A. Normative and policy frameworks

68. Persons with albinism in Europe are protected by existing constitutions, legislation and policies relating to fundamental human rights principles of equality and non-discrimination as well as specific legislation on disability health, education, employment and rare diseases and conditions.<sup>43</sup> There are no specific trends of human rights violations, although data are sparse and the majority of the information received did not provide information from a human rights perspective.

## B. Main human rights issues

### 1. Non-discrimination

69. According to the submissions received, stigmatization and discrimination exist, sometimes as a result of myths, such as the myth that all persons with albinism have red eyes or that the condition generates mental health conditions.<sup>44</sup> Several submissions also referred to bullying of children with albinism in school.

70. In general, submissions indicate that there have been only a few reported cases of discrimination linked to appearance or perceived disability associated with albinism. However, social exclusion was reported in Turkey and acknowledged in the submission by Slovenia, in which it was stated that the absence of data on the matter

<sup>39</sup> France (Genespoir), Denmark (Danish Association of Albinism), Germany (National Organization for Albinism and Hypopigmentation) and Spain (Asociación de ayuda a personas con albinismo).

<sup>40</sup> Charlotte C. Krujit and others, “The Phenotypic spectrum of albinism”, *Ophthalmology*, vol. 125, No. 12 (December 2018).

<sup>41</sup> Natasha Healey and others, “Are worldwide albinism prevalence figures an accurate reflection? An incidental finding from a Northern Ireland study”, *British Journal of Ophthalmology*, vol. 98, No. 7 (2014).

<sup>42</sup> For example, submission from Germany (National Organization for Albinism and Hypopigmentation).

<sup>43</sup> Azerbaijan (State), France (Genespoir), Germany (National Organization for Albinism and Hypopigmentation), Netherlands (*Oogvereniging Albinisme*), Norway (Norwegian Association for Albinism), Slovenia (State), Spain (Asociación de ayuda a personas con albinismo), Turkey (Albinism Association) and United Kingdom (Roselle Potts).

<sup>44</sup> Submissions by *Oogvereniging Albinisme* and the Norwegian Association for Albinism.

does not mean that discrimination does not occur. A similar caveat was raised in some submissions concerning discrimination faced by refugee and immigrant persons with albinism in Europe.<sup>45</sup>

71. In a few cases in France, children with albinism were reportedly abandoned during their first months of life and subsequently placed in foster homes.<sup>46</sup> In Norway and Spain, adults and children with albinism face stigma and exclusion in the community owing to low vision. In Turkey, some people think that albinism is an infectious disease. As a result, parents do not let their children play with children with albinism.<sup>47</sup> In a few countries, it was reported that women and girls dye their hair to avoid discrimination or social exclusion.

## 2. Health

72. Generally, health care and essential health products for persons with albinism are available and accessible in Europe. However, some barriers to access exist.<sup>48</sup> For example, in the United Kingdom of Great Britain and Northern Ireland, persons with albinism may receive sunscreen free of charge with a prescription; however, prescriptions are not always granted by medical professionals, often because they lack knowledge on albinism or the belief that sunscreen is cosmetic and not a health need.<sup>49</sup> It was reported that in some countries, there is little knowledge about albinism among medical professionals to effectively assist persons with albinism in understanding their condition better.<sup>50</sup> This often causes late diagnosis of albinism, particularly in those with relatively high visual acuity.<sup>51</sup>

73. Barriers to health care appear to be more common in Slovenia and Turkey. In Turkey, there is limited access to psychological support and assistive devices such as visual aids, sunglasses and sunscreen for persons with albinism.<sup>52</sup> Sunscreens are not commonly subsidized or covered by public health insurance.<sup>53</sup> Even in private insurance programmes, skin and eye care coverage is often not included in policies for persons with albinism. Lack of proper understanding of existing impairments related to albinism can also hinder access to services normally accorded to persons with disabilities. For example, persons with albinism may be designated a level of 20 per cent to 100 per cent disability, depending on the hospital that conducts the assessment and the knowledge and expertise of the medical professional carrying out the assessment.<sup>54</sup> While variation in visual impairment in persons with albinism might explain this spectrum, the matter merits further study to clarify and standardize approaches as much as possible.

74. In some countries, there is insufficient information and support for parents of children with albinism, particularly after the birth of a child with albinism or when the condition is diagnosed.<sup>55</sup> Doctors have been known to erroneously inform parents that their child is totally blind or cannot leave the house because of potential sun

<sup>45</sup> France (Genespoir) and Finland (Finnish Albinism Association).

<sup>46</sup> France (Genespoir).

<sup>47</sup> Turkey (Albinism Association).

