SPECIAL PROCEDURES
UNITED NATIONS
HUMAN RIGHTS COUNCIL

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

**Official visit to Portugal**
**17 to 26 November 2025**

**Preliminary findings**

I would like to thank the Government of Portugal for inviting me to undertake an official visit from 17 to 26 November 2025, and for facilitating meetings with various Ministries and governmental departments as well as relevant committees of the National Assembly.

I extend my appreciation to the Ministry of Foreign Affairs, who supported and coordinated my visit. I also extend my gratitude to the Permanent Mission of Portugal to the United Nations in Geneva, which played a pivotal role in the planning of the visit.

Today I conclude my 10-day mission to Portugal following extensive meetings and engagements with government and non-governmental entities, and interactions with persons with albinism. During the visit, I held meetings in Lisbon, Coimbra, and Porto. In Lisbon, I met officials of the Ministry of Foreign Affairs, including the Secretary of State; Ministry of Education; Ministry of Labour, Solidarity and Security; Ministry of Home Affairs; Ministry of Health; Ministry of Justice; Ministry of Environment and Energy; Commission for Equality and Against Racial Discrimination; Parliamentary Working Group on the Inclusion and Rights of Persons with Disabilities and the Sub-committee on Equality and Non-Discrimination; Portuguese Ombudsperson; and the Agency for Integration, Migration and Asylum. I also visited the National Institute for Health Doctor Ricardo Jorge and spoke to a group of dedicated specialists on their research and its relevance to albinism. At the invitation of the Secretary of State for Foreign Affairs and Cooperation, I attended a plenary session of the Portuguese Commission for Human Rights and interacted with representatives from all major sectors of government.

While in Lisbon, several civil society organisations kindly made themselves available to meet with me and to exchange notes and share perspectives on a wide range of issues. These organisations include, the Portuguese National Confederation of Organisations of Persons with Disabilities; Portuguese Bar Association; Portuguese Council for Refugees; Child Care Institute; Portuguese Association of Supported Employment; Association of Human Rights Defenders; Medical Aid International and Check-In. In Coimbra, I visited the Center for Excellence in Gene Therapy and learned about the groundbreaking research being done there on rare diseases in collaboration with multiple research

institutions in Europe. In Porto, I visited the European Anti-Poverty Network and had conversations with the team on poverty and its implications on vulnerable communities, including persons with albinism.

All these meetings and engagements with government and non-governmental bodies and local activists were informative and provided me with insights into the institutional structures, legal and policy architecture related to disability issues relevant to persons with albinism in Portugal. I am grateful to all who took time from their daily work to share their valuable personal, professional and institutional perspectives. I would also like to extend my appreciation to persons with albinism, who were most generous with their time to meet and share their inspiring stories and personal experiences. I am confident that the constructive conversations that emerged from all these engagements will hopefully generate a sense of momentum in the efforts to make albinism issues more visible in law, policy and daily social interactions in Portugal.

As I conclude my visit, I am pleased to share some of my preliminary findings and recommendations. A longer report detailing the findings and recommendations of my visit will be presented to the United Nations Human Rights Council in March 2027.

**Context of the visit**

My visit to Portugal coincided with a time of increasing focus on the human rights situation of persons with disabilities, including persons with albinism globally, who despite some commendable progress, continue to face discrimination, abuse, and social stigma amongst others. The focus has also been relevant in the context of climate change and its broader implications on persons with disabilities, especially persons with albinism, whose lack of melanin, particularly in the face of increasing UV rays, make them susceptible to skin cancer and other skin damage from the rays. The visit was therefore useful as it provided a platform to undertake constructive conversations on albinism, including assessing good practices and highlighting gaps in legislative and policy frameworks that need further attention from the Government, particularly in relation to employment, education, healthcare, and family life. As albinism fundamentally remains misunderstood, the visit also served a valuable sensitization purpose both within Government and amongst the general population.

