NATIONAL POLICY ON ALBINISM IN NIGERIA

FEDERAL MINISTRY OF EDUCATION
2019
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2019
The National Policy on Albinism in Nigeria is in response to the numerous challenges encountered by Persons with Albinism (PWAs). In Nigeria, the socio-cultural system with its inherent myths and beliefs has put PWAs at a low stratum in all spheres of life. PWAs experience psychological challenges due to stigmatisation, discrimination and segregation.

This policy is intended to improve the status of PWAs by harnessing their full potentials and guaranteeing equal access to education, social, health, economic and political opportunities. It is multi-sectorial and provides a holistic approach to improving the standard of life of PWAs. The Policy is aimed at mainstreaming Albinism into every sector of development in Nigeria. Based on the issues stated above, the rights of persons in this group cannot be disregarded. It is hoped that effective implementation of this policy and its guidelines will guarantee improved conditions of life for PWAs.

The review of this policy became necessary in view of the following:

- Life span of the policy, which was to be reviewed after every five (5) years, having been developed and approved in 2013;
- Assent of the Disability Act by His Excellency, President Muhammadu Buhari GCFC;
- The merging of the National Policy on Albinism and the Implementation guidelines into a single document;
- Inclusion of Persons with Disabilities in the Electoral process;
- United Nations and African Union approval of Regional Action Plan on Albinism in Africa, with a view to mainstreaming Albinism into African States' policies and programmes;
- Inclusion of Albinism as a human right issue;
- Closing the gap on issues relating to Albinism and Disability; and
- Other emerging issues

I hereby endorse the National Policy on Albinism and urge all stakeholders to support and join in its implementation.

Malam Adamu Adamu
Honourable Minister of Education
The Federal Government has taken keen interest in Albinism and the challenges faced by PWAs in terms of their skin problems, vision, low self-esteem, myths, discrimination and stigmatisation. According to the Knowledge, Attitude and Practices (KAP) research documented by UNICEF (2011), the population of PWAS in Nigeria is estimated at about six million, out of which 40% are children.

To mitigate the learning challenges faced by PWAs and create educational access, a Blueprint on Albinism Education in Nigeria was developed by the Federal Ministry of Education. Consequently, the need for a more encompassing policy that will address the multi-faceted needs of Persons with Albinism became imperative.

In 2012, a Ministerial Committee was set up by the then Honourable Minister of State for Education, Chief (Barr.) Ezenwo Nyesom Wike, to develop a National Policy on Albinism. The multifarious committee comprised of representatives from the Federal Ministries of Education, Health, Women Affairs and Social Development, Justice, Finance, Labour and Employment, Budget and National Planning; other agencies and organisations namely: Office of the Head of the Civil Service of the Federation, National Population Commission (NPopC), National Human Right Commission (NHRC), Nigerian Educational Research & Development Council (NERDC), Universal Basic Education Commission (UBEC), National Orientation Agency (NOA), National Agency for Mass Literacy, Adult and Non-Formal Education (NMEC), Civil Society Action Coalition on Education for All (CSACEFA), Federal Capital Territory Administration Education Secretariat and The Albino Foundation (TAF).

The policy and its implementation guidelines will greatly improve the cultural, political and socio-economic well-being of PWAS, thereby giving them the opportunity to be useful to themselves and contribute their quota to national development.

Arc. Sonny S.T. Echono, fcia,
Permanent Secretary,
Federal Ministry of Education
The Federal Ministry of Education wishes to acknowledge the immense contributions of Ministries, Departments and Agencies (MDAs), namely: Health, Women Affairs and Social Development, Justice, Finance, Labour and Employment, Budget and National Planning, Office of the Head of the Civil Service of the Federation, National Population Commission (NPopC), National Human Right Commission (NHRC), Universal Basic Education Commission (UBEC), National Orientation Agency (NOA), National Agency for Mass Literacy, Adult and Non-Formal Education (NMEC), Nigerian Educational Research & Development Council (NERDC), Civil Society Action Coalition on Education for All (CSACEFA), Education Sector Support Programme in Nigeria (ESSPIN), Federal Capital Territory Administration Education Secretariat and The Albino Foundation (TAF) for their support and participation in the development of the National Policy on Albinism in Nigeria. This is to ensure that PWAS are mainstreamed into government Policies and Programmes.

We are grateful to the Development Partners especially the European Union (EU), African Union (AU), United Nations Children Education Fund (UNICEF) and German Government for their technical and financial Support. Finally, we also thank all the people that have assisted in the realisation of this policy.

Dr. Lami Amodu, fnim, fcipdm, fimc
Director, Basic and Secondary Education
Federal Ministry of Education
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<td>AIT</td>
<td>African Independent Television</td>
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<td>Nigerian Television Authority</td>
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<td>NTI</td>
<td>National Teachers Institute</td>
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NUC - National Universities Commission
OC (OA) - Ocular Albinism
OC (OCA) - Oculocutaneous Albinism
OHCSF - Office of The Head Of The Civil Service Of The Federation
PS - Private Sector
PWAs - Persons With Albinism
SMoE - State Ministries of Education
SNE - Special Needs Education
SUBEB - State Universal Basic Education Board
TAF - The Albino Foundation
TANA - The Albino Network Association
TETFUND - Tertiary Education Trust Fund
UBEC - Universal Basic Education Commission
UNESCO - United Nations Educational, Scientific and Cultural Organization
UNICEF - United Nations Children Education Funds
USAID - United States Agency for International Development
WAEC - West African Examinations Council
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The policy provides an informed perspective on the signs and symptoms, types, causes, incidences and risk factors faced by PWAs. It presents a situation analysis on the management, education, health, socio-cultural, Albinism rights and economic status of Nigerians with Albinism.

The policy framework captures the vision, mission, objectives, targets and expected outcomes. Implementation guidelines are also spelt out in details to include management and sustainability, functions and responsibilities of stakeholders, research, monitoring and evaluation. The institutional structure provides the framework for the establishment of key institutions that will address the social and health issues related to the state of Persons with Albinism and Hypo-pigmentation.