<sup>48</sup> France (Genespoir), Netherlands (*Oogvereniging Albinisme*), Norway (Norwegian Association for Albinism), Slovenia (State) and Turkey (Albinism Association).

<sup>49</sup> United Kingdom (Roselle Potts).

<sup>50</sup> France (Genespoir), Norway (Norwegian Association for Albinism), Slovenia (State) and Turkey (Albinism Association).

<sup>51</sup> Slovenia (State).

<sup>52</sup> Turkey (Albinism Association).

<sup>53</sup> Ibid.

<sup>54</sup> Ibid.

<sup>55</sup> Finland (Finnish Albinism Association) and Turkey (Albinism Association).

damage.<sup>56</sup> Often, civil society actors have to take up the role of providing advice relating to medical, psychological and early intervention support for parents.

### **3. Education**

75. There are relatively few barriers to education for persons with albinism in Europe. Reasonable accommodation as well as assistive devices are generally available for students with albinism and are usually provided free of charge. However, in some situations, teachers are unaware of how to provide support pursuant to existing policies on disability.

76. It was also reported that in many cases, the existing processes for requesting reasonable accommodation, including assistive devices, can be complex and lengthy. Parents are sometimes forced to proceed through tribunals and other quasi-legal processes to guarantee support for their children with albinism.<sup>57</sup>

77. Bullying of school-aged children was reported in nearly all the submissions received, ranging from sporadic instances to common occurrences. In some cases, children face social isolation in schools because of a lack of knowledge or understanding of the condition by teachers, classmates and parents.

78. Although there are laws on reasonable accommodation in Turkey, implementation is often inconsistent. Children with albinism reportedly lack adequate support such as books in accessible format.<sup>58</sup> Teachers are generally unaware of how best to support the needs of a student with albinism and parents are often unaware of the rights of their child. There is also inadequate awareness about the harmful effects of sun exposure during school breaks, unless parents inform the teachers of this serious health risk.

### **4. Employment and adequate standard of living**

79. Despite legislation proscribing discrimination on the basis of disabilities, nearly all submissions reported discrimination as a barrier to accessing employment. As in other regions, employers are often hesitant to hire a person with albinism owing to the perception that they will have difficulty performing their tasks because of their visual impairment, the cost of providing reasonable accommodation and the fear of the potential negative impact of their physical appearance in some customer service positions.

80. However, as a constituency of persons with disabilities, in some countries, persons with albinism have access to social support to compensate for unemployment or to supplement meagre income. In Denmark, this includes financial aid to families of a child below the age of 18 years. In other countries, it takes the form of social and tax benefits. In countries where the frameworks and policies governing the rights of persons with disabilities are robust and well-implemented, persons with albinism are more likely to benefit from existing services and programmes, thus enhancing the enjoyment of their right to work.

81. However, most of the submissions received did not particularly recognize a lack of adequate standard of living for persons with albinism in Europe or systemic discrimination against persons with albinism once in the labour market. This could be due to the absence of such situations, lack of data or the absence of a human rights approach in a majority of submissions received from civil society.

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<sup>56</sup> Turkey (Albinism Association).

<sup>57</sup> United Kingdom (Roselle Potts).

<sup>58</sup> Turkey (Albinism Association).

## 5. Access to justice and legal remedy

82. Legal advice and support, including pro bono services, are generally available to persons with albinism as a constituency of persons with disabilities. However, persons with albinism are not always aware of the existence of such services, nor are they generally aware of the human rights framework.<sup>59</sup> This may compound barriers to gaining access to assistive devices and reasonable accommodation as part of the right to health, equality and non-discrimination on the basis of disability, particularly in Turkey and Slovenia. It can also be an obstacle to building international solidarity on the issue of albinism worldwide and a hindrance to effective integration of albinism into relevant sectors such as disability, education and health.

## C. Best practices

83. Several civil society actors have been instrumental in promoting awareness and disseminating information on albinism. Albinism Europe, a network of 10 national organizations, focuses on raising awareness in the region.<sup>60</sup> In Belgium, civil society organizations, such as Ecran Total, Internationale Vrouwn and La Ligue pour la défense des Albinos, organize awareness-raising campaigns.<sup>61</sup>

84. In France, Spain, Turkey and the United Kingdom, among others, civil society groups organize awareness campaigns every year around International Albinism Awareness Day.<sup>62</sup> In Spain, several civil society organizations carry out awareness campaigns through books on albinism and short films and through local and national media.<sup>63</sup> The Albinism Association in Turkey has published a Turkish translation of *Raising a Child with Albinism: A Guide to the Early Years*, popularized by the National Organization for Albinism and Hypopigmentation in North America.

