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**Поощрение и защита всех прав человека,
гражданских, политических, экономических,
социальных и культурных прав,
включая право на развитие**

Посещение Соединенных Штатов Америки

Доклад Независимого эксперта по вопросу об осуществлении прав человека людьми с альбинизмом Мулуки-Анне Мити-Драммонд*

Резюме

В настоящем докладе Независимый эксперт по вопросу об осуществлении прав человека людьми с альбинизмом представляет выводы по итогам своего официального посещения Соединенных Штатов Америки, состоявшегося с 7 по 18 октября 2024 года. В докладе Независимый эксперт анализирует проблемы в области прав человека, с которыми сталкиваются люди с альбинизмом, в том числе с синдромом Германского-Пудлака, являющегося одной из разновидностей альбинизма. Признавая ряд позитивных инициатив в области политики и законодательной деятельности на федеральном уровне и уровне штатов, а также прогрессивное влияние Закона об американцах с инвалидностью, Независимый эксперт отмечает вопиющее неравенство в доступе людей с альбинизмом к услугам, в том числе в сферах образования, здравоохранения, транспорта и трудоустройства. Независимый эксперт также выражает обеспокоенность по поводу отсутствия дезагрегированных данных об альбинизме применительно не только к здоровью, но и к образованию, занятости, иммиграции и другим сферам жизни, что затрудняет проведение углубленного анализа положения в области прав человека людей с альбинизмом. Независимый эксперт выносит рекомендации по устранению выявленных пробелов и проблем.

* Резюме настоящего доклада распространяется на всех официальных языках. Сам доклад, содержащийся в приложении к резюме, распространяется только на том языке, на котором он был представлен.



Приложение

Доклад Независимого эксперта по вопросу об осуществлении прав человека людьми с альбинизмом Мулуки-Анне Мити-Драммонд о посещении ею Соединенных Штатов Америки

I. Introduction

1. In accordance with Human Rights Council resolution 46/12, and at the invitation of the Government of the United States of America, the Independent Expert on the enjoyment of human rights by persons with albinism undertook an official visit to the United States from 7 to 18 October 2024. The purpose of the visit was to engage with federal and state authorities, obtain updates on legislative and policy developments, review responses to challenges faced by persons with albinism and analyse the specific ongoing challenges of those with albinism, including those with Heřmanský-Pudlák syndrome in Puerto Rico. The Independent Expert is grateful to the Government of the United States for the invitation to conduct a visit and for facilitating meetings with various executive and departmental entities.

2. During her visit, the Independent Expert held meetings in Washington, D.C., in Atlanta, Georgia, and in San Juan, Arecibo and Quebradillas, Puerto Rico. In Washington, D.C., she met with representatives of the Department of State; the Department of Commerce; the Census Bureau; the Department of Homeland Security; the Department of Education; the Department of Health and Human Services; the National Security Council; the Domestic Policy Council; the Environmental Protection Agency; and the Equal Employment Opportunity Commission. She also visited the National Institutes of Health in Maryland and spoke to specialists carrying out research on various types of albinism, including Heřmanský-Pudlák syndrome. In Atlanta, Georgia, the Independent Expert met with persons with albinism from various walks of life and visited the Center for the Visually Impaired.

3. In San Juan, Puerto Rico, the Independent Expert visited a local hospital and met with specialist medical practitioners, including an ophthalmologist and an oncologist, who are involved in research relating to and treatment for persons with albinism, particularly Heřmanský-Pudlák syndrome, on the island. She also visited a special needs school at which students with albinism have been enrolled over the years. She met with the Director of the Office for the Protection of Persons with Disabilities (Oficina de Protección y Defensa de las Personas con Impedimentos). The Independent Expert visited and held discussions with representatives of the Puerto Rico branch of the Equal Employment Opportunity Commission, the Puerto Rico office of the Census Bureau, the Puerto Rico Science, Technology and Research Trust (Fideicomiso para Ciencia, Tecnología e Investigación de Puerto Rico), the Puerto Rico Consortium for Clinical Investigations (Consortio de Puerto Rico para la Investigación Clínica) and the independent living centre in San Juan (Movimiento para el Alcance de Vida Independiente). The Independent Expert also visited Arecibo and Quebradillas, on the northern coast of Puerto Rico, where she held several meetings with persons with albinism, including those with Heřmanský-Pudlák syndrome, and their families. Additional meetings with persons with albinism were conducted online due to difficulties in holding the meetings in person.

4. The Independent Expert expresses her appreciation to the Department of State, which supported and coordinated the visit, including by providing letters of introduction to facilitate meetings with various entities in both the mainland United States and Puerto Rico. The interactions with officials and meetings across several executive and departmental branches provided valuable insights into the human rights situation of persons with albinism and the various mechanisms, policies and legislative provisions to address the situation of persons with disabilities, including those with albinism.

5. The Independent Expert's visit was organized with the support and encouragement of dedicated individuals and entities in the mainland United States and Puerto Rico, who generously volunteered their time and resources. In this regard, the Independent Expert is

grateful to the National Organization for Albinism and Hypopigmentation and the Hermansky-Pudlak Syndrome Network, which provided technical and logistical support, including by arranging meetings with experts, local activists and persons with albinism, including members of the Heřmanský-Pudlák syndrome community in Puerto Rico. Similarly, the Independent Expert expresses gratitude to persons with albinism who met with her and shared their experiences, concerns and perspectives.

II. Background

A. Country overview

6. The United States is a union of 50 states with a diverse population of 334,914,895 as of 2023.¹ The country covers vast swaths of territory in North America and the Pacific Ocean. Since the ratification of its Constitution in 1788, the country has functioned as a constitutional democracy with a federal system of governance anchored around three distinct entities: the legislative, executive and judicial branches. The Government comprises numerous federal agencies and commissions discharging functions ranging from internal security and foreign policy to the protection of the rights and welfare of citizens. An integral part of the governance system is the states and local government architecture. Under the Tenth Amendment to the Constitution, states exercise powers and functions that are distinct from those of the federal Government, but they are modelled in a similar fashion, with three branches of government.