Funding and Resource Mobilisation spelt out the financial responsibilities of Federal, State, Local governments and other relevant stakeholders required to provide funds as support for the implementation of activities and programmes that will further advance the cause of PWAs.
1.1 BACKGROUND

Albinism is a global phenomenon that affects all race and gender. Persons with Albinism exist across all strata of humanity, and the internationally acclaimed common term used for persons affected with albinism is “Persons with Albinism” (PWAs).

PWAs have absence or reduced pigment in their eyes, skin or hair. This is as a result of the absence of a pigment called melanin which is essential for the full development of the retina. Lack of melanin in the development of the retina is the primary cause of visual impairment in PWAs. The general health of a child and an adult with Albinism is normal and the reduction in melanin pigment in the skin, hair and eyes does not affect the brain, the cardiovascular systems of the lungs, immune system or other parts of the body.

Albinism has no respect for colour of the skin, race, king, slave and age or sex. Necessary steps need to be taken to enhance the learning process of PWAs. The classroom teachers or literacy facilitators should appreciate the problems of pupils, students and adult learners with Albinism so as to be able to manage those challenges facing them in their learning situations.

Discriminatory socio-cultural myths and negative beliefs still permeate society’s perspectives and understanding about Albinism. Most of the prevailing knowledge of the larger society about Albinism is hinged on these socio-cultural myths and beliefs. The social inclusion, political engagement, security awareness and economic participation have become vital because the majority of them are poor, uninformed, uneducated and without any viable source of income. Specific areas of their lives require both governmental and societal intervention.

Human right violations against PWAs are continually being committed unhindered across the length and breadth of Nigeria. The right of the PWAs must be respected and protected. The need to secure the social-economic rights of PWAs will positively bridge the socio-economic gap that currently exists between them and other members of the society. This will provide the much needed balance that they require to positively exert their humanity, and integration into mainstream society.
1.2 CLINICAL DEFINITION

It is a congenital disorder characterised by complete or partial absence of pigment (melanin) in the hair, skin and eyes due to absence or defect of tyrosinase, a copper containing enzyme involved in the production of melanin. It can also be defined as a genetic condition that occurs as a result of reduction or absence of the production of pigment called Melanin (the pigment that protects the skin, eye and hair condition).

1.3 SIGNS AND SYMPTOMS

1.3.1 The signs and symptoms of albinism include:

i. Absence of colour in the hair, skin and iris;
ii. Lighter than normal skin and hair colour;
iii. Strabismus – crossed eyes;
iv. Photophobia – light sensitivity;
v. Nystagmus – involuntary rapid eye movement;
vi. Visual problems – functional blindness in infants and adults;
vii. High Refractive Errors- inability to focus clear images on the retina;
viii. Optic nerve hypoplasia;
ix. Foveal hypoplasia – underdeveloped fovea (part of the retina);
x. Inability to see clearly thereby requiring large print magnifiers; and
xi. Absence or decreased pigment in the eye.

1.4 TYPES OF ALBINISM

There are two (2) types of albinism which include:

i. Ocular (i.e. eyes); and
ii. Oculocutaneous (i.e. hair, skin and eyes)

The sub-types of albinism include:

OCA1: is due to a defect in the tyrosinase enzymes. There are two subtypes of OCA1.

OCA1a: People with OCA1a have a complete absence of melanin, the pigment that gives skin, eyes, and hair their colouring. People with this subtype have white hair, very pale skin, and light eyes.
OCA1b: People with OCA1b produce some melanin. They have light-coloured skin, hair and eyes. Their colouring may increase as they age.

OCA2: This type is less severe than OCA1. It is due to a defect in the OCA2 gene that results in reduced melanin production. People with OCA2 are born with light colouring skin, and their hair may be yellow, blond or light brown. OCA2 is most common in sub-Saharan Africans, African Americans and Native Americans.

OCA3: OCA3 is a defect in the TYRP1 gene. It usually affects dark-skinned people, particularly black South Africans. People with OCA3 have reddish-brown skin, reddish hair and hazel or brown eyes.

OCA4: OCA4 is due to a defect in the SLC45A2 protein. It results in a minimal production of melanin and commonly appears in people of East Asian descent. People with OCA4 have symptoms similar to those in people with OCA2.

Other rare forms of Albinism include:

i. Hermansky-Pudlak Syndrome (HPS): is a type of Albinism involving bleeding disorders, bruising, lung problem and intestinal disorder.

ii. ChediakHigashi Syndrome: it is characterised by abnormality in certain types of white blood cells lowering resistance to infection.

iii. Waardenburg Syndrome (WS): is an inherited disorder often characterised by varying degrees of hearing loss and changes in skin and hair pigmentation.

iv. Griscelli Syndrome: is an extremely rare type of Albinism. There are sixty (60) known cases worldwide. It involves immune deficiency and may also have neurological problems.

1.5 CAUSES AND RISK FACTORS

The gene that carries Albinism is a recessive gene or a gene that is not dominant. The recessive gene for albinism become expressed only when two (2) parents carrying the recessive gene pass them to the child.
The risk factors include:

i. Decreased vision;
ii. Blindness; and
iii. Skin cancer.

1.6 MANAGEMENT

Management goal is to relieve symptoms depending on severity and protect the skin and eyes from the sun to reduce complications. PWAs can manage their condition and live active life by:

i. Protecting the skin and eyes from the sun to reduce complications;
ii. Reducing exposure to sunburn by wearing long sleeved clothing, trousers and wide hats;
iii. Applying Sunscreen which should have a high Sun Protection Factor (SPF) – 50 and above. Sunglasses (UV Protected) may relieve light sensitivity;
iv. Wearing prescription lenses to manage vision problems and eye protection;
v. Eye muscle surgery to correct nystagmus (abnormal movement);
vi. People with family history of albinism or hypo-pigmentation may consider genetic counselling especially before marriage; and
vii. Undergo genome profile testing.