85. Some awareness campaigns are being conducted in collaboration with civil society organizations working on rare diseases.<sup>64</sup> Although albinism is often considered more a condition than a “disease”, such collaborations could help to amplify public understanding of albinism and increase scientific research.

86. In Denmark, health care is free,<sup>65</sup> and the Government provides diagnostic services and glasses until the age of 18 years.<sup>66</sup> In Spain, persons with disabilities enter a priority social security system and have access to specific health-care centres catering to their particular situation.<sup>67</sup>

87. In France, if parents have their children recognized as persons with disabilities under the disability legislation, they are given the necessary assistive devices, among other resources. These include computer software to enlarge documents, cameras to read information at long distances and personalized programmes to ensure that students have sunscreen when necessary.<sup>68</sup>

<sup>59</sup> Denmark (Danish Association of Albinism) and Norway (Norwegian Association for Albinism).

<sup>60</sup> Germany (National Organization for Albinism and Hypopigmentation), Netherlands (*Oogvereniging Albinisme*) and Spain (Asociación de ayuda a personas con albinismo).

<sup>61</sup> Belgium (Ecran Total).

<sup>62</sup> United Kingdom (Roselle Potts).

<sup>63</sup> Spain (Asociación de ayuda a personas con albinismo).

<sup>64</sup> Denmark (Danish Association of Albinism).

<sup>65</sup> Denmark (Danish Association of Albinism); health care is also free in Norway (Norwegian Association for Albinism).

<sup>66</sup> Denmark (Danish Association of Albinism).

<sup>67</sup> Spain (Asociación de ayuda a personas con albinismo).

<sup>68</sup> France (Genespoir).

88. In Germany, students with disabilities are given preferred access to scholarships, although this may not always happen in practice.<sup>69</sup> In Norway, financial support is provided throughout higher education for persons with disabilities.<sup>70</sup> In the United Kingdom, support for persons with disabilities is provided in primary and secondary school and in higher education settings. In the Netherlands, schools, employers and companies must conform to a general standard of accessibility.<sup>71</sup>

89. In Denmark, vision consultants represent children with albinism and are consulted by the schooling system on visual impairment.<sup>72</sup>

90. In Denmark, a grant is provided to employers for the purchase of assistive devices for reasonable accommodation of employees with disabilities.<sup>73</sup> The Government of Spain also offers grants for reasonable accommodation in the workplace.<sup>74</sup> Public employers and large companies in Germany often have a staff member in charge of ensuring that the hiring process does not discriminate against persons with disabilities.<sup>75</sup> In Slovenia, among other countries, persons with disabilities are entitled by law to accommodation such as necessary equipment, the adaptation of premises, training, counselling and adjustments to their working hours and shifts.<sup>76</sup> Courts are also obligated to provide documents in accessible formats for partially sighted persons free of charge.<sup>77</sup>

91. In Azerbaijan, there are a number of rehabilitation facilities that provide early intervention services for families and mothers of children with disabilities.<sup>78</sup>

92. In 2017, the Albinism Association in Turkey founded the Turkey Albinism Scientific Committee with several medical professors. The committee aims to increase knowledge and research on albinism<sup>79</sup> and build expertise on albinism among medical practitioners.

93. In 2019, the Spanish association representing persons with albinism, Asociación de ayuda a personas con albinismo, met with the Valencian Regional Administration in Spain. Shortly after that meeting, it was reported that a reference unit on albinism would be created at La Fe Hospital in Valencia.<sup>80</sup>

94. The European Union is working on improving collaboration on the treatment of rare diseases, which could potentially improve health-care services for persons with albinism.<sup>81</sup> In France, the Government has put in place a programme to certify rare disease reference centres within certain hospitals that are especially competent in their field. With regard to albinism, there are two centres specializing in dermatology and three in ophthalmology.<sup>82</sup>

<sup>69</sup> Germany (National Organization for Albinism and Hypopigmentation).

<sup>70</sup> Norway (Norwegian Association for Albinism).

<sup>71</sup> Netherlands (*Oogvereniging Albinisme*).

<sup>72</sup> Denmark (Danish Association of Albinism).

<sup>73</sup> Ibid.

<sup>74</sup> Spain (Asociación de ayuda a personas con albinismo).

<sup>75</sup> Germany (National Organization for Albinism and Hypopigmentation).

<sup>76</sup> Slovenia (State).

<sup>77</sup> Ibid.

<sup>78</sup> Azerbaijan (State).

<sup>79</sup> Turkey (Albinism Association).

<sup>80</sup> Spain (Asociación de ayuda a personas con albinismo).

<sup>81</sup> Finland (Finnish Albinism Association).

<sup>82</sup> France (Genespoir).

