

**THE ALBINO FOUNDATION**

**2015 ANNUAL REPORT**

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## **1.0 About The Albino Foundation**

Established in 2006, The Albino Foundation (TAF) is principally an organisation set up and run by Persons living with Albinism (**PWA**). TAF is an independent non-governmental organization registered in Nigeria with the Corporate Affairs Commission. We are a special focus organization advocating for the recognition, respect for the rights and socio-economic inclusion of people living with albinism. The Foundation works to create awareness about the social challenges that PWA face in Nigeria and the world by working with governments and development institutions in Programme areas that improve the health and social wellbeing of PWA in Nigeria as well as assist and empower them to find their rightful place in society. The Foundation has achieved national spread with 36 functional state chapters across the country including FCT, Abuja.

## **2.0 Vision**

The Albino Foundation envisions a society with equal opportunity for persons with albinism

## **3.0 Mission statement**

We are an advocacy organisation that empowers persons with albinism and educates the society on issues of albinism in Nigeria and the world

## **4.0 Our Values**

- **Accountability:** we are responsible and answerable for our actions
- **Commitment:** we are devoted to our cause
- **Stewardship:** we are caring and continuously improving our service delivery
- **Passion:** we are excited about what we do
- **Inclusiveness:** we embrace and collaborate with all who share our vision

## 5.0: Board of Trustees

The Foundation has a 5 member board of trustees comprising of highly esteemed individuals who have made their mark in their various fields of career and life endeavours. The board is responsible for the governance, organizational direction, policy and strategy formulation of the Foundation.

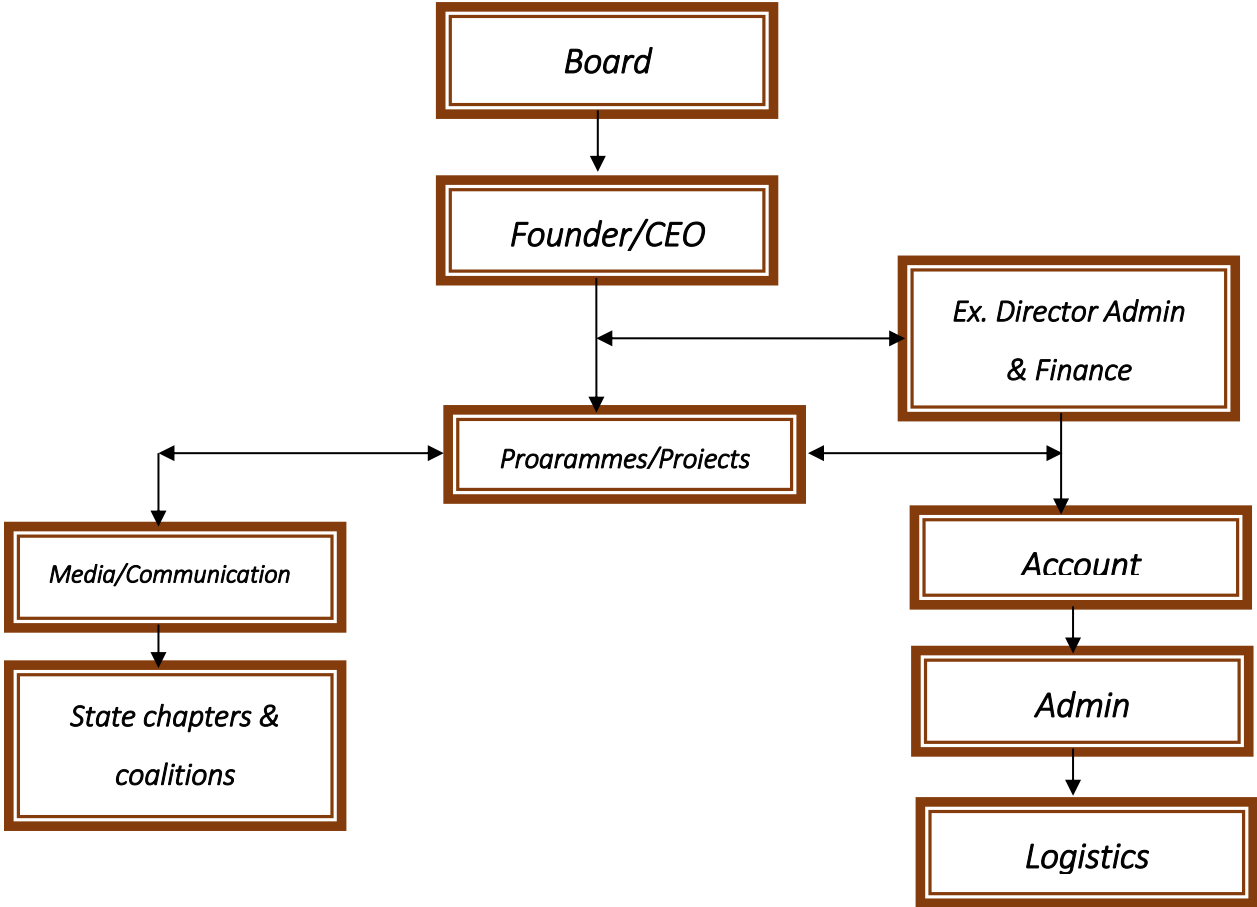
- Alhaji Shehu Shagari GCFR                      Grand Patron
- Dr Ndi Okereke                                      Chairman
- Dr Douglas Anele                                  Vice Chairman
- Jake Epelle    Founder/Chief Executive Officer
- Barr. Gabriel Arewele                              Secretary
- Prof. Mercy Olumide                                Member