7. The United States is the world's largest economy by nominal gross domestic product (GDP), with an output of US\$ 27.3 trillion as of 2023.² According to the International Monetary Fund, the United States economy accounted for 26 per cent of the global economy in 2023 in nominal terms and about 15.5 per cent based on purchasing power parity.³ The strength of its economy is bolstered by the adoption of the United States dollar as the leading currency for international transactions, while several countries also use the dollar as their official or de facto currency.⁴ Over the years, the growth and expansion of the United States economy has led to increased employment and household income. However, income inequalities remain high, affecting millions of people, with some 40 million people reportedly living in poverty.⁵

8. With 3.2 million residents, Puerto Rico is an unincorporated territory of the United States, and its residents have been citizens of the United States since 1917 through the Puerto Rican Federal Relations Act. Although residents of Puerto Rico have voting rights in local and municipal elections, they are disenfranchised from federal elections. In 1952, the United States Congress approved a territorial constitution allowing residents of Puerto Rico to elect a governor who has non-voting representation in Congress through a resident commissioner. Other political reforms were introduced in subsequent years to strengthen institutions in response to the crisis of governance and declaration of bankruptcy. In 2016, the Puerto Rico Oversight, Management, and Economic Stability Act was adopted, instituting a board to oversee the government of Puerto Rico. The board has significant authority over domestic public authorities, with powers to override decisions by elected officials and bodies.⁶

9. As an archipelago with 56 per cent of its population living in the coastal municipalities, and with a population density of almost 449 inhabitants per km², Puerto Rico

¹ See <https://data.worldbank.org/country/united-states> (accessed on 20 October 2024).

² Ibid.

³ See <https://www.imf.org/external/datamapper/profile/USA> (accessed on 25 October 2024).

⁴ George S. Tavlas, "The international use of currencies: the U.S. dollar and the euro", *Finance and Development*, vol. 35, No. 2 (June 1998), p. 46.

⁵ Jessica L. Semega, Kayla R. Fontenot and Melissa A. Kollar, *Income and Poverty in the United States: 2016. Current Population Reports* (United States Census Bureau, September 2017), pp. 12 and 17.

⁶ David A. Skeel Jr., "Reflections on two years of P.R.O.M.E.S.A.", *Revista Jurídica de la Universidad de Puerto Rico*, vol. 87, No. 3 (2018).

is highly vulnerable to hazards and climate-induced emergencies.⁷ In September 2017, Puerto Rico suffered two devastating hurricanes – Irma and Maria – which resulted in the deaths of thousands of people and significant destruction to property, infrastructure and services. The extensive damage disrupted electricity and water supply systems and caused a humanitarian crisis that led to at least 90 per cent of the population needing assistance.⁸ The hurricanes exacerbated the governance crisis in Puerto Rico, accelerated the economic collapse of major institutions, with public services, including hospitals and schools, particularly affected. Following the hurricanes, large numbers of Puerto Ricans, including medical doctors and specialists, lawyers, academics and young people, left the island for the mainland United States to escape economic hardship and environmental hazards and in search of employment and educational opportunities.⁹ The 2021 United States census estimated the current population of Puerto Ricans in the United States at 9,061,871, significantly higher than the 3.2 million who reside in Puerto Rico.¹⁰

B. Albinism, including Heřmanský-Pudlák syndrome

10. 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 and are particularly vulnerable in areas with a high ultraviolet (UV) index. Albinism is also accompanied by visual impairment, including varying degrees of reduced visual acuity, nystagmus, photophobia, refractive error, foveal hypoplasia, optic nerve misrouting and, sometimes, strabismus. While visual aids, such as bioptics, improve vision, they do not correct the visual impairment entirely. Bioptics are a type of spectacles that have telescopes fitted on them. Some states of the United States allow the use of bioptic telescopes for driving.

11. The combination of visual impairment and vulnerability to the sun means that persons with albinism are considered persons with disabilities, including under the Americans with Disabilities Act. Due to social stigma, persons with albinism face harassment, bullying and varying forms of microaggressions and attitudinal barriers. The Committee on the Elimination of Racial Discrimination has also determined that persons with albinism face racial discrimination on the ground of skin colour. This is particularly acute when a person with albinism is in an environment where the general population is of a much darker skin complexion.

12. Due to the lack of disaggregated data and absence of albinism-related questions in the national census, the exact prevalence of albinism in the United States is unknown, but it is estimated to range from 1 in 37,000 to 1 in 18,000. In recent years, several institutions and research consortiums in the United States, including the National Institutes for Health, have invested in research to better understand the mutation, manifestation and characterization of the genes associated with albinism. Thus far, seven forms of oculocutaneous albinism have been recognized. There are also rarer forms of albinism that are accompanied by further complications, while at least 11 genes are linked to Heřmanský-Pudlák syndrome, the variation of albinism most common in Puerto Rico.

13. Heřmanský-Pudlák syndrome is a rare form of albinism. In addition to a lack of melanin and visual impairment, persons with Heřmanský-Pudlák syndrome have a platelet

⁷ See <https://climateknowledgeportal.worldbank.org/country/puerto-rico/vulnerability> (accessed on 25 October 2024).

⁸ See Joan Benach and others, “What the Puerto Rican hurricanes make visible: chronicle of a public health disaster foretold”, *Social Science and Medicine*, vol. 238 (October 2019); and Havidán Rodríguez and Marie T. Mora, “Hurricane Maria: disaster response in Puerto Rico”, *Oxford Research Encyclopedia of Politics*, 28 September 2020.

⁹ See Jennifer Hinojosa, “Two Sides of the coin of Puerto Rican migration: depopulation in Puerto Rico and the redefinition of the diaspora”, *Centro Journal*, vol. 30, No. 3 (2018); and Alexis R. Santos-Lozada and others, “Puerto Rico exodus: long-term economic headwinds prove stronger than Hurricane Maria”, *Population and Environment*, vol. 42, No. 1 (2020).