1.7 SOCIO-CULTURAL IMPACTS OF ALBINISM

Albinism is a peculiar condition with health, social, psychological, cultural, economic and religious implications. It is pertinent to note that PWAs often face stigmatization, discrimination, segregation, rejection, low vision, skin cancer and killing for ritual purposes. This is as a result of some misconceptions about them. Cultures around the world have developed myths and superstitions regarding PWAs. Among these myths are:

i. That persons with albinism are sterile;
ii. Albinism is contagious;
iii. A child with Albinism has a slim chance of making it in life;
iv. PWAs have magical powers and as such their body parts could be used as concoctions to bring wealth etc.;
v. The presence of a PWAs in a family is a curse;  
vi. Having sexual intercourse with PWAs can cure HIV/AIDS; and  
vii. Albinism is a punishment from the gods or the ancestors for something wrong done by the parents.

PWAs are not respected in society, they face ridicule, discrimination and violence. They are often forced to operate in isolation due to negative mind-sets and attitudes of those around them. These social stigmas have lots of negative impact on PWAs which include:

i. Parents do not like to invest on a child with Albinism;  
ii. They are often ridiculed, victimized, ostracized and often drop out of school or develop withdrawal syndromes;  
iii. Many people avoid marrying PWAs; and  
iv. They are subjected to serious and extreme economic and social discrimination and are poor because they are unable to engage in meaningful economic activities.

1.8 ALBINISM RIGHTS

Every human being has rights, duties and responsibilities, which are provided for in National, Regional and International Instruments. These rights are contained in the 1999 Constitution of the Federal Republic of Nigeria as amended, particularly Chapter iv and are known as Fundamental Human Rights. Human Rights are equally applicable to all irrespective of race, colour, nationality, age, sex, religion, status and other differentiating attributes. PWAs are human beings and they are entitled to enjoy all Human Rights and freedoms without discrimination of any kind. When they suffer discrimination, violations and abuses, the human race suffers too. The promotion and protection of Human Rights in Africa is underpinned by the African Charter on Human and Peoples Rights (ACHPR), which provides for both civil and political rights as well as economic, social and cultural rights and the ACHPR was domesticated in Nigeria in 2004. Some of the rights are listed as follows:

i. Right to life;  
ii. Right to dignity of human person;  
iii. Right to personal liberty;  
iv. Right to fair hearing;  
v. Right to private and family life;  
vi. Right to freedom of thought, conscience and religion;  
vii. Right to freedom of expression and the press;
viii. Right to peaceful assembly and association;  
ix. Right to freedom of movement; and  
x. Right to freedom from discrimination;  

Other rights include:  
i. Right to health;  
ii. Right to education;  
iii. Right to meaningful employment;  
iv. Right to safety;  
v. Right to vote and be voted for etc.  

1.9 HUMAN RIGHTS INSTRUMENTS  

The promotion and protection of Human Rights are guaranteed by National, Regional and International Instruments such as.  
i. United Nations Universal Declaration of Human Rights, 1948;  
ii. International Covenant on Civil and Political Rights (ICCPR), 1966;  
iii. International Covenant on Economic, Social and Cultural Rights, 1966;  
iv. United Nations Conventions on the Rights of Persons with Disabilities;  
vii. The Protocol to the African Charter on Human and peoples' Rights on the Rights of Women in Africa (Maputo Protocol);  
viii. The Constitution of the Federal Republic of Nigeria; and  
ix. National Disability Act, 2019  

This policy shall:  
i. Give PWAs a sense of belonging;  
ii. Promote self-esteem and image;  
iii. Ensure the recognition of their potentials;  
iv. Enable PWAs develop maximally and contribute to national development;  
v. Promote access to education, health, employment, social rights and justice;  
vi. Protect Fundamental Human Rights and promote freedom
from stigmatisation, prejudices and stereotype;

vii. Increase awareness and mobilise support on issues concerning albinism; and

viii. Promote inclusiveness.

1.10 SITUATION OF ALBINISM IN NIGERIA

According to the Knowledge, Attitude and Practices (KAP) research documented by UNICEF (2011), the population of PWAs in Nigeria is estimated at about six (6) million, out of which 40% are children. This shows that Nigeria has a high prevalence rate. This notwithstanding, children with albinism are among the most vulnerable children in Nigeria. The unkind and rejecting attitudes of members of the society make it difficult for PWAs to deal with reality. The widespread ignorance about albinism among families and communities prevent most of them from sending their children to school or to develop their potentials.

Children with albinism are often bullied by peers; as a result, they lack assertiveness and self-confidence. Due to their visual challenges, they are often frustrated out of school. Also, exposure to the sun poses a health hazard which is oblivious to those around them. These issues prevent them from having full social or economic tools to live productive lives.

The Federal Government of Nigeria is making a concerted effort to address the numerous challenges of albinism. At the 57th National Council on Education (NCE) in Sokoto, 2010, a committee was set up to develop a Blueprint on Albinism Education in Nigeria. Sequel to this, the Blueprint was approved at the 58th National Council on Education held in FCT Abuja, 2011. May 5th was also approved as National Albinism Day to be observed annually. In line with Article 24 (Education) of the United Nations Convention on the Rights of persons with disability and Optional Protocol, approved and granted PWAs the “time and a half” concept (that is, a double and half of the original time) during examinations for all educational bodies.

The foregoing has culminated in the development of a National Policy on Albinism, which is geared towards mainstreaming Albinism into Nigerian society.
1.11 JUSTIFICATION

The plight of PWASs to live a healthy life should be properly addressed. Albinism is a peculiar condition with educational, health, social, psychological, cultural, economic and religious implications. It is painful to note that some PWAs lack the necessary support and care to manage their condition. Both the individuals and the country suffer, as skills of PWAs are not effectively utilised.

The high prevalence rate of Albinism in Nigeria and the inclusion of PWAs among vulnerable groups in the society necessitated the development of this Policy to address their peculiar needs and challenges. There is need for data bank and regular generation of comparable and applicable data on PWAs for purposes of planning, implementation, monitoring and evaluation, as well as advocacy and sensitisation.

