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LEGISLATIVE BRIEF

A BILL FOR THE ESTABLISHMENT OF NATIONAL AGENCY ON ALBINISM AND HYPOPIGMENTATION (NAAH) AND OTHER PURPOSES

SPONSOR: HON. LINUS OKORIE, FCA

Background

Albinism is a rare, non-contagious, genetically inherited condition present at birth. **In albinism, both parents must carry the gene for it to be passed on**, even if they do not have albinism themselves. The condition is found in both genders, regardless of ethnicity and in all countries of the world.

Albinism results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. As a result, **99.9% of persons with albinism are visually impaired and are susceptible to developing skin cancer**. There is no cure for the absence of melanin.

In Nigeria, owing to the incidence of the two types of albinism (ocular and oculacutaneous), it is estimated that there are **about 4 million persons with albinism**; and growing.

Unfortunately, this group of persons and other severe skin conditions such as **vitiligo** have not been adequately mainstreamed into the socio-economic and political development of the country.

The Need for the Bill

Albinism is still misunderstood not only in Nigeria but all over Africa and in other parts of the developing world. The physical appearance of persons with albinism is often the object of erroneous beliefs and myths influenced by superstition, which foster their **marginalization and social exclusion**. This leads to various forms of discrimination.

Women who give birth to children with albinism are often rejected by their husbands and their families, because of the lack of understanding of albinism. Children with albinism are frequently abandoned by their parents or, occasionally, the **victims of infanticide**, due to the belief that they may be a source of misfortune.

Further, children with albinism are likely to face bullying because of stereotypes based on the colour of their skin. The forms of discrimination faced by persons with albinism are interrelated. Their right to education, for instance, is affected by the challenges of school systems in addressing their vision impairment as well as mockery and abuse that can force children with albinism to drop out of school. A poor level of education, in turn, can lead to unemployment and affect their right to an adequate standard of living, consigning many to poverty.

The deeply entrenched prejudices persons with albinism face also impede them from accessing adequate health care, social services, legal protection and redress for rights abuses.

The worst expression of discrimination against persons with albinism is their **dehumanization**, which lays the foundation for physical attacks against them. Because some believe that they are magical beings or ghosts, they mutilate or even kill them so their body parts can be used for witchcraft rituals as is happening in some parts of Africa, including Nigeria. These attacks claim many lives and surviving victims and their families experience severe trauma.

It is pertinent to note that the passage of this Bill and the establishment of the Agency will in **cost the Federal Government of Nigeria minimally** since most of the funds will be coming from the United Nations systems who have recognised and established an office of an **Independent Expert on Albinism**. Already over four foreign missions, including France and the European Union have indicated interest in the process. It is our belief that when this bill is passed into law it will drastically solve many of these challenges faced by these vulnerable groups in our society.

Importance of the Agency

When established, the agency will seek to alleviate the many challenges faced by **persons with albinism, vitiligo and other persons with**

severe skin conditions in Nigeria. Specifically, the Agency shall be responsible for the following functions:

1. To formulate and implement policies and guidelines as appropriate for the education and social development of persons with albinism and other skin conditions;
2. To prepare schemes designed to promote social welfare of persons with albinism and the estimate of cost of implementing such schemes;
3. To promote and uplift the general social well-being of persons with albinism and vitiligo by encouraging the public to change their attitude toward these persons;
4. To enlighten the public and encourage persons with albinism and other persons with severe skin conditions;
5. Receiving of complaints of persons with albinism on the violation of their rights;
6. Support an individual's right to seek redress in court, investigation, prosecution or sanctioning (in appropriate cases) the violation of the provision of this Bill;
7. To coordinate, facilitate and deployment of resources for the prevention and treatment of skin related diseases on persons with albinism and vitiligo especially skin cancer;
8. Ensuring research development and education on persons with albinism and albinism issues;
9. To collect data and records on the education, socio-economic, and political status of persons with albinism, vitiligo and other skin conditions, which shall be a regular exercise so that persons with albinism are identified, and enumerated for planning and treatment;
10. To collaborate with the media to make information available in accessible format for persons with albinism, vitiligo and other severe skin conditions;
11. To serve as a pull for all monies from within and outside the country for the implementation of albinism cause;
12. Procuring of assistive devices for all persons with albinism;
13. To ensure the monitoring, evaluation and realisation of government policy objectives on persons with albinism, vitiligo and other skin conditions;
14. To facilitate the procurement of scholarship awards for persons with albinism up to university level;

15. To facilitate, promote and establishment of inclusive schools, vocational and rehabilitation centres for the development of persons with albinism;
16. Liaising with the public and private sectors as well as other bodies to ensure that the peculiar interests of person with albinism, vitiligo and other skin conditions are taken into consideration in every government policy, programme and activity;
17. Enforcement of compliance and imposing necessary sanctions and make appropriate orders;

MAJOR HIGHLIGHTS OF THE BILL

The Bill consists of **25 sections**, with the following forming the major highlights:

- A. **Sections 1-11** provide for the Agency and its Coordinating Council, including appointment of members, tenure, emoluments, functions, powers, structure, staffing, staff regulations and pension;
- B. **Sections 12-17** deal with financial provisions and audit;
- C. **Sections 18-23** cover the legal and administrative limitations, indemnity of officers, powers to give directives and regulations;
- D. **Section 24** is the interpretations; and
- E. **Section 25** is the short title.

Conclusion

Honourable colleagues, we cannot truly be representatives of the people if the most vulnerable in our communities are not adequately protected and empowered to live their lives to their full potential. The passage of this bill is a sure step in the direction of this necessary social and egalitarian protection of the weak and vulnerable. I therefore urge us all to support the passage of this Bill through second reading in order to alleviate the plights of **persons with albinism, vitiligo and other persons with severe skin conditions in Nigeria.**

This action will stand the test of time and is in firm accordance with the **Legislative Agenda** of this Honourable **8th House.**