¹⁰ Charles R. Venator-Santiago and Volodymyr Gupan, “Puerto Rican population change in the United States, 2016–2021”, Puerto Rican Studies Initiative for Community Engagement and Public Policy, Data Report DR 2022-1, September 2022, p. 1.

dysfunction, leading to prolonged bleeding. Those with certain types of Heřmanský-Pudlák syndrome are also known to develop pulmonary fibrosis, eventually requiring a double lung transplant. They may also have inflammatory bowel and kidney diseases. Based on existing records, Puerto Rico has the highest prevalence of persons with Heřmanský-Pudlák syndrome in the world, with an estimated prevalence rate of 1 in 1,800, with 1 in 22 persons being carriers of one of the genes. Persons with Heřmanský-Pudlák syndrome experience visual impairment, with an acuity level of between 20/50 and 20/400 and almost always with nystagmus.¹¹

14. According to data collated by the Hermansky-Pudlak Syndrome Network, two types of Heřmanský-Pudlák syndrome have been identified in Puerto Rico. Heřmanský-Pudlák syndrome type-1 is most common in the north-western area of Puerto Rico, especially in Aguadilla, Mayagüez, Moca, Camuy, Hatillo and Arecibo, while Heřmanský-Pudlák syndrome type-3 is predominantly found in the Barranquitas, Naranjito and Aibonito municipalities in the central area of Puerto Rico. Due to the absence of disaggregated data and census figures, the true number of persons with Heřmanský-Pudlák syndrome could be considerably higher than reported.

15. The Independent Expert was informed by the Hermansky-Pudlak Syndrome Network and specialists in Puerto Rico that the systemic complications of Heřmanský-Pudlák syndrome type-1 are particularly serious after middle age. They include pulmonary fibrosis, granulomatous colitis and bleeding. Pulmonary fibrosis has been reported to occur in almost 100 per cent of Heřmanský-Pudlák syndrome type-1 patients, resulting in death between 30 and 50 years of age in the absence of a lung transplant. Granulomatous colitis and severe bleeding can also cause death. There is currently no specific and effective treatment for most of the serious complications of the condition.

16. The Independent Expert is aware that there are other rare forms of albinism, including Chediak-Higashi syndrome and possibly Griscelli syndrome, in the United States. It was clear from the visit that there are persons with Chediak-Higashi syndrome in the United States, but she was unable to meet with them. It appears that even less is known about these forms of albinism. The Independent Expert notes the essential research being carried out by specialists at the National Institutes of Health on various forms of albinism, including Heřmanský-Pudlák syndrome and Chediak-Higashi syndrome, as a positive initiative. Such research, if carried out in a manner that respects and promotes human rights principles, will go a long way to ensuring the full enjoyment of rights by persons with albinism.

III. Context of the visit

17. The Independent Expert's visit to the United States occurred during a period of heightened political activity due to looming presidential, gubernatorial and congressional elections. This presented some challenges in relation to organizing some of the desired meetings with elected officials at the congressional and state levels. The visit was motivated by two main factors. First, the diversity of the population and prevalence of albinism in the United States provided a basis for gathering information and documenting the lived experiences of persons with albinism, including Heřmanský-Pudlák syndrome, evaluating responses to their human rights concerns and assessing clinical research, including the development of medical products to help to alleviate bleeding and the lung-, skin- and vision-related side effects of albinism. The visit was an opportunity to engage with authorities and stakeholders, obtain information on legislative and policy developments and review corrective measures, particularly in relation to the right to employment, education, healthcare, public participation and family life.

18. Second, despite the prevalence of albinism, and notwithstanding ongoing research, there is still an acute lack of knowledge, expertise and basic awareness of the condition and an even greater lack in relation to the Heřmanský-Pudlák syndrome variation of albinism. During pre-visit consultations with civil society organizations in the United States, the Independent Expert was informed that a large number of persons with Heřmanský-Pudlák

¹¹ See <https://www.hpsnetwork.org/hps-information/characteristics/> (accessed on 30 October 2024).

syndrome do not even know that they have the condition, as establishing that a person has it requires a genetic test or a specialized microscopic test to examine the structure of blood platelets (rather than the amount). Partly because of poor understanding, resources are not generally in place to make tests readily available. The knowledge gap breeds prejudice, discrimination and microaggressions towards affected persons. As the present report highlights, these have profound implications for the families of children with albinism, particularly mothers, who often disproportionately bear the burden of protecting their children from abuse and discrimination and of investing time and emotion to ensure their children have access to services.

IV. Legislative and policy framework

19. At the international human rights level, the United States has ratified the International Covenant on Civil and Political Rights,¹² the International Convention on the Elimination of All Forms of Racial Discrimination,¹³ the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment,¹⁴ and the Optional Protocols to the Convention on the Rights of the Child on the involvement of children in armed conflict¹⁵ and on the sale of children, child prostitution and child pornography.¹⁶ The United States signed the Convention on the Rights of Persons with Disabilities on 30 July 2009 but has not yet ratified it.

20. At the domestic level, the United States has a relatively extensive body of laws and policies on disability rights, which strengthen the enjoyment of rights by persons with albinism, who are recognized as persons with disabilities. While the United States Constitution entrenches equality and non-discrimination principles, the Rehabilitation Act of 1973 was the first major federal disability rights law. Sections 501, 503 and 504 of the Act prohibit discrimination based on disability in programmes, initiatives and activities funded and implemented by federal agencies and federal contractors, while section 508 mandates federal agencies to make information and communications technology accessible to persons with disabilities. Although section 508 applies only to agencies, the Independent Expert was pleased to discover that private employers tend to adopt standards to promote accessible technology. The Act requires federal agencies to make reasonable accommodation for any known disabilities unless such accommodation would cause undue hardship.

21. Title VII of the Civil Rights Act of 1964, which provides for non-discrimination based on colour (and not only race), is an important instrument in the protection of the rights of persons with albinism, since they are often discriminated against on the basis of their light complexion, including in comparison with others of the same race. Section 703 of the Civil Rights Act makes it unlawful for a person to be deprived of employment opportunities or to otherwise adversely affect his or her status as an employee, because of such individual's race, colour, religion, sex or national origin. Section 705 of the Act provides for the creation of the Equal Employment Opportunity Commission to enforce laws that make discrimination illegal in the workplace.