This policy is not oblivious of the widespread societal misconception of PWAs phenomenon in Nigeria and most parts of Africa, which informed the policy imperatives to zero down on the socio-cultural impacts of Albinism and all that need to be done as a first step, to change the negative societal perception of PWAs. Such understanding is key to addressing all other existing and emerging problems confronting PWAs.

The review of this policy became necessary in view of the following:

i. Life span of the policy, which was to be reviewed after every five (5) years, having been developed and approved in 2013;

ii. Assent of the Disability Act by His Excellency, President Muhammadu Buhari GCFR;

iii. The merging of the National Policy on Albinism and the Implementation guidelines into a single document;

iv. Inclusion of Persons with Disabilities in the Electoral process;

v. Approval of the United Nations and African Union Regional Action Plan on Albinism in Africa, with a view to mainstreaming Albinism into African States' policies and programmes;

vi. Inclusion of Albinism as a Human Right issue;

vii. Closing the gap on issues relating to albinism and disability; and

viii. Other emerging issues.
2.1 POLICY FRAMEWORK

The National Policy on Albinism takes particular cognizance of the various challenges of PWAs which cut across the four (4) core clusters of Fundamental Human Rights to survival, protection, development and participation in the general sphere of human endeavours. This Policy fully engages relevant Government Ministries, Departments and Agencies, the private sector, media, Civil Society Organizations and the development partners to intervene in activities and programmes that will maximally impact on the lives of PWAs. Examples of such activities and programmes are advocacy and sensitization, policy formulations and reviews, empowerment and capacity building.

It is against this background that the Vision, Mission, Core objectives, Policy targets and outcomes, implementation strategies are carefully articulated herein. This Policy also provides for the protection of the rights of PWAs, the roles and responsibilities of Government and other stakeholders.

2.2 VISION

An inclusive society where PWAs are given equal opportunity to develop their full potentials.

2.3 MISSION

To create awareness, strengthen advocacy and sensitization and empower PWAS to live a meaningful and independent life.

2.4 POLICY OBJECTIVES

i. To create broad based awareness, advocacy and sensitization on Albinism in the society;

ii. To protect and promote the Fundamental Human Rights of PWAs;

iii. To secure institutional participation, interventions and partnerships in addressing the needs and challenges of PWAs;

iv. To encourage and promote the establishment of economic life-skills training and empowerment programmes for PWAs;

v. To encourage institutions in public and private sectors to
promote research and data collection, analysis and dissemination on Albinism;

vi. To facilitate access to free skin cancer treatment for PWAs in Nigeria;

vii. To facilitate access to free eye and skin care services for PWAs in Nigeria; and

viii. To close the gap between Albinism and Disability.

2.5 POLICY TARGETS AND OUTCOMES

i. To achieve 60% progressive level of awareness and sensitization against socio-cultural discrimination, stigmatization and other negative perceptions against PWAs in Nigeria by 2025;

ii. To achieve 70% improvement in accessing free and qualitative health and social services for PWAs by 2025;

iii. To achieve 70% improvement in the learning conditions of PWAs in educational and other development institutions by 2025;

iv. To achieve 80% equal access to justice and freedom from discrimination for PWAs on basic rights and violations by 2025;

v. To achieve 90% level of institutional participation, intervention and partnerships in addressing the challenges and needs of PWAs in Nigeria by 2025;

vi. To achieve 70% level of institutional support and promotion on relevant research and database on PWAs in Nigeria by 2025;

vii. To ensure the establishment of Albinism Entrepreneurship and Innovative Centres (Skills Acquisition Centres) in Nigeria by 2025;

viii. To achieve 20% inclusion of Albinism issues in all sectors of the economy by 2025; and

ix. To ensure 60% electoral and political participation of PWAs by 2025.

2.6 GUIDING PRINCIPLES

The implementation of the National Policy on Albinism is based on the Constitution of the Federal Republic of Nigeria and existing policies, specifically, the National Policy on Education.

2.6.1 Principle 1: Education Plan

i. Establish more inclusive schools and equip them with visual
and other learning aids for PWASs across the Federation;

ii. Strengthen linkages and partnerships with NGOs, Private Sector and Development Partners to promote the education of PWAs;

iii. Government at all levels shall implement extra time of a double and half of the original time in accordance with the 58th NCE granted to PWAs in all examinations in the country;

iv. Teachers and students shall be provided with counselling services on the need to exempt PWAs from outdoor activities/corporal punishment under scorching sun;

v. Training and re-training of teachers, parents, health workers and other caregivers shall be encouraged to manage PWAs at all levels;

vi. Stakeholders at all levels of education shall replace black boards with modern instructional materials such as white boards, interactive boards, projectors, computers, and web resources in line with 61st NCE decisions;

vii. Curriculum on Albinism shall be developed by NERDC in collaboration with other stakeholders and the stand alone curriculum infused into career subjects of the present Basic Education curriculum;

viii. Qualified PWAs shall be employed where vacancy exists in all walks of life; and

ix. PWAs should sit in front rows in class, provided with note taker, recorder and photocopied materials in bold prints should be encouraged.

2.6.2 Principle 2: Health Plan

i. Provide free treatment centres for PWAs to test and treat skin cancer at all levels;

ii. Provide basic health information for prevention of eye and skin health issues related to Albinism at all levels;

iii. Private Sector, Civil Society Organizations and Development Partners to promote and support research on Albinism and Hypo-pigmentation; and

iv. Integrate health challenges of Albinism into existing national health care platform.
2.6.3 Principle 3: Socio-Cultural Plan

i. Increase awareness and sensitization using mass media and traditional methods of disseminating information to mitigate the myths and misconceptions associated with PWAs;

ii. Embark on community mobilisation to promote the self-esteem and image of PWAs;

iii. Sensitize the community to promote freedom from stigmatization, prejudice and stereotype of PWAs;

iv. Promote social integration for PWAs and their families in all sectors of the society;

v. Government shall promote inclusiveness in all ramifications of the society;

vi. Sensitize and advocate to government, policy planners, learners, parents, teachers and communities on the challenges of Albinism and its effects on the general well-being of PWAs; and

vii. Promote role models for PWAs especially children to give them a sense of belonging in the society.