## V. Latin America, North America and the Caribbean

95. Submissions were received from 18 stakeholders in 11 countries in the Latin American, North American and Caribbean region.<sup>83</sup> Most submissions mentioned the lack of data on persons with albinism in national censuses and surveys, except for the Plurinational State of Bolivia, whose National Single Registry Programme for Persons with Disabilities has registered only seven persons with albinism. Most of the data collected for the region stem from efforts by civil society such as membership drives and social media platforms. The reported numbers of persons with albinism, which range between 200 and 2,000, are therefore provisional estimates.

96. Within indigenous communities, oculocutaneous albinism type 2 has a moderate to relatively high prevalence with 1 person in 28 to 1 person in 6,500 reported in various indigenous communities in southern Brazil, southern Mexico, eastern Panama and the south-western region of the United States of America.<sup>84</sup> The prevalence of albinism among the Hopi Indians has been estimated at approximately 1 person in 200.<sup>85</sup> An even higher prevalence was observed among the Kuna Indians in Panama, with an estimated prevalence of 1 person in 160.<sup>86</sup>

97. The majority of persons with albinism in Argentina reside in urban areas, where access to public transportation and services for visual impairment and skin health might be better facilitated.<sup>87</sup> Similarly, in Chile, most persons with albinism live in Santiago de Chile.<sup>88</sup> In Colombia, most persons with albinism reside in 4 of the 32 departments (Boyacá, Antioquia (Santuario and Marinilla specifically), Cundinamarca and Valle Del Cauca).<sup>89</sup> In Ecuador, most reside in the provinces of Manabí, Santo Domingo de los Tzáchilas, Tungurahua, Azuay, Chimborazo and Pichincha,<sup>90</sup> and in Haiti, most persons with albinism live in non-urban remote areas.<sup>91</sup> The Kuna indigenous peoples in Panama reside in the archipelago of San Blas on the Atlantic coast. In recent years, many have migrated from the island to the mainland, to Veracruz and Arraijan in West Panama Province and Kuna Negra in the Province of Panama.<sup>92</sup>

98. The general lack of data on persons with albinism has resulted in limited knowledge on their situation in the region and may negatively affect the realization of their fundamental rights. The Independent Expert notes the need for Member States to include data on person with albinism, not only in the national census, but in relevant sectoral surveys such as health, education, disabilities and rare conditions, as a matter of urgency and in the context of leaving no one behind. Data can be collected by

<sup>83</sup> Governments of Bolivia (Plurinational State of), Ecuador and Guatemala and civil society organizations in Argentina, Chile, Colombia, Ecuador, Guatemala, Haiti, Mexico, Panama, Paraguay and Venezuela (Bolivarian Republic of). See footnote No. 1.

<sup>84</sup> Charles M. Woolf, "Albinism (OCA2) in Amerindians", *Yearbook of Physical Anthropology*, vol. 48 (2005).

<sup>85</sup> Philip W. Hedrick, "Hopi Indians, 'cultural' selection, and albinism", *American Journal of Physical Anthropology*, vol. 121, No. 2 (2003).

<sup>86</sup> Irèn Kossintseva, "The moon children of Kuna Yala: Albinism in San Blas islands of Panama: Review, directions in research and aid", *Journal of the American Academy of Dermatology*, vol. 64, No. 2 (February 2011). Available at [https://www.jaad.org/article/S0190-9622\(10\)01212-0/fulltext](https://www.jaad.org/article/S0190-9622(10)01212-0/fulltext).

<sup>87</sup> Argentina (Simplemente Amigos).

<sup>88</sup> Chile (Organización No Gubernamental de Desarrollo Albinos).

<sup>89</sup> Colombia (Albinos de Corazón and Albinos por Colombia).

<sup>90</sup> Ecuador (Fundación de Albinos Piel de Angel).

<sup>91</sup> Haiti (Fondation Albha).

<sup>92</sup> Panama (Giaconda Gaudiano).

including a specific question on albinism in national censuses, in accordance with the method recommended by the Washington Group on Disability Statistics.<sup>93</sup>

## **A. Normative and policy frameworks**

99. Most countries in the region have no albinism-specific national laws or policies. Instead, persons with albinism are protected under the Constitution and disability and health legislation. Colombia's Law No. 1680 (2013), for example, provides for comprehensive care for visually impaired and blind persons, such as ensuring reasonable accommodation.

100. Despite these legal frameworks, the pervasive lack of awareness about albinism often renders the practice of such laws meaningless in the lives of persons with albinism. Moreover, persons with albinism are often unaware of their condition and the possibility of obtaining benefits under health and disability schemes. In some cases, institutions are also unaware or do not consider persons with albinism as qualifying for disability status because their vision problems are not considered severe enough.