22. In November 2009, the Genetic Information Nondiscrimination Act of 2008, which prohibits genetic information discrimination in employment, came into force. Title II of the Act prohibits discrimination against employees or applicants on the basis of available genetic information, especially the use of such information in making employment decisions or assessments. The Act also prohibits employers from requesting or obtaining genetic information from employees or disclosing such information to others. For the Act, genetic information includes information about an individual's genetic tests and the genetic tests of an individual's family members, as well as information about the manifestation of a disease

¹² Ratified on 8 June 1992. See https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?CountryID=187&Lang=EN.

¹³ Ratified on 21 October 1994.

¹⁴ Ratified on 21 October 1994.

¹⁵ Ratified on 23 December 2002.

¹⁶ Ratified on 23 December 2002.

or disorder in an individual's family members.¹⁷ The Act is an important law for persons with albinism, including Heřmanský-Pudlák syndrome, whose conditions have a genetic origin.

23. The Americans with Disabilities Act of 1990 improves on the Rehabilitation Act of 1973 and provides a wide-ranging protection regime for persons with disabilities. Title 1 of the Americans with Disabilities Act imposes an obligation on employers to provide reasonable accommodations to job applicants and employees with disabilities and prohibits discrimination based on disability in all aspects of employment. To ensure accessibility and ease of movement, public service providers are required to make services accessible to persons with disabilities, including on trains, trams and buses (Title II), while accommodations for persons with disabilities are mandated in buildings and public spaces (Title III). The Americans with Disabilities Act was amended in 2008 to expand the definition of "disability", with an impact on all prior provisions of the Act, including those related to employment practices, government programmes and private entities.

24. The impact of this body of laws and policies has meant that, progressively, federal and state institutions have been required to adhere to non-discrimination laws and provide support to ensure access to reasonable accommodations and assistive devices for persons with albinism in education and employment. Under the Department of Education, a number of initiatives exist to enhance the quality of education and improve the learning environment for persons with albinism: the Comprehensive Center Network (CCNetwork) provides support to states and local education agencies to increase performance among schools designated for improvement; the National Center on Safe Supportive Learning Environments offers information and technical assistance to schools on improving the school environment and conditions for learning; and the American Printing House for the Blind produces educational materials adapted for students who are legally blind, including textbooks, Braille typewriters and microcomputers. In the state of Georgia, the Georgia Parent Infant Network for Educational Services, which is part of the Department of Education, provides support to families of children up to 5 years of age with visual impairment.

25. In the area of employment, the Equal Employment Opportunity Commission operates 53 offices across the United States and Puerto Rico with the primary function of providing legal and conciliation support to those whose rights have been violated in the workplace, including in relation to accessing reasonable accommodation at both the federal and the state levels. The Independent Expert was informed that, in cases where conciliation fails, the Equal Employment Opportunity Commission intervenes through amicus briefs where there is a legitimate public interest. The Independent Expert was encouraged to see that the Job Accommodation Network provides complementary online information to help employers with free and confidential workplace accommodations, including for albinism, as well as the conditions accompanying Heřmanský-Pudlák syndrome.

26. In Puerto Rico, the authorities promulgated Law No. 109 of 2022 on the Public Policy of the Government of Puerto Rico on Persons with Albinism and Heřmanský-Pudlák Syndrome. The law, among other things, seeks to ensure that persons with albinism, including Heřmanský-Pudlák syndrome, have access to necessary services and specialist doctors, as well as drugs and treatments. The Independent Expert is encouraged by the progressive elements of the law, which seek to address the concerns of persons with albinism, including Heřmanský-Pudlák syndrome, in Puerto Rico. Article 4 of Law No. 109 mandates the Puerto Rico Department of Health to establish a collaborative agreement with the Medical Sciences Campus of the University of Puerto Rico to provide a special support process, in order to ensure adequate and timely access to specialists, while article 5 imposes an obligation on medical doctors and specialists to refer babies born with albinism to undergo a Heřmanský-Pudlák syndrome type-1 genetic test. The law also requires the Puerto Rico Health Insurance Administration and private health insurers to include the cost of genetic testing in their coverage. However, the law is yet to be implemented.

¹⁷ See <https://www.eeoc.gov/genetic-information-discrimination#:~:text=Title%20II%20of%20the%20Genetic,applicants%20because%20of%20genetic%20information.>

27. Other entities, such as the Puerto Rico Office for the Protection of Persons with Disabilities, also provide support to persons with disabilities facing discrimination. The independent living centre in San Juan (Movimiento para el Alcance de Vida Independiente) provides a wide range of support to persons with disabilities to help them to develop independent living skills to lead dignified lives. During a visit to the centre's office in San Juan, the Independent Expert was briefed on its programmes, including mentorship, training and peer-to-peer learning experiences on practical daily struggles such as using a cane, crossing roads at traffic lights, accessing sidewalks and navigating through public spaces and busy shopping environments. The Independent Expert was pleased to learn that 70 per cent of the centre's 50 employees are persons with disabilities and that persons with albinism are included in the activities and programmes.

V. Gaps and challenges

A. Absence of disaggregated data

28. An important element of a rights-based analysis is the availability of disaggregated data, which helps to assess the level of implementation of laws and policies and provide pointers for advocacy and engagement. During the visit, the Independent Expert noted that there is an absence of reliable data on the prevalence of albinism in the United States and the status of compliance with existing bodies of laws and policies on the provision of specific support to persons with albinism as persons with disabilities. According to the Department of Health and Human Services, 1 in 37,000 people in the United States has one of the many forms of albinism, with oculocutaneous albinism type-1 and type-2 most common. This is lower than the reported global prevalence of 1 in 20,000 and the national prevalence reported by the National Organization of Albinism and Hypopigmentation of 1 in 18,000 to 1 in 20,000. In the absence of a comprehensive data-collection programme, it is highly likely that the existing figures on the prevalence of albinism do not represent the actual number.

