

REPORT OF THE 2017 INTERNATIONAL ALBINISM AWARENESS DAY CELEBRATION HELD ON THE 13TH OF JUNE 2017 AT THE NATIONAL HUMAN RIGHTS COMMISSION, ABUJA NIGERIA.

1.0 Executive Summary

The 2017 International Albinism Awareness Day Celebration was held in Nigeria, specifically by all the state chapters of The Albino Foundation (TAF) and in Abuja where the major event was held by the foundation's headquarters at National Human Rights Commission. The day, June 13th every year, was set aside by the United Nations General Assembly to draw attention to states and members of the public on the issues and challenges faced by persons with albinism and albinism community all over the world.

The theme for this year's celebration was Advancing with Renewed Hope. To mark the day in Nigeria, there was a press conference and a workshop to educate and sensitize persons with albinism, parents and members of the public on the health challenges affecting persons with albinism and how to mitigate them and assist albinos build self-confidence for the overall development of their wellbeing.

Present at the event were the founder/CEO of the foundation, Mr. Jake Epelle and the Vice Chair of the foundation, Dr. Douglas Anele. Also present were representatives of German, Switzerland, French and Botswana Ambassadors to Nigeria.

Resource persons who are very knowledgeable in the field presented papers. Topic treated at the workshop included "Skin Cancer Prevention in Albinism," "Managing Low Vision in Albinism," and "Confidence-Building in Persons with Albinism."

In Attendance at the press conference were 25 media houses while 161 persons, 91 Female and 70 Male were at the workshop.

2.0 Background

The Albino Foundation (TAF) celebrated the International Albinism Awareness Day on the 13th of June 2017 in a grand style. The celebration was a follow up to the United Nations General Assembly declaration at its sixty-ninth session on December 14th, 2014, that June 13 every year should be celebrated as International Albinism Awareness Day. The day is intended to raise the consciousness of people worldwide concerning the negative impacts of widespread discrimination, stigmatization, dehumanization, human rights abuse and brutal killings of persons with albinism (PWA) around the world, especially in Africa. The International Albinism Awareness Day celebration was to draw the attention of states and members of the public to

the issues and challenges faced by persons with albinism and albinism community all over the world.

The theme for this year's celebration was *Advancing with Renewed Hope*.

The Foundation used the opportunity to call on countries, organizations of United Nations systems and other international and regional organizations, as well as the media, civil society groups, including non-governmental organizations and individuals, to support the cause of albinism not only in Nigeria, but also globally. The foundation also called on the human rights treaty bodies and special procedures of the Human Rights Council to continue to give attention, within their respective mandates, to the situation of persons with albinism.

This year's event was celebrated in Nigeria in all the 36 states of the federation by The Albino Foundation State Chapters, while the main event was celebrated in Abuja.

To mark the day, the foundation paid a courtesy visit to the president of the Nigeria Senate, Dr. Bukola Saraki. The high point of discussion was the National Albinism and Hypopigmentation Bill before the Parliament. The head of the delegation and vice chair of the board, Prof Douglas Anene pleaded with the Senate President and the Senate in general for quick passage of the albinism bill before the National Assembly, which when signed into law will ameliorate the many challenges confronting the albinism community in Nigeria. The President of the Senate assured the foundation that he would lobby his colleagues to ensure the passage of the bill. Also, present at the meeting were some Principal Officers of the Senate.

3.0 Technical Session I

3.1 Live programmes on electronic media Houses

In a build up towards the celebration of the day, The Founder/CEO, Mr. Jake Epelle; The Vice Chair of the board who is also a person with albinism, Prof Douglas Anene and the head of Media and Communication of the foundation, Mr. Afam Kasim were on different platforms hosted live to various radio and television stations within the FCT, Abuja to discuss issues on albinism and the important of the International Albinism Awareness Day celebration. Media houses visited included: Federal Radio Corporation of Nigeria, Nigeria Television Authority, Television Continental, WazobiaMax Television, WE FM and Channels Television.

3.2 Press Conference

To mark the day in Abuja, the event was divided into two sessions, namely, a press conference and a workshop to educate and sensitize persons with albinism, parents and members and of the public on the health challenges affecting persons with albinism and how to mitigate those problems. It also articulated various ways albinos can build their self-confidence for the overall development of their wellbeing. The stage was set with a short documentary in which some successful persons with albinism, including a model and a minister from Tanzania, gave insights into the challenges they faced as persons with albinism and how they were able to overcome those challenges.