101. In the submissions of several countries, it is indicated that inclusive education laws and policies are available in the country and that persons with albinism are supported with reasonable accommodation.

102. The Independent Expert notes, however, that many submissions refer to policies related to visual impairment but very few address the issue of the right to health of persons with albinism, especially in the prevention and treatment of skin cancer. In this regard, civil society organizations in some countries have been the driving force in advocating for specific measures on the right to health for persons with albinism through law and policy. In Argentina, for example, a national albinism bill was presented in the National Congress and has been approved by one of the three necessary parliamentary commissions. In Brazil, two bills are that address the enjoyment of human rights by persons with albinism, in particular the right to health, are pending in the Parliament.<sup>94</sup>

103. Several Member States have legislation referring to orphan or rare diseases and conditions, which also include albinism. Colombia recognizes orphan diseases as being of special interest and has adopted norms aimed at guaranteeing social protection by the State. The oculocutaneous albinism form of albinism has also been included as one of 106 rare diseases published in the Official Gazette of Ecuador.<sup>95</sup>

## **B. Main human rights issues**

### **1. Non-discrimination**

104. Lack of knowledge about albinism in the region often leads to discrimination fuelled by myths and misconceptions. The submissions indicate that persons with albinism face discrimination as a result of their physical appearance in Argentina, Chile, Colombia, Ecuador, Guatemala, Haiti, Mexico, Panama and Paraguay. Reactions to persons with albinism vary from admiration and curiosity to rejection and bullying. Some have experienced discrimination on the basis of a belief that

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<sup>93</sup> See comment: <http://www.washingtongroup-disability.com/people-albinism-included-washington-group-questions/>.

<sup>94</sup> The adoption of these bills is the subject of a communication sent by the Independent Expert to the Permanent Mission of Brazil to the United Nations, available at [https://www.ohchr.org/Documents/Issues/Albinism/OL\\_BRA\\_June2018.pdf](https://www.ohchr.org/Documents/Issues/Albinism/OL_BRA_June2018.pdf).

<sup>95</sup> Submission by Ecuador.

albinism is contagious. Some persons with albinism have reportedly been insulted for not conforming to the prevailing standards of “beauty” and others have been harassed because, owing to their fair skin, they appear to conform to an ideal of “beauty” that is foreign.

105. The Independent Expert observes that there were few references to norms regarding the prevention of discrimination on the basis of skin colour, although multiple reports from the region refer in particular to discrimination on that ground.

106. In addition, discrimination on the basis of visual impairment was reported by all respondents as a common occurrence in key domains, including social, education, health and employment.

107. Submissions show that the exclusion of persons with albinism is a common reality in Latin America and parts of the Caribbean, especially for women, and those living in rural areas in particular. Persons with albinism are sometimes rejected by their parents and relatives at birth because they do not resemble their family members. Some submissions indicated that the success of persons with albinism often depends on the level of family support they receive at home and in the community, as well as the level of accurate public awareness about albinism.

## **2. Health**

108. Persons with albinism in Latin America and parts of the Caribbean face several barriers to the enjoyment of the right to health, including affordability, accessibility and quality of health care. In Paraguay, only 2 per cent of persons with albinism reportedly had received adequate dermatological care and only 5 per cent had consulted a dermatologist at least once in their lives.<sup>96</sup> In rural areas, geographical distances and transportation costs limit access to health-care services. In addition, services and products required by persons with albinism are often excluded from free national health plans. For example, sunscreen is sometimes considered a cosmetic rather than an essential health product.<sup>97</sup>

109. Access to specialists, including dermatologists and ophthalmologists, sometimes entails a lengthy waiting process. Furthermore, there is often weak and inaccurate knowledge on albinism among health professionals in general. Consequently, they often misdiagnose patients, conduct unnecessary health examinations or provide erroneous information to persons with albinism or parents of children with albinism, which can affect their overall health and longevity. In certain instances, health professionals refuse to attend to persons with albinism, owing to prevailing stereotypes and stigma against those with the condition. There is also a lack of psychological care for persons with albinism, many of whom struggle with the cumulative effects of ongoing discrimination, exclusion and bullying.

## **3. Education**

110. There are both attitudinal and physical barriers to access to education, often resulting in low school attendance for persons with albinism. Some parents withhold their children with albinism from school owing to the belief that their low vision and condition render them incapable of learning. In Haiti, some parents do not send their children with albinism to school at all, given the shorter life span associated with the condition and a belief that education is not a worthwhile investment.<sup>98</sup> In Colombia,

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<sup>96</sup> Paraguay (Albinos Paraguay).

<sup>97</sup> Colombia (Albinos de Corazón).