2.6.4 Principle 4: Economic Plan

i. Provide viable career options for PWAs that will not expose them to health hazards;

ii. Government shall carry out enlightenment campaigns to educate the public that PWAs have the same potentials to contribute to the socio-economic well-being of the nation;

iii. Employment slots shall be given to PWAs in all walks of life; and

iv. Encourage and promote the establishment of economic life-skills, training and empowerment programmes for PWAs to contribute to the society.
3.1 INSTITUTIONAL STRUCTURE FOR ALBINISM IN NIGERIA

The Institutional Structure for Albinism is to ensure the inclusion of Albinism in the National Disability Commission as established by the Disability Act. A person with albinism should be a member of the board of the Disability Commission. A Department shall be created within the Commission to cater for Albinism, which will be headed by a Director. The Commission will facilitate the establishment of an Albinism Centre, which will be responsible for the following services:

i. Provide best possible clinical care for individuals with known or suspected diagnosis of Albinism and Hypo-pigmentation cases;

ii. Provide counselling and support for individuals with Albinism and their families;

iii. Conduct research to better understand the multiple aspects of Albinism and Hypo-pigmentation; and

iv. Educate the public on Albinism and Hypo-pigmentation through advocacy and sensitisation.

3.2 THE NATIONAL ALBINISM CENTRE

The National Albinism Centre shall partner with The Albino Foundation, other albinism focus groups, CSOs and other relevant agencies of government to address the educational, social and health issues directly related to the state of PWAs and Hypo-pigmentation in Nigeria. The National Albinism Centre shall be situated in the Federal Capital Territory, Abuja, with regional sub-centres located across the six geopolitical zones of the country. Each sub-centre shall be equipped to replicate and make available to the public the quality of services available at the Centre.

The Centre shall focus on the following areas:

i. Social and Clinical Research: This arm of the Centre shall be responsible for all research activities into areas impacting on Albinism and Hypo-pigmentation;
ii. Treatment Clinics: The clinics shall be equipped with the state-of-the-art medical equipment and administrative capacity to provide specialised and subsidized health services to PWAs and those afflicted with Hypo-pigmentation issues. The clinics shall include an eye clinic, skin clinic and a state-of-the-art clinical test centre;

iii. Empowerment Department: Shall be responsible for the empowerment of PWAs economically through vocational skills that will ensure they live productive lives;

iv. Hospice Services: The Centre shall also be equipped to provide counselling services to PWAs with specific regards to educational, social and health issues. This is with a view to providing a platform for the rehabilitation of people who have been socially discriminated as a result of their Albinism condition.
SECTION 4

NATIONAL POLICY ON ALBINISM IN NIGERIA

FEDERAL MINISTRY OF EDUCATION
2019
4.1 IMPLEMENTATION STRATEGIES

4.1.1 Legal
i. Effective law enforcement shall be put in place in response to attacks and violations against PWAs; and
ii. Orientate and empower appropriate agencies, institutions and bodies to ensure that the Fundamental Human Rights of PWAs are effectively protected and enforced.

4.1.2 Education
i. Provide visual and other learning aids for PWAs through Special Needs Education Branch at Federal, State and Local government levels;
ii. Support school Counsellors and teachers in their duties of counselling and guiding students on the Albinism phenomenon in Basic, Secondary and Tertiary Institutions;
iii. Increased advocacy and broad-based awareness and sensitization by the media, Ministries, Departments and Agencies, private sector and other stakeholders against negative societal perceptions of Albinism; and
iv. Train and re-train teachers, parents, health workers and other care-givers to understand the challenges and management of PWAs.

4.1.3 Health
i. Health Care workers and midwives shall be trained and retrained on how to handle PWAs
ii. Provide basic information and essential medical services for the prevention of eye and skin health issues related to Albinism;
iii. Provide counselling and psycho-social services for PWAs by health systems stakeholders in public and private sectors; and
iv. Secure free, accessible, qualitative treatment and rehabilitation of PWAs with skin cancer, sunburn and low vision at all levels of government.
4.1.4 Social Security and Other Services

i. Relevant Government Agencies, Civil Society Organizations and Development Partners shall extend their purview to alleviating the challenges of Albinism;

ii. Stakeholders shall partner with The Albino Foundation and other albinism focus groups to intervene in activities and programmes to support the provision of visual, dermatological and other aids for PWAs in communities; and

iii. Social welfare schemes should be inclusive of PWAs to facilitate their socio-economic well-being.
5.1 MANAGEMENT AND SUSTAINABILITY

5.1.1 MANAGEMENT

5.1.1.1 Coordination Mechanism
The National Disability Commission in collaboration with relevant stakeholders shall be responsible for the coordination, monitoring and evaluation of all Albinism activities in the country and shall establish a framework for implementation. The Coordination Mechanism requires effective consultation and participation by all Stakeholders at all levels. The stakeholders shall include: Federal, State and Local Governments, Media, Civil Society Organizations, Private Sector, Communities and Development Partners.

5.1.1.2 Albinism Consultative Coordinating Committees
There shall be committees at Federal, State, Local Government and Community levels.

5.1.1.2.1 Federal
The National Albinism Coordinating Committee shall include representatives of Ministries, Departments, Agencies and other Stakeholders:

i. Education;
ii. Women Affairs and Social Development;
iii. Health;
iv. Justice;
v. Information;
vi. Budget and National Planning;
vii. Finance;
viii. Labour and Employment;
ix. Office of the Head of the Civil Service of the Federation;
x. Federal Capital Territory Administration (Education Secretariat)
xii. National Population Commission;
xii. National Orientation Agency;
xiii. National Human Rights Commission;
xiv. Civil Society Organizations;
xv. Non-Governmental Organizations;
xvi. Private sector;
xvii. Professional Groups;
xviii. Development Partners;
xix. Albinism Coordinators/Desk Officers at Federal, State and Local Government;
xx. Media.

