

**UNOFFICIAL ENGLISH TRANSLATION**

**RESOLUTION No. 725, OF NOVEMBER 9, 2023.**

*Establishes the National Policy for Comprehensive Health Care for People with Albinism*

The Plenary of the National Health Council (CNS), at its Three Hundred and Forty-Eighth Ordinary Meeting, held on November 8 and 9, 2023, and in the use of its regimental powers and attributions conferred by Law No. 8,080, of September 19, 1990; by Law No. 8,142, of December 28, 1990; by Complementary Law No. 141, of January 13, 2012; by Decree No. 5,839, of July 11, 2006, and complying with the provisions of the Constitution of the Federative Republic of Brazil of 1988 and related Brazilian legislation; and

Health is everyone's right and duty of the State, guaranteed through social and economic policies aimed at reducing the risk of disease and other health problems, and the universal and equal access to actions and services for its promotion, protection, and recovery.

Whereas, according to the constitutional provision, comprehensive care, with priority for preventive activities, without prejudice to care services, is one of the SUS guidelines;

In reference to the Brazilian Law No. 8080, dated September 19, 1990, which sets forth the conditions for the promotion, protection, and recovery of health, organization, and operation of relevant services;

In line with the Decree No. 8142, of December 28, 1990, which provides for community participation in the management of the Unified Health System (SUS) and intergovernmental transfers of financial resources in the health area;

Considering Decree No. 7508, of June 28, 2011, which regulates Law No. 8,080, of 1990, to provide for the organization of the SUS, health planning, health care, and inter federative articulation;

Whereas, around the world, people with albinism face discrimination and stigma and in many countries, even become victims of physical attacks;

Considering the importance of ensuring equality and inclusion for people with albinism, with health promotion for people with this genetic condition that results from the lack of melanin in hair, skin, and eyes; and

Considering that people with albinism are more prone to complications such as skin cancer and blindness, it is, therefore, necessary to define the guidelines of a national policy and a line of care with a view to preventing complications and promoting the health of people with albinism.

**HAS DECIDED**

To approve, in accordance with Annex I of this resolution, the National Policy for Integral Health Care for People with Albinism (PNAISPA).

FERNANDO ZASSO PIGATTO  
President of the National Health Council

I ratify CNS Resolution No. 725, of November 9, 2023, pursuant to Law No. 8.142, of December 28, 1990.

NÍSIA TRINDADE LIMA  
Minister of State for Health

## ANNEX I

### ESTABLISHES THE NATIONAL POLICY FOR COMPREHENSIVE HEALTH CARE FOR PEOPLE WITH ALBINISM

#### CHAPTER I GENERAL PROVISIONS

Art. 1: The National Policy for Comprehensive Health Care for People with Albinism (PNAISPA) is established within the scope of the Unified Health System (SUS).

Art. 2: For the purposes of this Resolution, the following definitions are considered:

- I. **Equity:** the concept of equity is related to the principle of social justice and intends to recognize the different needs and specificities of populations, seeking to mitigate situations of social injustice. Health equity presupposes the State's recognition that everyone has the right to good health, identifying social, territorial, and cultural differences, considering the habits and courses of life and the needs of specific groups, acting to reduce the impact of inequalities, in the sense of inclusion and individual and collective access.
- II. **Social vulnerability:** individual and collective conditions of responses to risks arising from the economic, social, and political context. This concept aligned with the idea of the Social Determinants of Health and the dimensions of urban infrastructure, human capital, income, and work contained in the Social Vulnerability Index (IVS/IPEA) that are expressed through exclusion, discrimination, barriers to access public policies, violation of human rights, among others.
- III. **Specific and vulnerable populations:** people with albinism, homeless population, black population, Roma/Romani people, populations deprived of liberty, former prisoners and socio-educational system, migrant populations, refugees and stateless people, the population of Lesbian, Gay, Bisexual, and Transgender (LGBT), the population of the countryside, forest and waters and indigenous populations.
- IV. **People with albinism:** those affected by a non-contagious, genetically inherited health condition, whose transmission may be autosomal recessive or linked to the X chromosome. This health condition refers to a genetic anomaly that interferes with the production and distribution of melanin in the skin, hair, and eyes, which may lead to low vision and variation in the types of manifestation of albinism. Albinism affects all races regardless of sex, ethnicity, or social class, and in practically all countries of the world with varying prevalence, it is classified into three macro categories: ocular, partial, and oculocutaneous.
- V. **Primary Health Care:** “a set of individual, family and collective health actions that involve promotion, prevention, protection, diagnosis, treatment, rehabilitation, harm reduction, palliative care, and health surveillance, developed through integrated care practices and qualified management, carried out with a multidisciplinary team and directed to the population in a defined territory, over which the teams assume sanitary responsibility” (BRASIL, 2017).
- VI. **Specialized Health Care:** specialized service provided by SUS to the population, reference services for the establishment of technical standards in urgent and emergency care; hospital; home care, and patient safety. Specialized Care has as its attributions the implementation of