<sup>98</sup> Haiti (Fondation Albha).

some children with albinism are withdrawn from school at a young age, confined at home or forced to support the family.<sup>99</sup>

111. Lack of provision of reasonable accommodation for low vision is one of the most significant barriers to education, given that it causes learning delays and dropouts. Even when assistive devices are mandated by policy or available, students with albinism and their schools may be unaware of their availability.

112. Furthermore, teachers sometimes lack proper understanding of albinism and its related vision impairment.<sup>100</sup> In classes with outdoor activities such as physical education, the needs of students with albinism are not always accommodated, including requests to adjust uniforms for better sun protection.

#### **4. Employment and adequate standard of living**

113. Lack of or incomplete formal education becomes a barrier to gaining access to employment for persons with albinism. In many cases, lack of reasonable accommodation in the workplace further leads to low employment success rates for persons with albinism. Consequently, persons with albinism often find outdoor employment, which exposes their skin to the sun and increases the risk of cancer.

114. Discrimination and stigma are additional barriers to gaining access to the labour market. Employers often underestimate the capacities and abilities of persons with albinism. Some employers are unwilling to hire persons with albinism because they do not want to be liable if the person suffers burns or other injuries on the job related to low vision.<sup>101</sup>

115. Financial loans to start businesses are often inaccessible to persons with albinism owing to lack of sufficient collateral, given that they are often from an economically disadvantaged background.<sup>102</sup> In Paraguay, 20 per cent of the total population with albinism live in poverty, 30 per cent of whom are women with children with albinism.<sup>103</sup> In Haiti, women who are reportedly abandoned by the father of their baby upon the birth of a child with albinism often have meagre means and are forced to beg on the street to support their families.<sup>104</sup>

#### **5. Access to justice and legal remedy**

116. Most submissions indicated the presence of general legal aid schemes in the respective countries. However, persons with albinism and their families are often unaware of their rights and how to effectively enforce them.

### **C. Best practices**

117. Some submissions highlighted the importance of International Albinism Awareness Day, which allows stakeholders, including civil society, to draw attention to the plight of persons with albinism. Traditional and social media have been actively used by civil society to highlight issues faced by persons with albinism, including marginalization, stigmatization and discrimination, and could also contribute positively to the protection of their rights by sensitizing the population.

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<sup>99</sup> Colombia (Albinos de Corazón).

<sup>100</sup> Argentina (Albinismo Argentina), Colombia (Albinos de Corazón and Fundación Albinos por Colombia) and Haiti (Fondation Albha).

<sup>101</sup> Colombia (Albinos de Corazón and Fundación Albinos por Colombia).

<sup>102</sup> Colombia (Albinos de Corazón).

<sup>103</sup> Paraguay (Albinos Paraguay).

<sup>104</sup> Haiti (Fondation Albha).

118. Artists from the region have also improved awareness of albinism. For example, on 14 December 2018, Robben X, a musician with albinism from the United States and an advocate for the rights of persons with albinism, especially with respect to bringing an end to bullying, performed at the Palais des Nations in Geneva. In December 2018, the Office of the United Nations High Commissioner for Human Rights subsequently designated him as an official Champion for Human Rights, an initiative that recognizes advocates around the world for human rights causes.<sup>105</sup>

119. In Ecuador, articles 47 and 48 of the Constitution recognize the rights of persons with disabilities and provide for the measures necessary for the exercise of those rights through plans and programmes that equalize the opportunities of persons with disabilities. In Argentina, a protocol was developed for all educational levels, to draw attention to the needs of students with albinism.<sup>106</sup>

120. In the Plurinational State of Bolivia, a disability card gives cardholders access to benefits such as special fares for public transportation, credit and microcredit programmes. Health care is also free for persons with disabilities, including services for monitoring health risks related to albinism and genetic counselling.

121. Colombia has produced a Guide for Persons with Disabilities on Access to Justice and a Protocol for Inclusive Legal Consultation and Centres for Conciliation and/or Arbitrage for Persons with Disabilities, which can benefit persons with albinism in terms of seeking effective remedies.

## VI. Middle East and North Africa

122. The Independent Expert noted a significant lack of data on persons with albinism in the Middle East and North Africa region. Based on the submissions received, only two stakeholders provided inputs,<sup>107</sup> namely, the Islamic Republic of Iran and Jordan. The Independent Expert did, however, receive various clinical studies indicating that persons with albinism reside in the region, including in Algeria, Egypt, the Islamic Republic of Iran, Jordan, Morocco and Tunisia. Except for a newly minted group in Morocco, there is little indication of the presence of civil society organizations in the other listed countries.