**Albinism in Portugal**

Albinism is a rare, non-contagious, genetically inherited condition characterized by a lack of melanin pigment in the hair, skin and eyes. It occurs in all races, ethnicities and genders. Due to a lack of melanin, persons with albinism are susceptible to skin cancer. The condition is also accompanied by visual impairment, including varying degrees of visual acuity, nystagmus, photophobia, and sometimes strabismus. The combination of visual impairment and vulnerability to the sun means that persons with albinism are considered persons with disabilities, including under Portugal's legal framework on disability, especially law No.38/2004. The exact prevalence of albinism in Portugal is unknown, due to lack of data in the national census and governmental bodies. But a

recent study indicates that the prevalence of albinism in Europe is between 1 in 12,000 and 1 in 15,000.

**Positive initiatives**

The legislative and policy framework that governs the rights and welfare of persons with disabilities, including persons with albinism, is sufficiently broad in Portugal with a fair degree of alignment with international standards. At the international human rights level, Portugal has ratified the ICCPR, CERD and CRPD, amongst others. Article 71 of the Constitution of Portugal provides that persons with disabilities enjoy full rights and are subject to duties enshrined in the Constitution except where their condition renders them incapable to do so. The provision imposes an obligation on the State to develop and implement a national policy that includes prevention, treatment, rehabilitation, and integration for persons with disabilities, as well as promote public awareness and support families.

As persons with albinism are recognized as persons with disabilities, their right to non-discrimination based on disability at the national level is protected by a legal framework composed of four core laws. These include Law No. 38/2004, which focuses on prevention, habilitation, rehabilitation, and participation of persons with disabilities; Law No. 46/2006, which prohibits disability-based discrimination and sets up social security and support architecture; and Law No. 54 of 2018 covers inclusive education; and Law No. 163 of 2006 (as amended in Jan 2024 by Law No. 10 of 2024) deals with mobility for students with low visual acuity. Implementation of this framework is vested in the National Institute for Rehabilitation which is responsible for planning, coordination and handling of complaints on disability-based discrimination, while the Secretary of State for Social Inclusion provides strategic coordination of the legal and policy architecture on disability rights.

In my interaction with government officials and civil society organisations, I noted several positive elements of the disability rights architecture which, if implemented coherently, will strengthen the enjoyment of human rights by persons with albinism in Portugal. Prominent amongst this is the Assistive Product Allocation System (SAPA) which was created in 2009 to provide wide ranging support to vulnerable persons with disabilities in the areas of education, health, employment and skills development. Administratively, access to SAPA is coordinated through three government ministries – health, education, and employment - with the later having the department on social protection and employment responsible for managing the entry points for accessing support. In order to access support, a person must have a Multiuse Medical Certification of Disability (*Atestado Médico de Incapacidade Multiúso* - AMIM) which gives access to some benefits, access to the quota system, reasonable accommodations, and assistive devices. According to the National Health Service (NHS), the certificate is for those with disabilities or serious medical condition, this effectively includes albinism as a genetic disorder. Depending on the degree of disability assigned to the user, the Multiuse Medical Certification of Disability entitles its holder to access a range of benefits and tax

exemptions, including free access to NHS services at the point of contact and priority service, exemption from car tax, non-urgent patient transport, social protection and support, as well as scholarships in higher education.

While I found no albinism-specific provision in the legal and policy framework, I was informed by several government entities that the legislative architecture is sufficiently broad to protect the human rights of persons with albinism taking into consideration their unique condition. They provided examples of support structures with programs that promote the right to health, education and employment of all. In the area of education, Law No. 54 of 2018 was an innovative approach to inclusive education with the recognition that every student has a specific need with access to reasonable accommodations and assistive devices, including magnifiers for students with low visual acuity. Efforts to tackle bullying are being undertaken in schools through the citizenship education program and the introduction of a mandatory course on human rights and respect for diversity for all levels of study in schools. I take note that a new legislative framework is being developed and is expected to be in place by September 2026 to further strength the all-inclusive policy.

I am also encouraged to learn that a number of organisations outside of the state system also provide intervention support through training, advocacy and other initiatives. As an umbrella organisation, the Portuguese National Confederation of Organisations of Persons with Disabilities (CNOD), undertakes research, launches campaigns and carries out advocacy and sensitization on the situation of persons with disabilities across Portugal. Similarly, the Portuguese Association of Supported Employment (APEA) undertakes crucial interventions on behalf of individuals seeking to access the labour market. As persons with albinism face barriers in access to services, these interventions play a crucial role in promoting the rights of persons with disabilities through specialised support to help them lead independent lives and access the labour market.