the SUS care regulation policy; the certification of charitable entities that provide complementary services to the public health network, support in the development of innovative mechanisms that strengthen the organization of the System and the capacity of its management in the three spheres of government; the blood and blood products policy; and the policy of people with disabilities.

Art. 3: The guidelines provided for in this Resolution concern the responsibilities and attributions of the Ministry of Health, without prejudice to the States, Municipalities, and the Federal District, safeguarding the powers and autonomy of each federated entity.

## **CHAPTER II COMPREHENSIVE HEALTH CARE FOR PEOPLE WITH ALBINISM**

### **SECTION I STRATEGIC AXES**

Art. 4: The following are strategic axes of the National Policy for Integral Health Care for People with Albinism:

- I. Perform the situational health diagnosis, containing the stratified mapping of all people with albinism in the states and municipalities;
- II. Carry out actions/activities aimed at internal training courses for health professionals focused on people with albinism, considering the specificities of each territory, as well as promoting the insertion of these contents in undergraduate courses in the field of health, and specializations;
- III. Foster and strengthen health actions for the expansion, qualification, and maintenance of care activities aimed at people with albinism;
- IV. Encourage and create actions that enable the sensitization of health professionals, managers, and workers of the SUS, as well as society in general about people with albinism;
- V. Create strategies to expand the care of this population in view of their specific health needs, adapting the work process of the Family Health Teams;
- VI. Create, feed, qualify, and monitor health indicators that include these people;
- VII. Feed, qualify, and monitor information systems considering the need to create specific fields for people with albinism;
- VIII. Map within the territories the good practices of care and attention to people with albinism in order to multiply them to other federated entities giving visibility to this population;
- IX. Promote dialogue with other social policies, civil society organizations, and community leaders to foster intersectoral actions to strengthen and expand the care of people with albinism;
- X. Promote the connectivity of Health Care Networks, seeking the identification of newborns with albinism still in the nursery, and the reception of this family until hospital discharge or natural birth center. Refer them to primary care that will coordinate care and integrate the family in specialized care, as well as make available to the Stork Networks, Psychosocial Care, Chronic, and People with Disabilities, among others, as necessary.

**SECTION II  
GENERAL GUIDELINES**

Art. 5: The general guidelines of the National Policy for Comprehensive Health Care for People with Albinism are:

- I. Organize the line of care for people with albinism, seeking to promote comprehensive care, enunciating actions of promotion, prevention, protection, diagnosis, treatment and rehabilitation, harm reduction, palliative care, and health surveillance;
- II. Incorporate in the permanent education policy issues related to people with albinism with a focus on the specificities of health care;
- III. Promote access to information, guidance, and genetic counseling to family members and people with Albinism regarding this health condition;
- IV. Encourage research in the various areas of scientific technical knowledge about albinism and its specificities in health.

**SECTION III  
OF OBJECTIVES**

Art. 6: The National Policy for Comprehensive Health Care for People with Albinism has the general objective of promoting Comprehensive Care for People with Albinism, and ensuring the prevention and treatment of sequelae resulting from this health condition.

Art. 7: The specific objectives of the National Policy for Comprehensive Health Care for People with Albinism are:

- I. Ensure and prioritize the access of people with albinism in the SUS, articulating the actions of promotion, prevention, protection, diagnosis, treatment and rehabilitation, harm reduction, palliative care, and health surveillance, as recommended in the National Primary Care Policy;
- II. Identify, combat, and prevent situations of human trafficking, abuse, exploitation, and moral harassment, as well as the most diverse types of human rights violations;
- III. Improve the quality of health information systems, through the inclusion of specific fields for the health issues of people with albinism;
- IV. Identify the health particularities of people with albinism considering the transversality inherent to other specific populations, linked to territorial conditions that may aggravate their health condition, such as rural population, forest and waters, quilombola population, indigenous population, among others;
- V. Define and agree, with the three spheres of government, indicators, and goals for the promotion of health equity, considering people with albinism and their specific needs, as well as monitor and evaluate the agreed goals and indicators;
- VI. Draw the epidemiological profile of albinism in Brazil, based on data from Health Care Services, in order to build the Line of Care for People with Albinism, organizing its flow of assistance;
- VII. Qualify health information with regard to data collection, processing, and analysis, considering people with albinism;