29. The Independent Expert's interactions with authorities at the federal and state levels revealed that disaggregated data on albinism is not readily available, not only in relation to health, but also in relation to education, employment, immigration and other areas of life, making it challenging to conduct an informed rights-based analysis of the situation of persons with albinism in the country. While the Independent Expert noted that the authorities have privacy concerns in relation to data collection, she urged them to develop appropriate data-protection protocols to enable data collection on albinism, including Heřmanský-Pudlák syndrome and other rarer forms of albinism, in accordance with existing federal and state laws. This could include using the national census or the American Household Survey, with appropriate privacy protocols, to introduce questions on albinism. The Independent Expert reiterated that, without appropriate disaggregated data, it is impossible to identify the prevalence of albinism in the country and the distribution of persons with albinism and, ultimately, to ensure an appropriate response to the challenges that they face, including the allocation of an appropriate budget.

30. In Puerto Rico, grass-roots activism and advocacy by local activists and the Hermansky-Pudlak Syndrome Network pushed through Law No. 109 of 2022 on the Public Policy of the Government of Puerto Rico on Persons with Albinism and Heřmanský-Pudlák Syndrome. Article 7 attempts to integrate a mandatory data-collection protocol within the functions of the Puerto Rico Birth Defect Surveillance System of the Department of Health. It states that this entity will be responsible for identifying and subdividing the types of albinism, including Heřmanský-Pudlák syndrome, and will prepare a report at the end of each year for submission to the Puerto Rico Statistics Institute for statistical analysis and publication. The Independent Expert commends the authorities for the positive aspects of Law No. 109 and urges them to expedite its implementation.

31. The importance of the disaggregation of data for the promotion of the rights of persons with disabilities is echoed in article 31 of the Convention on the Rights of Persons with Disabilities, which requires States parties to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect

to the Convention, taking into account the need to comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities. The article further states that the information collected is to be disaggregated, as appropriate, and used to help to assess the implementation of States parties' obligations under the Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights. While the United States has yet to ratify the Convention, article 31 provides good practice that could enhance data on albinism.

B. Health: health and insurance concerns

32. Access to healthcare is a concern for persons with albinism, who require specialized health services due to their albinism, including regular visits to an ophthalmologist for their eyes and to a dermatologist due to their vulnerability to skin cancer. The Independent Expert was informed by several individuals and families that, as these visits are to specialists, the consultations are not automatically covered by Medicaid¹⁸ or Medicare.¹⁹ Those with private health insurance through their work or other sources may have such consultations covered under their insurance plan. However, depending on the level of coverage, a visit to these specialists may cost from US\$ 50 to US\$ 150. Specialized spectacles, which are necessary for persons with albinism because of their reduced visual acuity and sensitivity to sunlight, range from US\$ 300 to US\$ 800. In addition, sunscreen is rarely covered by medical insurance and costs US\$ 5 to US\$ 20 per bottle. While the Independent Expert recognizes and welcomes the work carried out by the Department of Health and Human Services and the Food and Drug Administration in relation to skin cancer and regulation, respectively, it is important to note that the most prevalent forms of skin cancer impacting persons with albinism – squamous cell carcinoma and basal cell carcinoma – do not appear to be covered by these initiatives.

33. In addition to ophthalmologists and dermatologists, those with Heřmanský-Pudlák syndrome require access to haematologists and may even require visits to gastroenterologists. Those with Heřmanský-Pudlák syndrome type-1, which appears to be the most common type of the syndrome in Puerto Rico, will require access to pulmonologists. These services are not only out of the financial reach of most persons with albinism, who do not have medical insurance that covers this, but there is also an acute shortage of relevant professionals, and the waiting lists to see them can be as long as six months or more. However, even where a specialist is available, the disparity in insurance coverage could have profound implications for access to healthcare. Residents in Puerto Rico pay social security contributions and therefore are eligible for social security benefits upon retirement. However, they are excluded from Supplemental Security Income and the Medicare Part D Low-Income Subsidy.

34. The disparities are further compounded by the higher rates for treatment for and coverage of chronic diseases and genetic conditions such as albinism under medical insurance.²⁰ In the mainland United States, enrolment in Medicare Part B is automatic, while, in Puerto Rico, a proactive process of enrolment is necessary, but many opt not to enrol to avoid decreased social security income.²¹ The Independent Expert is concerned that procedural and systemic disparities in the insurance coverage architecture are forcing Puerto Ricans in need of access to medical care to choose between stability in income flow and the imperative for coverage.

¹⁸ Medicaid is a joint federal and state programme that helps to cover medical costs for some people with limited income and resources. See <https://www.hhs.gov/answers/medicare-and-medicaid/what-is-the-difference-between-medicare-medicaid/index.html#:~:text=Medicaid%20is%20a%20joint%20federal,state%20runs%20its%20own%20program>.

¹⁹ Medicare is a federal health insurance programme for people aged 65 or older, and some people under 65 with certain disabilities or conditions. A federal agency known as the Centers for Medicare and Medicaid Services runs Medicare.

²⁰ Natalio J. Izquierdo, "Co-management of patients with Heřmanský-Pudlák syndrome in Puerto Rico: a role model", a briefing prepared for Independent Expert, October 2024.

²¹ Ibid.

35. Persons with Heřmanský-Pudlák syndrome type-1 face recurring costs and other challenges. More often than not, they will eventually require a double lung transplant. These services are not available in Puerto Rico, and travel to the mainland is therefore required for the procedure. While public health insurance will often cover the cost of the procedure, there are a number of additional costs associated with the transplant, including flights for the individual and supporting family members to the mainland; rental accommodation, food and bills for the duration of the procedure and recovery time, since the individual and supporting family members will be unable to work during this time; and the cost of a car to get to and from medical appointments, since the procedure makes it impossible to travel by public transportation. Persons needing a transplant face the additional challenge of having to wait for up to three years to get listed for lungs, have a successful transplant and recover. In Arecibo, Puerto Rico, a family explained to the Independent Expert how they had organized activities to mobilize funds to pay for a lung transplant for their daughter. The Independent Expert also learned of cases where others had died while waiting for matching lungs.