While I note the above positive legislative, policy and other measures, I also note a number of concerns which impact on the implementation and effectiveness of the above.

**CONCERNS AND CHALLENGES**

- **Data and statistics**

Throughout my visit, officials in government institutions and non-governmental entities repeatedly highlighted the lack of statistics on persons with albinism in Portugal. In particular, they highlighted the practice of lack of disaggregated data across health, education, employment, immigration and other sectors, and attributed this to the requirement for strict compliance to data protection and privacy policies. While noting the concerns, I underlined that high-quality, secure and disaggregated data is critical for making evidence-based policy decisions that address specific needs and inequalities, and for monitoring progress of human rights implementation and development goals. I also emphasized that the absence of disaggregated data is impeding efforts to determine the prevalence of albinism in Portugal, area distribution of persons with

albinism and the specific challenges they face in their daily lives, including access to services. It therefore impacts on the development of effective measures and budgeting for the protection and promotion of the rights of persons with albinism. As there is currently no organisation dedicated to the promotion of rights of persons with albinism in Portugal, data on albinism would be useful in the determination of the nature and provision of essential support for persons with albinism.

- **Disability related support**

While legislative and policy provisions are in place to promote the rights of persons with disabilities, in practice support – including access to assistive devices - only appears to be available in part to those with a Multiuse Medical Certification of Disability attesting a disability level of 60% or more. The determination on the level of disability is carried out by a panel of specialised doctors, including a family doctor representing the individual and five other doctors—most of whom are focused on occupational health. Challenges in accessing the certification, particularly with that level were highlighted by individuals and organisations I met during the visit. These pointed out that officially an applicant should know within 60 days of applying, the date and time of their appointment for the certification determination. However, the appointments can take up to two years with the possibility that their condition could deteriorate during that time. The prolonged wait time is further aggravated by the seeming scarcity of family, doctors who assist in the process. This is even more of a problem in rural areas where there are fewer family doctors available.

To qualify as a person with a disability, an individual must have a disability or condition included in the National Table of Disabilities due to Work Accidents and Occupational Diseases (Decree-Law No. 352/2007, of October 23). This table includes ophthalmological (chapter V), and dermatological conditions (chapter XI), but the latter section is mainly focused on eczema and does not refer to albinism or any condition that makes people vulnerable to skin cancer/skin damage from the sun. Quite noteworthy is that oncological conditions are also recognized in the table (chapter XVI), and specifically occupational cancer based on causality, that is, on the unequivocal relationship between the injury and the risk factors present in the exercise of the professional activity. This is clearly relevant to albinism and the risk of skin cancer from outdoor occupation. However, the provision on oncology in the table does not specifically mention skin cancer, nor do relevant legal provisions which identify occupational carcinogens recognize the sun as a carcinogenic.

Some persons with albinism were unaware of the existence of the certification or how to go about getting it. For those, who were aware, some were unable to obtain certification of 60% or above. Experiences recounted by persons with albinism I met indicated that successfully obtaining an attestation of disability of a minimum of 60% appears to be dependent on having the support of a good family doctor with knowledge of albinism who can help in advocating for this. Even for those who were able to obtain

the certification, practically all of them stated that they did not have access to free of subsidised assistive devices and had to pay for them.

- **Health**

By virtue of their lack of melanin and low visual acuity, persons with albinism often require specialized health interventions throughout their life. In particular, they need access to ophthalmologists to regularly monitor their eyes, and dermatologists for regular skin cancer screening and treatment where necessary. In Portugal, the entry point to these specialized services and the health system as a whole, is through a family doctor, who makes initial assessment, diagnosis and referrals. Several persons with albinism and organizations I interacted with raised serious concerns over the challenges of accessing a specialized doctor at initial request or point of need with long waiting time of sometimes over a year. Many persons with albinism often resort to private medical service providers to help address critical visual and skin condition at a cost often beyond their financial reach.

Organizations and persons with albinism I interacted with highlighted the lack of consistency and clarity with what is available and how to obtain these. For example, some persons with albinism were able to obtain prescriptions for glasses, magnifiers and even sunscreen at times, but there was no corresponding financial support to help purchase these devices and products.