5.1.1.2.1.1 Functions and Responsibilities

i. Policy formulation and implementation on Albinism; Advocacy, campaign and sensitization;
ii. Research & human capital development;
iii. Collection and collation of data on Albinism for the purpose of planning and programming;
iv. Ensure the creation of employment opportunities for PWASs at the Public and Private Sectors;
v. Maintaining uniform standard on Albinism Education nationwide;
vi. Harmonization of Albinism activities nationwide; and
vii. Ensure effective monitoring and evaluation of the policy implementation.

5.1.1.2.2 States

i. Women Affairs and Social Development;
ii. Education;
iii. Health;
iv. Justice;
v. Information;
vi. Finance;
vii. Civil Society Organizations;
viii. Private sector;
ix. Professional Groups;
x. Development Partners;
xi. Albinism Coordinators/Desk Officers; and
xii. Media
5.1.1.2.1 Functions and Responsibilities

i. Provide technical and administrative support to the Albinism Consultative Committee;

ii. Mobilize resources to support the implementation of the Policy;

iii. Appoint Desk Officers to coordinate and monitor the implementation of Albinism activities, programmes and projects;

iv. Promote collaboration among government Agencies, Civil Society Organizations, and Private Sectors;

v. Ensure the creation of employment opportunities for PWAs at the Public and Private Sectors;

vi. Submit quarterly reports to the National Committee;

vii. Ensure regular feedback on Albinism activities to the national body;

viii. Carry out other functions as may be necessary to support the implementation of the Policy; and

ix. Ensure effective monitoring and evaluation of the policy implementation.

5.1.1.2.3 Local Government

i. Heads of relevant Departments/units (health, education, social welfare);

ii. Education Secretary;

iii. Traditional and/or Religious Leaders or representatives;

iv. Women Leader or representative;

v. Youth Leader or representative;

vi. Nigeria Union of Teachers representative;

vii. Health Workers;

viii. Market Men/Women;

ix. District Heads/Wards;

x. Civil Society Organizations; and

xi. Media
5.1.1.2.3.1 Functions and Responsibilities

i. Appoint Desk Officers to coordinate and monitor the implementation of Albinism activities;

ii. Identify Albinism needs in communities and initiate appropriate actions;

iii. Advise the Local Government Council on issues regarding Albinism activities;

iv. Ensure the creation of employment opportunities for PWAs at the Public and Private Sectors;

v. Ensure regular feedback on Albinism activities to the State;

vi. Carry out grassroots mobilization on issues on Albinism;

vii. Carry out any other functions that may be assigned to it by the National and State Consultative Committees towards the implementation of Albinism activities; and

viii. Ensure effective monitoring and evaluation of the policy implementation.

5.1.1.2.4 Community Level

i. Traditional and/or Religious Leaders;

ii. Village Heads or Representatives;

iii. Heads of schools;

iv. Opinion Leaders;

v. Civil Society Organisations;

vi. Youth Leader or representative;

vii. Market men/women or representative;

viii. Traditional Birth Attendants; and

ix. Head of community Health Centre.

5.1.1.2.4.1 Functions and Responsibilities

i. Collaborate with local government to ensure implementation of Albinism activities;

ii. Take census and registration of PWAs in
the community;

iii. Carry out grassroots mobilization on issues on Albinism;

iv. Ensure regular feedback on Albinism activities to the local government;

v. Carry out any other functions that may be assigned to it by the State and Local government Consultative Committees towards the implementation of Albinism activities and programmes; and

vi. Ensure effective monitoring and evaluation of the policy implementation.

5.1.2 SUSTAINABILITY MEASURES
Sustainability measures shall include specific indicators and activities designed to provide empirical evidence of the progress or otherwise of the Policy in the immediate, medium and long terms. The measures shall also serve as basis for the identification of future needs as it relates to the policy implementation. The focus shall be on six (6) priority areas: political will, advocacy, capacity building, partnership, National Consultative Committee on Albinism and social mobilization.

5.1.2.1 Political Will
i. The political will of the leadership of the Federal, State, and Local Governments is pertinent to the successful implementation and continuous drive of the policy;

ii. The strategy of policy dialogue shall be adopted by the government to allow for integration of emerging issues that shall arise during the implementation process;

iii. Government at all levels shall ensure effective communication flows and engender interactions among all stakeholders to foster closer linkages and attain higher level of implementation;

iv. Governments at all levels shall give priority to the successful inclusion of PWAs into mainstream society with special focus on four (4) dimensions of societal inclusion – health, education, economic, employment and engagement; and

v. Government shall also make concerted efforts to ratify
and domesticate all international instruments for empowerment of PWAs.

5.1.2.2 Advocacy

i. Advocacy, education, sensitization and mobilization of all stakeholders at all levels shall be an integral part of the implementation process to drive the process across all levels; and

ii. Government at Federal, State, Local and community levels shall promote policy dialogues and lead advocacy efforts to reduce stigmatization and discrimination against PWASs in Nigeria.

5.1.2.3 Partnership

i. Government shall strengthen partnerships at all levels among stakeholders; and

ii. Relevant stakeholders responsible for the coordination and implementation of this Policy shall adopt a political form of cooperation.

5.1.2.4 Capacity Development

i. Government at all levels shall establish entrepreneurial skills training centres both at the local and community levels with a view to empowering PWAs;

ii. Create special employment considerations for PWAs; and

iii. Initiate, strengthen and implement care and support programmes for PWAs.

5.1.2.5 Social Mobilization

i. The media shall be encouraged to develop cultured appropriate information, enlightenment and education programmes targeted at PWAs and the general public; and

ii. Traditional, opinion and religious leaders shall facilitate the process of social inclusion and participation of PWAs in their groups and communities.
5.2 RESEARCH, MONITORING AND EVALUATION

5.2.1 RESEARCH
The Department of Albinism in the National Disability Commission in collaboration with Special Education Division of FME shall carry out routine monitoring and evaluation of projects/programmes meant for PWAs in Nigeria. Planning, Research and Statistics Department of the National Disability Commission shall undertake research on policy mandate, improvement and implementation on all Albinism programmes with a view to enhancing quality service delivery.