36. Despite the high prevalence of Heřmanský-Pudlák syndrome in Puerto Rico, there is no testing of those with albinism to determine whether they have it. This leads to late detection, and some may never know that they have it, meaning that they do not receive essential medical treatment and may even receive treatment that will likely have an adverse impact on the success of a much-needed lung transplant in the future. In one encounter, the Independent Expert was informed by an individual that her years of receiving blood transfusions had meant that she was struggling to find compatible lungs. In another interaction with the Independent Expert, a person with albinism complained about constant fatigue, breathing problems, bruising easily and occasional bleeding but had been told by a doctor that she had nothing to worry about in relation to Heřmanský-Pudlák syndrome, despite showing signs of the syndrome. Her dilemma could have been resolved with testing by a specialist.

37. The Independent Expert was informed in several meetings that the protracted governance crisis in Puerto Rico and the high turnover of specialist doctors leaving the territory for the mainland had led to a serious shortage of medical doctors, with specialists in albinism, including Heřmanský-Pudlák syndrome, regularly moving to better resourced hospitals in the mainland United States. In this regard, the Independent Expert commended the work of the Hermansky-Pudlak Syndrome Network, which has regular clinics in Puerto Rico bringing relevant specialists to examine and provide specialized care to those with Heřmanský-Pudlák syndrome on the island every three to six months. These clinics have provided a lifeline to many people with Heřmanský-Pudlák syndrome, to help them to manage their condition and access services free of charge that would otherwise have been costly. The clinics have also created a network of community support for persons with Heřmanský-Pudlák syndrome in remote areas, who are mostly disconnected due to a poor public transportation system.

C. Education: challenges of access and reasonable accommodation

38. The legislative and policy framework at the federal level appears broad, with significant provisions on access to education and reasonable accommodations for persons with disabilities. Most states offer a variety of assistive devices for visual impairment, support from orientation and mobility teachers to enable individuals to travel to and from school or work, extra time in examinations and a variety of other forms of support. However, the level of enforcement of laws and policies markedly differs from state to state, and sometimes from one school district to another. In addition, despite initiatives from the Department of Education to promote safe inclusive learning environments through the National Center on Safe Supportive Learning Environments and other initiatives, bullying and name-calling at school were raised as a concern during the Independent Expert's meetings in Georgia and Puerto Rico.

39. In her meetings with persons with albinism in Georgia, the Independent Expert was informed that the necessary reasonable accommodations in relation to visual impairment were generally made available at various levels of the school system. All, however, highlighted that receiving the accommodations had largely been due to self-advocacy or

strong advocacy on their behalf by their parents. They all also stated that they had not received any accommodation in relation to their sensitivity to the sun, particularly for their skin. Sunscreen had to be purchased, and its application in schools at the pre-primary stage was a challenge, as many school administrations had a policy that prohibited teaching staff from applying sunscreen to pupils, and pupils of pre-primary age are too young to appropriately apply it themselves. This meant that pupils had to come to school with the sunscreen lotion already applied, thus reducing its effectiveness due to the long duration of the application.

40. In Puerto Rico, the Independent Expert interacted with persons with albinism and their families in San Juan, Arecibo and Quebradillas, who recounted experiencing considerable disruptions to their children's education due to several barriers, including lack of knowledge of albinism on the part of teachers, poor and inconsistent provision of reasonable accommodation measures in schools, inadequate provision of assistive devices and large-print documents, and denial of requests for extra time in tests. In two cases, persons with albinism had been forced to discontinue their studies due to poor accommodations in schools. Others recounted instances in which teachers had themselves been the source of bullying, harassment and name-calling. They stated that these incidents had negatively affected their confidence levels and had diminished their trust in the education system.

41. The Independent Expert notes that, in Puerto Rico, before the introduction of the Americans with Disabilities Act, parents had enrolled children with albinism at the Loaiza Cordero Institute for Blind Children in San Juan. However, soon after the entry into force of the Act, most schools transitioned to an inclusive model, allowing children to attend the mainstream public school system.²² While the Independent Expert welcomes the transition to inclusive education for children with albinism, she notes the concern of some regarding the apparently weakened specialized support for students with visual impairment, as well as the gap in the training for teachers on effectively educating children and young adults with low vision and other visual impairments. The Independent Expert maintains that inclusive schools are more in line with international human rights standards for children with albinism, but that such schools must be truly inclusive, with the provision of reasonable accommodation, including assistive devices, and teachers properly capacitated to support students.

42. The Independent Expert reiterates the need for a comprehensive review of the education system, especially in Puerto Rico, to update teaching methodologies and introduce modern assistive technologies. Addressing inadequate knowledge or lack of knowledge of albinism, including Heřmanský-Pudlák syndrome, within the school system should be part of the review carried out to inform effective intervention measures, including tailored sensitization programmes for teachers, parents and medical practitioners. This will help to address some of the concerns raised in Puerto Rico, including poor responses to emergency needs of persons with albinism, including Heřmanský-Pudlák syndrome, during school hours. However, even in the mainland United States, persons with albinism and their families are sometimes compelled to move to other states where educational facilities and related services are more accessible or, in some instances, to enrol their children in specialized schools for blind persons to have better prospects of reasonable accommodations, including reliable access to assistive technologies.

D. Employment: shortfall in opportunities and workplace accommodation

43. The Americans with Disabilities Act imposes obligations on employers to provide reasonable accommodation to individuals with disabilities, including persons with albinism. Where the Act is violated or its reasonable accommodation threshold not met, individuals can pursue legal action through litigation or file complaints with the Equal Employment Opportunity Commission. During interactions with enforcement entities, the Independent Expert was informed that adequate provisions existed within the Americans with Disabilities Act, the Genetic Information Nondiscrimination Act and the Civil Rights Act to protect persons with albinism from discrimination and harassment in the workplace. However, few cases involving persons with albinism appeared to have been litigated, and courts tended to

²² Ibid.

adopt a narrow threshold of what constituted harassment in the context of albinism. Moreover, lack of disaggregated data meant that there was no readily available information on cases brought by persons with albinism related to workplace discrimination based on disability or colour.