At the press conference, the keynote address was presented by the Chairman of the occasion and Vice-chair of the board of the foundation, Dr. Douglas Anele, Associate Professor of Philosophy at the University of Lagos, Akoka. He noted that the most challenging problems facing persons with albinism are not skin cancer and low vision but the cruel discrimination, stigmatization and rejection which they experience in their families, schools, social gatherings, etc. He also identified the problem of accessing social amenities especially in the workplace. He added that persons with albinism are highly intelligent and can overcome skin cancer challenges by wearing protective clothing, and that low vision aids can be provided by the parents. He charged parents to give adequate care and attention to their children with albinism. He informed that the albino foundation is working very hard to secure vision aids and sunscreen lotions which will be made affordable to every member.

Representatives of the EU and ECOWAS ambassadors, while delivering their goodwill messages, pledged continued support to the good work of the foundation. They called for the speedy passage of the albinism bill before the National Assembly. Moreover, the representatives urged National Human Rights Commission to do more in promoting the rights of persons with albinism in Nigeria. Also present at the press conference were representatives of the ambassadors of Germany, Switzerland, French and Botswana. They all commended the remarkable achievements of TAF over the years and pledged that their principals will render assistance to the Foundation whenever they are called upon to do so.

Founder/CEO of the foundation, Mr. Jake Epelle, while welcoming the participants at the occasion, thanked them, particularly the German government, for their support and partnership with the foundation. He called on governments at all levels in Nigeria to support the cause of albinism, especially the passage of the albinism bill before the National Assembly, which has provisions for mitigating the various challenges confronting the albino community in Nigeria. He thanked most especially the press for their unalloyed support to the cause of albinism in Nigeria.

There were questions and answers at the end of the press conference.

4.0 Technical Session II

4.1 Workshop

The workshop which commenced immediately after the press conference was aimed at further educating and sensitizing persons with albinism, parents and members of the public who were present at the event on how to mitigate the health challenges facing persons with albinism. Topics treated at the workshop were “Skin Cancer Prevention in Albinism; Managing Low Vision in Albinism; and Confidence-Building in Persons with Albinism.

4.1.1 Skin Cancer Prevention in Albinism

Dr. Olarenwaju Falodun, a dermatologist with the National Hospital, Abuja, while delivering his paper on ‘Skin Cancer Prevention in Albinism’ identified melanoma and non-melanoma

skin cancers. He explained that melanoma skin cancers occur in persons with albinism because of excessive exposure of the skin to the sun. According to him, insufficient presence of melanin in albinos damages their skin when exposed to the sun for even short period of time, especially between 10 am and 4 pm. He called for the protection of the skin of persons with albinism from the sun right from infancy. Dr. Falodun advised persons with albinism to monitor their skin and report any changes no matter how small.

4.1.2 Managing Low Vision in Albinism

The paper was presented by Dr. Onyinye Edi, CEO of Classy Vision Ltd. She noted that presently, there is no absolute solution to low vision in albinism, but added that there are visual aids that can help to improve the sight of a person with albinism. She gave examples such as contact lens, eyes glasses, specialized telescopes etc. While underscoring the fact that the visual problems of albinos are not identical, she explained several strategies that can be used by albinos for managing visual challenges.

4.1.3 Confidence-Building for Persons with Albinism

This topic was skillfully handled by Dr. Wale Oni, a psychiatrist and also a person with albinism. He implored members to identify their strengths and limitations and work towards surmounting the challenges posed by their nature. He enjoined persons with albinism to be the best in whatever they are good at. He suggested confidence- building for persons with albinism to start from the family. He advocated that families should support the acquisition of knowledge by persons with albinism. Additionally, he advised parents and other family members to show them love, know their competencies and limitations, as well as engage in regular advocacy for assisting albinos in schools and elsewhere. Parents and guardians of persons with albinism should always report cases of abuse, discrimination and rejection to the appropriate authorities or to the foundation when such cases are not adequately addressed to their satisfaction. He urged persons with albinism to be bold and fearless and stand for their rights, and asked them not to use their albinism as an excuse to beg for alms.

Members of the audience made some comments and asked relevant questions which were skillfully handled by the resource persons.

5.0 Closing

The closing remark was given by Mr. Afam Kasim, Head, Media and Communication of TAF. He thanked all participants for making the event a memorable one. He prayed to God to keep all the participants alive to witness 2018 International Albinism Awareness Day celebration.

In Attendance were 161 persons, 91 Female and 70 Male.