- VIII. Establish strategies and actions for planning, monitoring, and evaluating the National Policy for Comprehensive Care for People with Albinism, built in a participatory manner with civil society actors;
- IX. Monitor and evaluate indicators and targets for the health of people with albinism, aiming to reduce macro-regional, regional, municipal, and state inequities;
- X. Encourage and guarantee, while still in the maternity hospital and other locations, the health care of the newborn, observing the health specificities arising from albinism.
- XI. Ensure access to dermatological care, supplies and medicines, therapies, and other adjuvant treatments, essential for the prevention and treatment of sequelae resulting from Albinism.
- XII. Ensure access to specialized ophthalmic care, as well as assistive technology resources (optical and non-optical equipment), as adjuvants in the treatment of low vision.
- XIII. Promote access to information, guidance and genetic counseling for family members and people with Albinism.

#### **SECTION IV THE SKILLS**

Art. 8: The Ministry of Health is responsible for:

- I. Encouraging and ensure the implementation of the National Policy for Comprehensive Health Care for People with Albinism;
- II. Strengthen comprehensive health care for people with albinism at all stages of life cycles, considering the specific needs of children, young people, adolescents, adults, and the elderly;
- III. Promote the inclusion of this Policy in the National Health Plan, in line with local and regional realities, and in the Multiannual Plan (PPA), when it involves expenses related to programs of continuous duration, pursuant to §1 of article 165 of the Federal Constitution of 1988;
- IV. Foster, define, and manage the budgetary and financial resources for the implementation of this Policy, agreed in the Tripartite Intermanagerial Commission (CIT);
- V. Consolidate, analyze, and disseminate stratified data on people with albinism, considering their specificities and insert health information into the system under the responsibility of the Ministry of Health;
- VI. Coordinate, monitor, and evaluate the implementation of the National Policy for Comprehensive Health Care for People with Albinism at the federal level;
- VII. Encourage the insertion of people with albinism in the information systems of the Ministry of Health, as well as articulate with other partners the inclusion of these people in other national databases;
- VIII. Establish instruments and indicators for follow-up, monitoring, and evaluation of the National Policy for Comprehensive Health Care for People with Albinism;
- IX. Encourage and support health education and promotion actions for managers, health professionals, users, and other social actors, focused on the health specificities of people with albinism;
- X. Encourage the participation of people with albinism in Health Councils;
- XI. Create and implement the National Technical Committee for Integral Health of people with albinism;
- XII. Establish mechanisms to promote the production of knowledge on the health issues of people with albinism;

- XIII. Develop and publish information, communication, and continuing education materials on the Comprehensive Health of People with Albinism;
- XIV. Promote technical and financial support for the implementation of this Policy;
- XV. Strengthen partnerships with national, international, governmental, and non-governmental bodies and organized civil society to strengthen and qualify health actions for people with albinism;
- XVI. Encourage studies and research on the access of people with albinism to health services and actions; and
- XVII. Ensure access to essential inputs and medicines for the prevention and treatment of sequelae resulting from albinism, according to the medical protocol;

Art. 9: The state health management is responsible for:

- I. Promote the implementation of the National Policy for Comprehensive Health Care for People with Albinism at the state level;
- II. Foster, define, and manage the budgetary and financial resources for the implementation of this Policy, agreed upon in the Tripartite Intermanagerial Commission (CIT);
- III. Promote the inclusion of this Policy in the National Health Plan, in line with local and regional realities, and the Multiannual Plan (PPA), when it involves expenses related to programs of continuous duration, pursuant to §1 of article 165 of the Federal Constitution of 1988;
- IV. Coordinate, monitor, and evaluate the implementation of the National Policy for Comprehensive Health Care for People with Albinism at the federal level;
- V. Identify the health needs of this population at the state level and technical and financial cooperation with the Municipalities, so that they can do the same, considering the opportunities and resources;
- VI. Establish instruments and indicators for follow-up, monitoring, and evaluation of the National Policy for Comprehensive Health Care for People with Albinism;
- VII. Encourage the creation of spaces (committees, technical areas, working groups, among others) to promote equity for the implementation of the National Policy for Comprehensive Health Care for People with Albinism in a participatory manner;
- VIII. Develop and support permanent education actions for health workers, focused on the health specificities of people with albinism;
- IX. Stimulate and strengthen the representation of people with albinism in State and Municipal Health Councils and Health Conferences;
- X. Support the implementation of municipal instances to promote health equity for people with albinism;
- XI. Establish mechanisms to promote the production of knowledge on the health issues of people with albinism;
- XII. Adopt dissemination actions, aiming at the socialization of information and health actions for the promotion of the integral health of people with albinism;
- XIII. Provide support and technical cooperation to municipalities and enable partnerships in the public and private sector to strengthen health actions for people with albinism;
- XIV. Foster intersectoral articulation, including partnerships with governmental and non-governmental institutions, with a view to contributing to the process of implementing this Policy;