44. Despite the progressive provisions of the Americans with Disabilities Act, the Independent Expert found, during her interactions with persons with albinism, that ensuring equal opportunities in employment and workplace accommodations remain challenging across the United States. While overt cases of discrimination based on albinism were seemingly rare, many expressed hesitancy about requesting workplace accommodations or disclosing their disability at the time of applying for jobs. In some cases, the process for requesting accommodations and the delay in accessing them tended to discourage persons with albinism from requesting further accommodations. Many have also opted to tolerate and ignore microaggressions at work.

45. The Independent Expert also noted disparities in workplace accommodations from one profession to another. While some employers and institutions were supportive of persons with albinism and willing to provide accommodations, including by restructuring jobs, making worksites and workstations accessible and modifying schedules and equipment, others were reluctant and sometimes unwilling. The legal profession and some specialized medical entities were identified as slow to adjust work practices to accommodate persons with albinism. The uneven and sometimes vast disparities in laws and policies suggest that persons with albinism living in certain states may have different experiences of access to employment, public services and workplace accommodation. The Independent Expert urges the Government of the United States to undertake a review with the objective of promoting uniformity.

46. The Independent Expert was informed in several meetings in San Juan, Arecibo and Quebradillas that unemployment among persons with albinism, particularly Heřmanský-Pudlák syndrome, was high due to imbalances in workplace accommodations. Those who live in the suburbs of San Juan or remote communities sometimes quit jobs because of poor access to transportation, and environmental health hazards and their impact on their lung and skin conditions. This is exacerbated by the unwillingness of employers to accommodate alternative schedules or remote work, as well as to provide other reasonable accommodations to ensure that persons with albinism, including Heřmanský-Pudlák syndrome, can perform their jobs effectively.

E. Accessibility: poor access to transportation

47. In the towns that the Independent Expert visited outside San Juan, no public transportation exists linking the communities with the capital. When required to undertake travel from rural towns to San Juan to access vital medical and educational services, families without private vehicles are compelled to make decisions well in advance and, in limited cases, book private taxi services, which are expensive and almost beyond the financial reach of persons with albinism. For those with Heřmanský-Pudlák syndrome, who often live in remote areas and require regular consultations with specialists, including ophthalmologists and haematologists, the poor transportation links between San Juan and rural communities are a major concern. In some cases, persons with Heřmanský-Pudlák syndrome have to carry oxygen supplies when using public transportation. The Independent Expert urges the local and federal authorities to improve access to transportation, including by operationalizing special services linking rural and urban communities in Puerto Rico.

48. Concerns were also raised regarding the poor accessibility of public infrastructure. This was a concern to varying degrees in both Georgia and Puerto Rico. In Georgia, some areas are more accessible than others. In general, a lack of tactile paving, audible signals and appropriate contrast to make public spaces more accessible and obstructions on sidewalks were mentioned in both places. Electric scooters, which can be rented in Georgia, were mentioned as a particular concern due to the fact that they are left haphazardly on sidewalks. A special needs professor in Washington, D.C., recounted to the Independent Expert several incidents in public spaces when abandoned electric scooters in walkways had resulted in

injuries to pedestrians, with one having to undergo surgery due to serious injuries to his legs. On university campuses, students with albinism and with poor vision face dangers posed by the reckless use and abandonment of electric scooters.

F. Stigma and discrimination: perceptions and unconscious biases

49. While the Independent Expert did not document any physical violence against a person with albinism during her visit, she was informed of incidents of microaggressions, unpleasant innuendos and unconscious biases. Most of the persons with albinism with whom the Independent Expert met had stories of being degraded through name-calling or being made the subject of jokes or constantly stared at. In Arecibo, Puerto Rico, individuals with albinism recounted incidents of bullying in school, where they had been called names such as “Casper”, “clown” and “cotton”, among many others. A mother lamented that, while she had made efforts to prepare her daughters for this kind of scenario, the experiences were traumatizing and affected their confidence and self-esteem.

50. Lack of knowledge of albinism has profound implications for families with children with albinism, particularly mothers. In all her meetings, the Independent Expert reiterated that mothers with children with albinism are formidable human rights defenders who deserve recognition and support. Even in situations where persons with albinism can lead normal lives, mothers are almost certainly required to become activists and advocates, engaging with teachers, medical practitioners and local government authorities to ensure the application of anti-discrimination laws and access to services for their children. One mother informed the Independent Expert that she had resorted to the services of a private lawyer to ensure that her children with albinism were provided with reasonable accommodations in accordance with the Americans with Disabilities Act.

51. The Independent Expert heard distressing stories of mothers with children with albinism who had been told by medical doctors that their children would not be of much use in life, perhaps showing that the lack of knowledge also applies to some medical professionals. The Independent Expert calls upon federal and local authorities to collaborate with the commendable non-profit organizations working with limited resources to help to raise awareness of albinism and mitigate stigma and discrimination.

G. Albinism and climate change: vulnerability of Puerto Rico

52. Concerns were raised regarding the perceived increasing heat, which was assumed to be resulting in an increase in UV rays, and its impact on the skin of persons with albinism. The lack of melanin pigmentation and increased UV rays mean that persons with albinism are more vulnerable to skin damage, photoaging and skin cancer. While many, particularly in the mainland United States, had access to sunscreen, the high cost of consulting a dermatologist was mentioned as concerning.

53. Those in Puerto Rico further highlighted the impact of climate change-related disasters on persons with Heřmanský-Pudlák syndrome in particular. Puerto Rico is highly vulnerable to climate change-related emergencies.²³ In September 2017, Puerto Rico suffered two devastating hurricanes: Irma and Maria. Following Hurricane Maria, the power supply throughout the island was disrupted. The Hermansky-Pudlak Syndrome Network highlighted the loss of oxygen supplies, and even air conditioning in homes, faced by those with pulmonary fibrosis as contributing to at least one death and likely more during that time. While in-depth research was not carried out in that connection, it is also very likely that some may have sustained severe injuries resulting in profuse bleeding and may have faced a lack of access to medical facilities during this time. While the Independent Expert notes that the Environmental Protection Agency has issued guidance on climate change and the health of

²³ See <https://climateknowledgeportal.worldbank.org/country/puerto-rico/vulnerability> (accessed on 25 October 2024).

persons with disabilities²⁴ and a document on integrating environmental justice into emergency response preparedness and management,²⁵ it is clear that more research is needed to better understand the disproportionate impact of climate change and climate-related disasters on persons with albinism, in particular Heřmanský-Pudlák syndrome.