123. The Independent Expert received information from the Iranian Albinism Association, whose main objective is to encourage the Government to seriously consider the needs of persons with albinism and devise a plan to address them. The Association also focuses on increasing awareness and knowledge about albinism in the country by combating negative stereotypes, supporting parents of children with albinism, facilitating employment and income generation and providing services to persons with albinism in remote areas. To date, the Association has registered some 300 members, who meet in Tehran once a year for an event called the “Iranian Albinism Association Congress”.

124. Information received indicated that there are no official compiled data on the prevalence of albinism in the Islamic Republic of Iran. Weak or low vision and high susceptibility to skin cancer are two of the primary concerns for persons with albinism in the country. These issues affect several human rights, including the right to health, education and non-discrimination. There is a real need to ensure the eligibility of

<sup>105</sup> See <https://albinism.ohchr.org/story-robdarius-rob-en-x-brown.html>.

<sup>106</sup> Argentina (Simplemente Amigos).

<sup>107</sup> Submissions by Jordan (Rasha Zassin Muslim Al Shalah) and Iran Albinism Association, available at [www.albinismngo.ir](http://www.albinismngo.ir).

persons with albinism for State-provided benefits or schemes related to disability and health, especially in relation to preventive and curative measures for skin cancer.

125. Other issues reported include stigmatization and discrimination, including public humiliation; social obstacles to marriage, an institution that facilitates rights and privileges; access to employment; and social exclusion associated with the physical appearance of persons with albinism, in particular girls.<sup>108</sup>

126. The information received on Jordan indicates that there is a lack of data on persons with albinism.<sup>109</sup> A large part of the population of persons with albinism is reportedly unaware of how to deal with their challenges. There appears to be no public campaign or awareness-raising on the issue.

127. It was also noted in the submission that persons with albinism face social exclusion, including stigmatization and discrimination based on colour, such that name-calling and taunting are normal occurrences. There is a lack of acceptance in society in terms of social relationships and marriage in particular, which affects persons with albinism regardless of gender.

128. Although persons with albinism are noted as being able to enjoy the same rights under law as persons with disabilities, barriers exist in practice.

129. Reasonable accommodation at school and the workplace is difficult to obtain largely owing to cost. In addition, students with albinism reportedly face bullying in school. For mothers of children with albinism, there is a lack of early intervention, including resources and social support upon the birth of their child. Persons with albinism themselves need to be educated about their condition and how to access their human rights, including through State benefits to which they might be entitled under disability and health schemes.

130. In the light of the lack of information available, the Independent Expert emphasizes the need for governments and stakeholders in the region to focus on raising awareness and promoting public knowledge relating to albinism. Importantly, there is a need for support in obtaining assistive devices and providing reasonable accommodation to persons with albinism at school and in the workplace. The best practices set out in the present report as well as the recommendations below will assist stakeholders in this region in taking the necessary measures to significantly improve the enjoyment of human rights by persons with albinism in their respective jurisdictions.

## VII. Conclusions and recommendations

**131. The human rights situation of persons with albinism varies worldwide. However, particular challenges are common throughout all regions, namely, deep misunderstanding and mystification of the condition, which give rise to various forms of discrimination, from normalized name-calling, taunts, bullying, social exclusion and stigmatization on one end to attacks and other extreme forms of violations on the other. Moreover, persons with albinism generally face vulnerable health situations that in many cases affect their life span, lack of reasonable accommodation for visual impairment, discrimination based on colouring and, in many cases, extreme poverty.**

**132. The Independent Expert affirms what is generally known: that there is a positive correlation between overall development in a country and the enjoyment**

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<sup>108</sup> See <https://www.iranhumanrights.org/2018/11/people-with-albinism-struggle-to-access-crucial-treatment-and-support-in-iran/>.

<sup>109</sup> Jordan (Rasha Zassin Muslim Al Shalah).

of human rights by persons with albinism. It is therefore fitting that the Sustainable Development Goals target the most marginalized by pledging to leave no one behind, beginning first with the furthest behind.

133. Similarly, there appears to be a positive correlation between the physical visibility of persons with albinism in their community and the depth of discrimination they face. The more they stand out in their community, the more they are likely to face acute social exclusion and intersecting discrimination. The inverse is also true.

134. Paradoxically, this visibility, or hypervisibility in some cases, of persons with albinism has been accompanied by invisibility in all spheres of social discourse and human rights practice. Logically, this is related to their numbers or their minority status, quantitatively speaking. It is also linked to a state of “in-between-ness”,<sup>110</sup> namely, they are often perceived as not black or melanated enough, not white enough, too white, too blind, not blind enough, having multiple disabilities, having no disabilities or not disabled enough. These contradictory perceptions naturally derive from a combination of ignorance of the condition of albinism, ignorance of the meaning of disabilities as defined by the Convention on the Rights of Persons with Disabilities, a persistent medical approach to disability and ignorance about intra-ethnic forms of racial discrimination, as well as the biological variance in the condition itself, which results in differing levels of pigmentation and diverse levels of visual impairment.