Government at all levels, Development Partners, and other Stakeholders shall provide enabling environment and financial support for continuous research on Albinism in Nigeria.

For successful implementation of the policy, the following shall be carried out:

i. Promote, adequately fund and encourage research on Albinism;
ii. Disseminate and publicise research findings on Albinism for use by all stakeholders; and
iii. Update database on key performance indicators on Albinism.

5.2.2 MONITORING AND EVALUATION
For successful implementation of the National Policy on Albinism, an effective monitoring and evaluation system shall be established. This provides the basis for assessing progress on programme implementation for standard and quality.

This shall be carried out through:

i. Tracking of existing problems and causes, as well as proffering solutions;
ii. Information generated for future planning; and
iii. Dissemination of reports to all stakeholders.
SECTION 6

NATIONAL POLICY ON ALBINISM IN NIGERIA

FEDERAL MINISTRY OF EDUCATION
2019
6.1 FUNDING AND RESOURCE MOBILIZATION

6.1.1 Financial Responsibility
Funding required for the implementation of Albinism Education, Health and Social development shall be obtained from the following sources:

i. Federal Government;
ii. State Government;
iii. Local Government;
iv. Private Sector;
v. Development Partners;
vi. CSOs; and
vii. Others

6.1.2 Mode of Funding
Federal, State and Local Governments shall:

i. Make annual budgetary allocation and prompt release of funds through MDAs;
ii. Interventions from DPs, CSOs, Private Sector in critical areas of infrastructure, instructional materials, medical bills, etc to support teaching and learning process of PWASs in Nigeria;
iii. Ensure maintenance and supervision of all Albinism programmes to promote equality and service delivery; and
iv. Support participation of Albinism professionals in national and international conferences;

In order to explore more funds to support Albinism in Nigeria, other agencies shall support PWAs financially and materially as part of their Corporate Social Responsibilities to this group.

i. Government shall encourage development partners and others like CSOs, PS, FBOs, Community groups and philanthropic individuals to fund critical aspects such as building of a database for PWAs in Nigeria, advocacy against harmful cultural practices of PWAs etc.

ii. Maintenance of import waivers for health related drugs and materials for the prevention and treatment of skin cancer related diseases for PWAs.
6.1.3 Others
Support in form of cash and kind from:

i. Development Partners (DPs)
ii. Civil Society Organizations (CSOs)
iii. Private Sector (PS)
iv. Faith Based Organizations (FBOs)
v. Non-Governmental Organizations (NGOs)
vi. Community
vii. Individuals and philanthropists
SECTION 7

NATIONAL POLICY ON ALBINISM IN NIGERIA

FEDERAL MINISTRY OF EDUCATION
2019
7.1 IMPLEMENTATION GUIDELINES AND ACTION PLAN

The Implementation Guidelines and Action Plan shall be systematically followed to improve the lives and learning achievement of PWAs.

### 7.1.1 Policy Formulation in Respect of Albinism

<table>
<thead>
<tr>
<th>S/N</th>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>DELIVERABLES</th>
<th>TIMELINE</th>
<th>COLLABORATING BODIES</th>
<th>SOURCES OF FUNDS</th>
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<tr>
<td>5</td>
<td>Government Support</td>
<td>FME to create a budget line on albinism programmes in line with ERGP</td>
<td>Funding for programmes and projects provided</td>
<td>2019 to 2021</td>
<td>Federal Ministries of Education, Labour &amp; Employment, Health and Women Affairs, FCTA, NERDC, TAF &amp; other albinism groups, NMEC, SMoE, UBEC, SUBEB, NTA, AIT, TR CN, FR CN, NBTE, NECO, JAMB, WAEC, ETF</td>
<td>FME, NERDC, UBEC, UNICEF, UNESCO, Private Sector and Development Partners (DPs)</td>
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<td>Funds for albinism programmes and activities provided</td>
<td>2019 to 2025</td>
<td>Private Sector, Foundations and DPs</td>
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<td></td>
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<td>Employment provided for PWAS</td>
<td>2019 to 2025</td>
<td>Government at all levels and private sector</td>
<td>FME, NERDC, UBEC, UNICEF, UNESCO, Private Sector and Development Partners (DPs)</td>
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<td></td>
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<td></td>
<td>Information on Albinism Integrated into existing National Policies</td>
<td>2019-2025</td>
<td>Federal, State and Local Governments</td>
<td>FME, NERDC, UBEC, UNICEF, UNESCO, Development partners,</td>
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<td></td>
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<td>Assistive Devices provided for PWAS in ERCs</td>
<td>2019-2025</td>
<td>TAF &amp; other albinism groups FME, NERDC</td>
<td>FME, Development partners, CSOs</td>
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<td></td>
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<td></td>
<td>Data and number of PWAS provided</td>
<td></td>
<td>National Bureau of Statistics, Ministry of Budget and National Planning, Finance, National Population Commission, DPs, CSOs</td>
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<tr>
<td>No.</td>
<td>Establishment of the National Albinism Consultative Committee</td>
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</table>
| 6   | - Set up a Consultative Committees at Federal, State and Local Government  
- Organise meetings for the Consultative Committees at the Federal State and Local Government  
- To ensure synergy and effective implementation of Albinism programmes and activities at the federal, state and Local Government levels | Role Models identified and showcased as successful PWAS  
| 7   | Establishment of Department of Albinism in the National Disability Commission | Department of Albinism established. | 2019-2025 | Presidency, National Assembly, National Disability Commission, Federal Ministry of Justice |
| 8   | Establishment of National Albinism Centre | National Albinism Centre established | 2019-2025 | National Disability Commission, TAF & other albinism groups EU, DPs, German, French & Swiss Governments |