## 6.0: Organisational Focus

With a view to impacting all persons living with albinism in Nigeria, Africa and the world, our focus as an organization is categorized into five major areas:

- **Healthcare:** The aim of Persons with Abinism Healthcare Project is to reduce and mitigate health related problem associated with albinism such as sunburn, skin cancer and eye related problems
- **Legislation and Policy Advocacy:** The aim of the Legislation and Policy Advocacy on Albinism is to ensure total mainstreaming of albinism programmes and policies into every sector of development in Nigeria
- **Social Awareness:** The aim of the Albinism Education and Social Awareness project is to properly educate and orientate Nigerians about the true state of albinism and to help promote understanding, acceptance and socio-economic inclusion of PWAs into mainstream society.
- **Learning and Education:** The aim of the project is to ensure that persons with albinism especially children with albinism have access to qualitative education
- **Economic Empowerment:** The aim of the project is to enhance the operational capability of the Foundation and ensure that PWA live independent lives

7.0 TAF Organogram



## **8.0: Statement from the Founder/CEO**

It is another end of the year where we have to inform members of the public what we were able to do in the past one year. The challenges confronting persons with albinism in Nigeria and Africa in general cannot be mitigated in one year. However, the foundation were able to record some successes within the year under review notwithstanding the numerous challenges experienced by the foundation, such as the stoppage of the free skin cancer treatment by National Hospital, Abuja. This project is one of the most cherished projects of the foundation due to the challenges faced by persons with albinism affected by skin cancer in accessing medical treatment. Though, the foundation is putting everything in place to ensure that in 2016 the free skin cancer treatment is continued not only at the National Hospital but also in all other teaching hospitals across the country.

One of the achievements of the foundation in the year 2015 was the development of a five year strategic plan for the foundation. The document was developed by some management of the foundation, experts and friends of the foundation who are knowledgeable in strategic planning development, and reviewed and validated by all the 36 state coordinators.

Another important achievement by the foundation in the year under review was the successful celebration of the maiden edition of International Albinism Awareness Day, which was celebrated globally. The celebration, which was marked by the foundation in Abuja brought in all the coordinators and some members of the foundation from all the states of the federation.

Several advocacy visits were carried out by the foundation towards ensuring that issues affecting persons with albinism are mainstreamed into the socio-economic, cultural and political development of the country.

The foundation would not have been where we are today without the support of many individuals, governments, members of the public, stakeholders and corporate organisations. However, we will continue soliciting for your support in ensuring that the foundation continuously affects the lives of these most vulnerable groups in the society. We request that you join the foundation in making 2016 a fruitful one.

**Jake Epelle**  
**Founder/CEO**

## **9.0: Activities carried out in 2015**

### **9.1 Development of the foundation's five year strategic plan, 9<sup>th</sup> to 11<sup>th</sup>, February, 2015**

The development of the foundation's five year strategic plan (2016 to 2020) was born out of the desire by the board and management of the foundation to repositioning the foundation towards meeting her set goals of mitigating the numerous challenges facing persons with albinism in Nigeria and the world. It was on this premise that the foundation wrote and contacted her consultants and friends who are experts and knowledgeable in strategic planning process and development to assist the foundation in developing a five year strategic document that will be equal to none.

Those that were part of the strategic plan development included: the founder/CEO of the foundation, Mr. Jake Epelle, Prof. Kate Nwufo, Prof Emeka Eneh, Mr. Tony Epelle, Mr. Dulapo Tukur, Mr. Emeka Orji, Mrs. Enya Epelle, Mr. Damian Ivom, Miss Oluchi Iwuoha and Mr. Afam Kasim.

A draft of the strategic document took three days intensive work to produce. The document was categorised into seven parts which include: Introduction, Evaluating Organisational Resources and Capabilities, Organisational Structure and Management, Programme Thematic Areas and Goals, Strategic Actions, Monitoring and Evaluation, and 2016–2020 Budget Projection.

### **9.2: National Albinism Day Celebration**

The National Albinism Day Celebration which is being celebrated May 5<sup>th</sup> every year was ratified by Nigeria's Federal Executive Council, the highest decision making body in Nigeria in 2012 after a strong advocacy effort by the foundation to federal government of Nigeria. The National Albinism Day Celebration was aimed at sensitising the public on the many challenges facing persons with albinism in Nigeria and the world generally. Since the approval of National Albinism Day Celebration in 2012, the foundation has been organising series of activities to mark the day.