VI. Conclusions and recommendations

54. The Independent Expert's visit to the United States offered her an opportunity to engage with multiple entities and individuals on the human rights situation of persons with albinism. The Independent Expert found that several legislative and policy developments had contributed to the progressive improvement of the rights of persons with albinism. Uniform implementation of key laws would further strengthen a rights-based regime for persons with albinism.

55. The engagements with federal and state authorities and perspectives from civil society and persons with albinism have shaped the analysis and recommendations included in the present report. While encouraged by the commitment of the executive and departmental entities with whose representatives she met during the visit, the Independent Expert has formulated the recommendations set out below to address key concerns and challenges to ensure the full protection of the human rights of persons with all forms of albinism.

56. With regard to disability rights, the Independent Expert recommends that the Government of the United States:

- (a) Accelerate the ratification of the Convention on the Rights of Persons with Disabilities to complement and strengthen the domestic disability rights framework;
- (b) Review, strengthen and align the work and terms of reference of offices or commissions on disability rights at the state level and in Puerto Rico with international human rights law standards and approaches regarding disability rights;
- (c) Undertake a review of the disparities in the implementation of laws and policies on disability rights to ensure uniformity across the country;
- (d) Encourage the executive and legislative authorities in Puerto Rico to accelerate the implementation of Law No. 109 of 2022 on the Public Policy of the Government of Puerto Rico on Persons with Albinism and Heřmanský-Pudlák Syndrome.

57. With regard to research and data collection, the Independent Expert recommends that the Government of the United States:

- (a) Develop a data-collection system on albinism, including rarer forms of albinism such as Heřmanský-Pudlák syndrome and Chediak-Higashi syndrome, with information disaggregated by state, gender, age and other factors;
- (b) Carry out a comprehensive situational analysis of albinism in the country;
- (c) Initiate and develop sustainable data-governance and data-protection protocols in Puerto Rico.

58. With regard to awareness and sensitization, the Independent Expert recommends that the Government of the United States:

- (a) Develop and implement a sensitization campaign on all types of albinism in collaboration with civil society organizations;
- (b) Develop a rights-based training programme to improve understanding of albinism among teachers, healthcare workers and key public service providers.

²⁴ See <https://www.epa.gov/climateimpacts/climate-change-and-health-people-disabilities> (accessed on 5 November 2024).

²⁵ See <https://nepis.epa.gov/Exe/ZyPURL.cgi?Dockey=PI017XX0.txt> (accessed on 5 November 2024).

59. With regard to health, the Independent Expert recommends that the Government of the United States:

- (a) Ensure that free genetic testing for Heřmanský-Pudlák syndrome and Chediak-Higashi syndrome is offered and recommended for all children born with albinism;
- (b) Establish a lung transplant facility in Puerto Rico with adequate resources and expertise;
- (c) Initiate a review of the state of the healthcare system in Puerto Rico;
- (d) Build the capacity of health professionals to respond to the needs of persons with all forms of albinism, and particularly Heřmanský-Pudlák syndrome in Puerto Rico, including through continuing professional development programmes and the development of treatment protocols or guidelines on all types of albinism;
- (e) Make sunscreen available as a form of essential drug or assistive product for all persons with albinism;
- (f) Provide access to a dedicated primary healthcare nurse with knowledge of all forms of albinism to mothers when children are born with albinism;
- (g) Address the gaps in the healthcare system in Puerto Rico by training and recruiting more dermatologists, oncologists, haematologists, pulmonologists, gastroenterologists and ophthalmologists, with incentives to retain them.

60. With regard to research and capacity-building, the Independent Expert recommends that the Government of the United States:

- (a) Build the capacity of relevant professionals working in the fields of disability rights, childcare and social work and in other relevant fields to respond to the needs of persons with all types of albinism, particularly Heřmanský-Pudlák syndrome in Puerto Rico;
- (b) Provide funding and capacity development for organizations working on albinism, including Heřmanský-Pudlák syndrome;
- (c) Support institutions undertaking research on all forms of albinism, including in Puerto Rico.

61. With regard to mobility, the Independent Expert recommends that the Government of the United States:

- (a) Harmonize the use and availability of bioptics for driving nationwide;
- (b) Improve public transportation infrastructure, including by developing a uniform signage system across all states and in Puerto Rico;
- (c) Encourage local government authorities to develop protocols on the use of electric scooters to minimize risks to the visually impaired.

62. With regard to education, the Independent Expert recommends that the Government of the United States:

- (a) Integrate mandatory training on all forms of albinism for all medical schools, with a built-in continuous learning programme for practitioners;
- (b) Review the implementation of the reasonable accommodation provision in the Americans with Disabilities Act and address gaps in the availability of accommodation at all levels of the school and university system;
- (c) Undertake a comprehensive review of the education system, especially in Puerto Rico, to update teaching methodologies and introduce modern assistive technologies;
- (d) Review anti-bullying measures to ensure a safe inclusive learning environment for persons with albinism.

63. With regard to employment, the Independent Expert recommends that the Government of the United States:

(a) Address disparities in workplace accommodations from one profession to another and ensure awareness-raising on the reasonable accommodation needs of persons with albinism of any form;

(b) Develop collaboration between the Equal Employment Opportunity Commission and national organizations working on albinism, including Heřmanský-Pudlák syndrome, to address workplace discrimination and provide disaggregated data on discrimination because of disability and colour.

64. With regard to climate change, the Independent Expert recommends that the Government of the United States:

(a) Ensure the availability of disaggregated data on the impact of climate change on persons with disabilities, including by type of disability, age, gender, socioeconomic status and geographical location, with a view to ensuring appropriate response measures for those most disproportionately affected;

(b) Carry out research into the impact of climate change on persons with albinism, particularly in Puerto Rico, considering the high prevalence of albinism and climate change-related disasters in Puerto Rico.