- **Education**

Since the enactment of Law 54 of 2018, an inclusive education policy has been in place. A major element of the inclusive system is the provision of education to all persons with specific needs, including disabilities. Under this scheme, for example, every child receives a Technical Pedagogical Report, which is the individualised report and plan for a child with specific needs. Some persons with albinism mentioned receiving large print documents and extra time in exam as reasonable accommodation, as well as sitting in front to better see the board while at school. However, others stated that nothing was known about their condition and they had to learn alone to adapt to their environment without support.

Access to reasonable accommodation at tertiary level seems to be dependent on the will and knowledge of the tertiary institution and student. I was informed by the Ministry of Education that this disparity was due to the autonomy granted to higher education institutions who develop their own framework for responding to students' needs. They further noted that support for students in these institutions is through ministries of health, employment and social welfare rather than the department of education.

The limitation of access to reasonable accommodation has impacted choices for education and career paths. One woman with albinism recounted how she had wanted to pursue a career in the arts but was discouraged from doing so due to her visual impairment. She therefore studied a course not of her primary preference. She indicated

that with improved access to reasonable accommodations, she is currently studying graphic arts.

While much has been done since the enactment of Law 54 on inclusive education for special needs students, including the introduction of Law No.10 of 2024, which addresses challenges of mobility for students with low visual acuity, there is need for consistency and standardisation in the approach across the country. There are concerns that the implementation of law 54 of 2018 is neither universal nor robust across the country, partly due to resources and oversight constraints.

- **Employment**

The legal and policy framework on the right to employment and support mechanism in Portugal have provisions that are relevant to persons with albinism. Equal opportunities in the choice and type of work are guaranteed by the Constitution and relatively promoted in both the public and private sectors. To encourage implementation, disability quotas exist to ensure active access to the labour market for persons with a minimum of 60% attested disability. I am encouraged that, individual campaigners and organisations such as the Portuguese Association of Supported Employment (APEA) have invested resources in supporting companies to meet the employment disability quota by accommodating persons with disabilities. APEA also provides individualised training for persons with disabilities as well as disseminate list of companies that hire persons with disabilities. Both the National Institute for Employment and Vocational Training and the National Institute for Rehabilitation provide support to persons with disabilities seeking employment, including through trainings, but these seem to be limited to certain technical/vocational training limiting areas of employment.

However, despite the constitutional guarantees, the experiences of persons with albinism in their search for employment reveal glaring disparities between laws and policy. While some have found work, others highlighted experiencing discrimination with some employers clearly preferring to hire individuals without albinism. Some persons with albinism recounted how after successfully passing job interviews, they were overlooked and were told they had not been successful. In another example, a person with albinism was hired after a competitive process but was relieved of his job few days later and was told that this was due to his low vision despite the job being that of a voice picker which is described as a hands-free and eye-free job. Some indicated that the challenges they face in accessing the labour market is largely due to their albinism. None of the persons with albinism made any attempt to file a discrimination complaint with the authorities.

While my visit has not documented any physical violence against a person with albinism in Portugal, there have been instances of micro-aggressions, unpleasant stares and curious questioning from some members of the public. In some instances, these are clearly due to lack of knowledge of albinism and prior interaction with persons with albinism. However, some recounted instances where their albinism caused discomfort leading to their employers to terminate their contracts.

For those who were successfully hired, access to reasonable accommodations in the workplace remains a major barrier. For the most part, this appears to be only enforceable for those with a certified disability of 60% or more. Provision of reasonable accommodation for those with less than 60% appears to be dependent on the goodwill of employers. I am concerned that the limitation in the service and the element of goodwill implies that persons with albinism whose work requires prolonged exposure to the sun are not guaranteed access to sunscreen, glasses and magnifiers. This means additional costs incurred by persons with albinism in a country with a low minimum wage.