135. As such, persons with albinism have consequently fallen through the cracks of programmes, policy and action plans that would have otherwise protected them from discrimination, especially in the domains of health and education.

136. Despite such challenges, there are remarkable trends of progress. Cases of attacks are on the decline in some countries. Laws and policies of general application are so well-implemented in certain countries that persons with albinism are able to enjoy their human rights with minimal hindrance. International Albinism Awareness Day has been a resounding success globally and continues to hold enormous potential in furthering public education on the condition and raising awareness on persons with albinism and their human rights. There has also been an unprecedented growth in civil society groups representing persons with albinism. These successes have culminated in an important opportunity to carry out the recommendations set out below.

137. The Independent Expert recommends that Member States in general:

(a) Publicly condemn, at every opportunity, including on International Albinism Awareness Day on June 13, all forms of bullying, exclusion, discrimination and stigmatization against persons with albinism;

(b) Support, both financially and technically, civil society organizations representing person with albinism in their efforts to drive public awareness on albinism, including public education targeting key domains such as education and health, and in the provision of various forms of support to persons with albinism and their family members;

(c) Include albinism in national censuses, using the relevant guiding comment by the Washington Group on Disability Statistics, and also use surveys

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<sup>110</sup> First used, in the context of persons with albinism, by Senator Isaac Mwaura of Kenya to describe his experience as a person with albinism and his observations as an advocate for their human rights.

**and situational analyses, to collect data on persons with albinism disaggregated at a minimum by gender, age, health status and rural-urban prevalence;**

**(d) Ensure that reasonable accommodation is provided to persons with albinism in the school system;**

**(e) Make quality sunscreen accessible, available and affordable in both rural and urban areas to persons with albinism, at little or no cost and without bureaucratic hindrances;**

**(f) Include, where possible, skin cancer prevention programmes in health policies that fight cancer in general;**

**(g) Include information on persons with albinism and their rights in training curricula generally and, in particular, in the training of specialists in all relevant sectors, especially disability, education, health, employment, justice and law enforcement, racial discrimination, diversity and statistics;**

**(h) Deliberately seek out and include qualified persons with albinism in significant government and public offices;**

**(i) Use the best practices identified in the present report as the basis for concrete measures to enhance the human rights situations of persons with albinism.**

**138. The Independent Expert recommends that States in which extreme violence against persons with albinism has been reported:**

**(a) Implement specific measures on prevention, protection, accountability and non-discrimination listed in the regional action plan to end attacks and related human rights violations as endorsed by the African Commission on Human and Peoples' Rights and the Pan-African Parliament;**

**(b) Collaborate with civil society organizations representing persons with albinism in making decisions affecting their human rights;**

**(c) Conduct security needs assessments for persons with albinism;**

**(d) Ensure full access to justice for victims and their family members.**

**139. The Independent Expert recommends that civil society organizations representing persons with albinism as well as researchers and those promoting their human rights and well-being:**

**(a) Incorporate and centralize the human rights approach in advocacy, public education, research and all other domains of work, to mitigate the negative consequences of the medical or charity approach to persons with disabilities;**

**(b) Collaborate with key actors, advocates, experts and researchers in relevant domains, including disability, health, education and rare conditions;**

**(c) Partner with and support researchers in various domains to promote the collection of credible and reliable data on persons with albinism;**

**(d) Develop national, regional and global collaboration platforms, including through networks and action plans, to promote and replicate best practices and to include the human rights situation of persons with albinism in various national, regional and international human rights and development forums, in a coherent, strategic and effective manner.**

**140. The Independent Expert recommends that national human rights institutions:**

**Effectively incorporate and address the human rights situation of persons with albinism in their work;**

**141. The Independent Expert recommends that international organizations:**

**(a) Seek out and include organizations for persons with albinism in capacity-building and training activities relating to human rights generally as well as in the specific domains of disability, health and education;**

**(b) Support the operations of civil society groups representing persons with albinism with technical and financial assistance to help them to graduate from weak volunteer-driven societies to professional groups with dedicated staff to advocate for themselves and their human rights in all relevant forums, especially in countries where human rights violations are extreme and need to be monitored and reported;**

**(c) Deliberately seek out and include persons with albinism in all public discussions on human rights, including relevant national and international mechanisms and processes, as well as in particular discussions, such as in regional forums tasked by the United Nations to follow up on the implementation of the Sustainable Development Goals.**

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