**Notes:**
- PWAS: People with Albinism and Skin Disorders
- DPs: Development Partners
- CSOs: Civil Society Organizations
- IDPs: Internally Displaced Persons
- FME: Federal Ministry of Education
- NERDC: National Ethnic Religion Development Commission
- TAF: The Albinism Foundation
- NMEC: National Minimum Education Commission
- UBEC: Universal Basic Education Commission
- ETF: Education Trust Fund
- EU: European Union
- SMoE: State Ministry of Education
- SUBEB: State Universal Basic Education Board
- ETF: Education Trust Fund
- CSOs: Civil Society Organizations
- IDPs: Internally Displaced Persons
- NERDC: National Ethnic Religion Development Commission
- TAF: The Albinism Foundation
- NMEC: National Minimum Education Commission
- UBEC: Universal Basic Education Commission
- ETF: Education Trust Fund
- EU: European Union
- SMoE: State Ministry of Education

**Presidency, National Assembly, National Disability Commission, Federal Ministry of Justice**


**National Bureau of Statistics, Ministry of Budget and National Planning, Finance, National, Population Commission, DPs, CSOs**

**Presidency, National Assembly, Federal Ministries of Justice, Education, DPs, CSOs, National Disability Commission**

**Presidency, National Assembly, National Disability Commission, TAF & other albinism groups EU, DPs, German, French & Swiss Governments**

**Presidency, National Assembly, National Disability Commission, TAF & other albinism groups EU, DPs, German, French & Swiss Governments CSOs**
### 7.1.2 Education, Information and Attitude Formation

<table>
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<tr>
<th>S/N</th>
<th>ISSUES</th>
<th>STRATEGIES</th>
<th>DELIVERABLES</th>
<th>TIME LINE</th>
<th>COLLABORATING BODIES</th>
<th>SOURCES OF FUNDS</th>
</tr>
</thead>
</table>
| 1   | Inadequate knowledge and appreciation of Albinism | Development of Handbook and fliers on Albinism in Nigeria  
Development of Teachers’ Guide for education on Learners with Albinism | Increased National awareness on Albinism  
| 2   | Fostering Respect (Stereotyping and stigmatization) | Development of Self-esteem booklets for PWAS developed  
Seminars to teach social integration for PWAS, their families, and others interested in learning | Self-esteem booklets for PWAS developed  
Social integration documents developed | 2019-2025 | Federal Ministries of Health, Education, Labour & Employment, Justice, Information, Women Affairs, OHCSF, National Human Rights Commission, NERDC, TAF & other albinism groups, NMEC, SMoE, SUBEB, NTI, FRoC, NBTE, NECO, NMN, WAEC, ETF, Private Sector, CSOs and IDPs | FME, NERDC, EU, World Bank, DFID, USAID, UNICEF, UNESCO, WB, NECO, Private Sector, TAF & other albinism groups, CSOs, and International Development Partners (IDPs) |
### 7.1.3 Health Care, Prevention, Treatment and Management

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<tr>
<th>S/N</th>
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<tr>
<td>3.</td>
<td>Establishment of a Research Centre on Albinism domiciled in a Federal University in Nigeria</td>
<td>Identify the University Advocacy engagement to Universities</td>
<td>Research Centre established</td>
<td>2019 - 2025</td>
<td>Federal Ministries of Health, Education, Finance, Budget and National Planning, Federal University, TET fund, TAF &amp; other albinism groups, NUC, Central Bank of Nigeria</td>
<td>Central Bank of Nigeria, Federal Ministries of Finance, budget and National Planning, PS, DPs, German Government EU etc.</td>
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### 7.1.4 Capacity Building and Service Delivery

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<tr>
<th>1</th>
<th><strong>Build</strong> Capacity of teachers, health workers, parents and caregivers for effective implementation and coordination of National Policy on Albinism</th>
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<tbody>
<tr>
<td><strong>Organise sensitization workshops for teachers on accessible inclusive quality education</strong></td>
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<td><strong>Organise sensitization workshops for health workers on accessible healthcare for PWAS</strong></td>
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<tr>
<td><strong>Organize workshop for parents and caregivers on Albinism issues</strong></td>
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<td><strong>Organise sensitization workshops for community leaders</strong></td>
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<td><strong>Capacity of teachers, health workers, parents, caregivers and community leaders built on understanding Albinism</strong></td>
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<td><strong>2019</strong> - <strong>2025</strong></td>
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<tr>
<td><strong>FME, FMoH, NERDC, NTI, SUBEBs, NIEPA, NECO, UBEC, NBTE, WAEC, JAMB, LGEAs, NGOs, NCCE, COE, CSOs, TAF &amp; other albinism groups DPs</strong></td>
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<tr>
<td><strong>To ensure inclusion of PWAS in the educational system</strong></td>
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<tr>
<td><strong>Teachers’ Guide developed and Albinism contents infused</strong></td>
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<tr>
<td><strong>Federal Ministries of Education, Health, Budget and National Planning, Finance, NERDC, UBEC, NBTE, WAEC, NMEC, SUBEB, TAF &amp; other albinism groups</strong></td>
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<td><strong>To provide enabling environment and financial support for continuous research on issues relating to Albinism in Nigeria.</strong></td>
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<tr>
<td><strong>Research findings on Albinism issues disseminated and publicized</strong></td>
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<tr>
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<td><strong>Federal Ministries of Health, Education, National Orientation Agency, Justice, Information, Labour &amp; Employment, and Women Affairs and Social Development FCTA, OHCSF, National Population Commission, NERDC, TAF &amp; other albinism groups NMEC, SMoE, SUBEB, NTA, FRNC, NBTE, NECO, NMEC, WAEC, ETF, Private Sector, CSOs and IDPs</strong></td>
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</tr>
</tbody>
</table>
## 7.1.5 Socio

The Albino Foundation (TAF):
TAF address: albinofoundation@aol.com
National Organization for Albinism and Hypo-Pigmentation: www.albinism.org
International Albinism Centre: www.albinismdb.medium.edu
Hermansky-Pudlak Syndrome Network: www.hpgnetwork.org
United Nations: https://albinism.ohchr.org
<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Organization</th>
<th>Gender</th>
<th>Phone Number</th>
<th>Email Address</th>
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<tbody>
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