While I am encouraged that a system exists to provide support to employers to help ensure adequate provision of access to assistive devices, the process seems bureaucratic with requested devices taking long to arrive often defeating the purpose of the system. As a result, companies seem reluctant to utilise it and may prefer to provide assistive devices through their own means. In some cases, companies may elect not to provide reasonable accommodations or assistive devices at all. Persons with albinism we spoke to stated that they do not insist on these even if they are entitled to them due to the effort and negativity this may produce. As one person with albinism stated, “It is easier for employers to dismiss you than to provide reasonable accommodation.” I urge the Government to undertake a review with the aim of making the system work efficiently to encourage employers to utilise it to access reasonable accommodations for employees.

- **Migrants and Refugees**

The rise of tensions and political sentiments over migration across most part of the world has brought multiple challenges for migrants. In Portugal, immigrant population has sharply increased in the past five years rising from half a million to one and a half million, according to the Agency for Integration, Migration and Asylum(AIMA). Historically, persons with albinism who migrated to Portugal traditionally came from Portuguese speaking countries such as Mozambique, Angola, Cape Verde, Sao Tome and Timo-Leste. This trend has recently evolved with large numbers of migrants and refugees coming from Asian countries. While Portugal is yet to ratify the International Convention of Migrant Workers, the constitutional provisions on equality, non-discrimination, right to education and health appear to apply to migrants. As a small proportion of the migrants include persons with albinism, the same rights also apply.

However, access to services have been significantly challenging for migrants in generally, and migrants with albinism in particular. Some of the people I interacted with highlighted difficulties in accessing health due to their inability to obtain a national health service number as a result of their unresolved immigration status. Another person with albinism recounted that bureaucracy and a prolonged wait to obtain his residency documents from the Agency for Integration, Migration and Asylum, which has been compounded by restructuring and backlogs in processing documents for migrants and refugees. This delay also impacts the type of work contracts migrants with albinism

get from employers, as they await resolution of their residency statuses. I am encouraged that despite the rising political rhetoric, some local organisations provide support services to assist with legal advice, accommodation and integration of migrants and asylum-seekers, including the Portuguese Refugee Council.

Most of the migrants with albinism I met had stories of being treated with respect and dignity, while expressing gratitude for a welcome stay. This generally involves migrants from Portuguese speaking countries with similarities of language with the local population possibly a major factor in their reception.

I am concerned that despite the major rise in the population of migrants and refugees, the Migration Agency has no disaggregated data on persons with albinism or other disabilities in the country. It is critical that a data collection exercise to determine the numbers and distribution of persons with albinism be initiated as a matter of priority.

**Preliminary recommendations**

My visit to the Portugal has been both informative and valuable in offering insights into the legal and policy framework that govern the human rights of persons with disabilities. As persons with albinism are considered persons with disabilities, the framework also applies to them. However, my preliminary finding is that while this framework is sufficient to ensure adequate protection of the rights of persons with albinism, the Government should do more to address gaps and inconsistent implementation. My engagements with the authorities and perspectives from individuals and non-governmental organizations I met, will help shape a comprehensive report which I will present to the UN Human Rights Council in March 2027.

The following are my preliminary recommendations to the Government of Portugal:

- Develop a comprehensive data collection system across all departments of government on albinism
- Review the SAPA system with a view to addressing gaps and ensuring clarity and effective functioning of the support system
- Reevaluate the National Strategy for the Inclusion of Persons with Disabilities and recognise persons with albinism as persons with disabilities in line with international human rights standards
- Review the Multiuse Medical Certification of Disability, modalities of work of the panel of doctors, and the accompanying legal framework in consultation with organisations representing persons with disabilities to ensure that conditions such as albinism are recognised as disabilities and individuals with such conditions are able to access necessary reasonable accommodations and assistive devices regardless of the assessed level of disability
- In line with the recent decision of the WHO's Essential Medicines List Committee, include sunscreen on the list of essential drugs for persons with albinism
- Review and harmonise school and workplace accommodations to ensure adequate access and clarity for persons with albinism

- Develop and implement a sensitization campaign on albinism in schools, universities and within the healthcare system
- Support non-governmental organisations working in the disability space with funding and representation in key policy discussions
- Build the capacity of health professionals to respond to the needs of persons with albinism, including through continuing professional development programs
- Harmonize the implementation of the inclusive education system to ensure standardization and universality in access to quality support
- Accelerate the regularisation of migrants and refugees with albinism to ensure greater access to health, education and the labour market.

End