- XV. Encourage and participate in the preparation of Municipal Plans for the promotion and protection of the health of people with albinism;
- XVI. Encourage the participation of civil society representing patients and family members, in the instances of social participation of the SUS, aiming at the social control of the Policy;
- XVII. Strengthen and prioritize assistance, and support for the diagnosis of people with albinism, as well as the integrality of the points of care of the HCN, especially in Primary Care and Specialized Health Care, through the articulation of actions and procedures with a view to transversality and equity in health;
- XVIII. Draw the epidemiological profile of people with albinism in the State, based on data from the Municipal Assistance Services, as well as carry out and keep updated the registration of people diagnosed and treated in the HCN, enabling the improvement of planning and meeting the needs of this population at the local level;

Art. 10: The municipal health management is responsible for:

- I. Promoting the implementation of the National Policy for Comprehensive Health Care for People with Albinism at the state level;
- II. Strengthen and prioritize Primary Health Care, as well as its essential and derivative attributes, considering the integral health care of people with albinism, as well as training municipal managers and health professionals in improving the work process regarding the care of this population;
- III. Foster, define, and manage the budgetary and financial resources for the implementation of this Policy, agreed in the Tripartite Intermanagerial Commission (CIT);
- IV. Promote the inclusion of this Policy in the Municipal Health Plan, in line with local realities and needs, and the Pluriannual Plan - sectorial PPA, when it involves expenses related to programs of continuous duration, pursuant to § 1 of art. 165 of the Constitution;
- V. Coordinate, monitor, and evaluate the implementation of the National Policy for Comprehensive Health Care for People with Albinism at the federal level;
- VI. Identify the health needs of this population at the municipal level, considering the opportunities and resources;
- VII. Establish instruments and indicators for monitoring, monitoring, and evaluation of the National Policy for Comprehensive Health Care for People with Albinism;
- VIII. Encourage the creation of spaces (committees, technical areas, working groups, among others) to promote equity for the implementation of the National Policy for Comprehensive Health Care for People with Albinism in a participatory manner;
- IX. Develop and support permanent education actions for health workers, focused on the health specificities of people with albinism;
- X. Stimulate and strengthen the representation of people with albinism in State and Municipal Health Councils and Health Conferences;
- XI. Implement and/or implement municipal instances to promote equity in the health of people with albinism;
- XII. Establish mechanisms to promote the production of knowledge on the health issues of people with albinism;
- XIII. Adopt dissemination actions, aiming at the socialization of information and health actions for the promotion of the integral health of people with albinism;



- XIV. Enable partnerships in the public and private sector to strengthen health actions for people with albinism;
- XV. Foster intersectoral articulation, including partnerships with governmental and non-governmental institutions, with a view to contributing to the process of implementing this Policy;
- XVI. Elaborate Municipal Plans for the promotion and protection of the health of people with albinism;
- XVII. Encourage the participation of civil society representing patients and family members, in the instances of social participation of the SUS, aiming at the social control of the Policy;
- XVIII. Strengthen and prioritize assistance, and support for diagnosis of people with albinism, as well as the integrality of the points of care of the HCN, especially in Primary Care and Specialized Health Care, through the articulation of actions and procedures with a view to transversality and equity in health;
- XIX. Draw the epidemiological profile of people with albinism in the State, based on data from the Municipal Assistance Services, as well as carry out and keep updated the registration of people diagnosed and treated in the HCN, enabling the improvement of planning and meeting the needs of this population at the local level;

## SECTION V

### ORGANIZATION OF ACCESS AND INTEGRALITY OF CARE IN HEALTH CARE NETWORKS

Art. 11: The organization of access to and comprehensiveness of care in Health Care Networks must adhere to the following actions:

- I. Qualify health professionals working in the Family Health Teams in their various modalities (eSF, eAP, eSB, eCR, eSFR, and others) regarding albinism to promote the access of these people to Basic Health Units, reducing structural and attitudinal barriers;
- II. Accompany pregnant and postpartum women, signaling the possibility of the child being born with albinism, advising on early care to be taken;
- III. Encourage the performance of Neonatal Screening (heel prick test, ear prick test, eye prick test, and heart prick test), promoting the prevention of signs of albinism in early childhood, initiating skin, eye care, and vitamin D replacement;
- IV. Foster the integrality and priority of health care for children with albinism, enabling planned care by their professionals/reference services, together with the family, in which the child's therapeutic path is thought of, with the necessary assistance flows for their treatment previously articulated by them so that the family does not need to travel through the health system in search of the necessary care (exams, procedures, specialized therapies, among others);
- V. In the care of children and adolescents with albinism, pay attention to issues associated with family and community life, observing their mental health to prevent prejudice, violence, bullying, and any other forms of discrimination;
- VI. Carry out an active search and diversification of means for the provision of services for adolescents with albinism, to guarantee their access to PHC;

- VII. Qualify professionals working in the School Health Program (PSE) to promote health education actions for managers, teachers, students, and the community regarding albinism and the impact of their specific health needs on educational, social, and civil aspects;
- VIII. Enable access of people with albinism to the Psychosocial Care Network (RAPs) for the treatment of mental health issues;
- IX. Schedule the care of people with albinism at alternative times to the sun, in view of their extreme sensitivity to ultraviolet rays and heat (in the morning and/or at the end of the day);
- X. Guide, advise, and offer safe and appropriate physical activity practices for people with albinism, considering their specific needs;
- XI. Encourage the care related to the dietary health of people with albinism to resolve the impact of the low level of vitamin D, Calcium, Zinc, and other nutritional weaknesses resulting from this health condition;
- XII. Foster health education strategies on albinism and the specific needs of this population segment through actions in waiting rooms, in specific groups aimed at all life cycles within the territories;
- XIII. Promote care related to the sexual health and reproductive health of people with albinism, providing all necessary guidance, without discrimination for this health condition;
- XIV. Strengthen immunization actions of people with albinism, in view of vitamin D deficiency in this population, directly associated with the low immunity of the body;
- XV. Sensitize oral health teams regarding the impacts caused by the absence of vitamin D in dental care, as well as issues related to oral cancer and other oral diseases.

Single Paragraph. The actions listed above are guiding and can be complemented according to the reality and health needs of each territory.

### **CHAPTER III**

#### **HEALTH AND INTERSECTORIALITY**

Art. 12: The Federal Government, the States, the Municipalities, and the Federal District, respecting their spheres of competence, shall:

- I. Carry out intersectoral actions, as a way to strengthen and promote the implementation of the National Policy for Comprehensive Health Care for People with Albinism in a transversal and integrated way, composing commitments and co-responsibilities to reduce inequities and face the social determinants that unequally affect the health of this population.
- II. Foster intersectoral articulation between health and the areas of:
  - a. Education
  - b. social assistance
  - c. Culture
  - d. Agriculture
  - e. Works and housing
  - f. Environmental
  - g. Infrastructure
  - h. Justice

- i. Citizenship
- j. Human Rights
- k. Public Security
- l. Sports and Recreation
- m. Labor

Art. 13: The intersectoral and network articulation can consider other co-responsible sectors, paying attention to the needs presented by people with albinism, the objectives of the actions to be developed, and the conditions of the territories, among other variables, aiming at integral care to contribute to overcoming conditions that generate inequity and resulting sequelae.

#### **CHAPTER IV MONITORING AND EVALUATION**

Art. 14: The monitoring and evaluation of the implementation and implementation of the National Policy for Comprehensive Health Care for People with Albinism must be carried out through official health information systems and other monitoring instruments, and must:

- I. Establish instruments and indicators for control, monitoring, and evaluation of the National Policy for Comprehensive Health Care for People with Albinism;
- II. Define strategies for articulation with the State, Municipal, and Federal District management with a view to institutionalizing the monitoring and evaluation of the National Policy for Integral Health Care for People with Albinism;
- III. Qualify a decentralized and participatory management of the SUS, for the monitoring of the National Policy for Integral Health Care for People with Albinism;
- IV. Strengthen and expand the monitoring and evaluation of the National Policy for Comprehensive Health Care for People with Albinism in the states, municipalities and Federal District.

Art. 15: This Resolution shall enter into force on the date of its publication.