To celebrate this year's National Albinism Day, which had the theme "Mainstreaming albinism into the socio-economic development of Nigeria", the foundation organised a two day media awareness campaign in three media houses (NTA, WE FM, and FRCN) within the federal capital, Abuja. The National Albinism Day celebration was equally marked in all the 36 states of the federation. The foundation mandated all its chapters across the 36 states of the country to equally use the medium to go round the media houses within their respective states and discuss on various issues as it affect persons with albinism in their states.

### **9.3 Joint press conference between the foundation and Tanzania Embassy in Nigeria**

A joint press conference was organised between the foundation and the embassy of Tanzania on the 15<sup>th</sup> of May, 2015. The joint press conference was aimed at informing the press and members of the public on numerous proactive steps taken by the foundation and the Tanzanian government in stemming the stigmatisation, discrimination and the brutal killings meted to persons with albinism in Nigeria and Tanzania.

The Tanzanian Ambassador to Nigeria, Daniel Ole Njoolay stated that the government of his country condemns in no uncertain terms the persecution of persons with albinism going on in Tanzania. He added that the killings are all about the black magic, the juju men and the sorcerers who are after money. He enumerated many steps taken by the government of Tanzania to mitigating these unwarranted act against persons with albinism in his country.

The founder/CEO of the foundation also used the medium to inform members of the press that the killings meted to persons with albinism is not only in Tanzania but also in Nigeria. He gave example of a mother who chopped off the head of her baby in order to remain in her marriage after being threatened by her in-laws who wanted to do away with the child after discovering that the child is living with albinism. A total number of 18 media houses (NTA, FRCN, AIT, RayPower FM, WE FM, Cool FM, WAZOBIA FM, NigerianInfo FM, Vision FM, Hot FM, Kapital FM, Kiss FM, Aso Radio, Punch, Guardian, Thisday, Vanguard and Leadership Newspapers) attended the joint press conference.

#### **9.4 Advocacy visit to the Board and Management of National Hospital, Abuja**

On the 22<sup>nd</sup> of May, 2015, the foundation paid a courtesy visit to the board and management of National Hospital, Abuja. The aim of the visit was to plead with the board and management of the hospital not stop the free skin cancer treatment for persons with albinism in Nigeria who are affected by skin cancer. The Hospital is the only hospital in Nigeria that accepted to sign MoU with the foundation and the Federal Government of Nigeria to treat persons with albinism living with skin cancer. It was agreed that persons with albinism affected by skin cancer will be treated free of charge while the government of Nigeria through the Ministries of Finance and Health offset the bill.

Unfortunately, with the change in government in Nigeria over \$263,000 is being owed the hospital. The board and management assured the foundation that the hospital will continue to treat persons with albinism irrespective of the debt owed to them. Till date 1,120 persons with albinism affected with skin cancer have been treated. It is worth mentioning here that persons with albinism is the only vulnerable group in Nigeria receiving such gesture from the government. In the advocacy visit with foundation were nine media houses (NTA, FRCN, AIT, RayPower FM, WE FM, Punch, Guardian, Thisday and Vanguard). The foundation has written to the President and Vice president for a courtesy visit. The primary aim of the visit was to plead with both the president and vice to offset the bill owed National Hospital and continue the free cancer treatment for persons with albinism in Nigeria and equally the full implementation of the National Policy on Albinism.



## **9.5 International Albinism Awareness Day Celebration Held On The 10<sup>th</sup> Through 13<sup>th</sup> Of June, 2015**

### **9.5.1 Media visits**

#### **9.5.1.1 Visit to BBC Hausa Service**

On June 10, the management and members of the foundation paid a courtesy visit to BBC Hausa Service. They were received by Bashir Sa'ad Abdullahi – Bureau Editor, Habiba Adamu – Senior Producer/BJ and Chris Ewokor – English Reporter. The Bureau Editor started off by welcoming everyone and introduced the members of his team. The Executive Director TAF, Enya Epelle, introduced the members of the foundation and thanked the management of BBC Hausa Service for the warm welcome. A brief presentation on Albinism and TAF was delivered by Oluchi Iwuoha, the Assistant National Programme/Project Specialist of the foundation. In her presentation she highlighted the various milestones that the foundation has achieved over the years.

The CEO of the foundation, Jake Epelle, highlighted the role that BBC Nigeria played in bringing albinism issues to the spotlight thereby capturing the attention of the United Nations Office. He further commended the Bureau for their unrelenting efforts in following up on the programmes of the foundation and urged the bureau to keep up the good work. The Bureau Editor once again thanked all and assured the foundation of their continual partnership.

#### **9.5.1.2 Courtesy Visit to Nigeria Info FM**

Again, as part of the celebration the foundation paid a brief courtesy visit to Nigeria Info on June 11, 2015. The Head of Station, Victor Nwaneri, welcomed the delegation. The CEO of the foundation thanked the management of Nigeria Info for the many times the foundation has been given free air time to feature in the station's programmes to discuss issues on Albinism. He further informed those present of the huge impact this has made on the public at large. He took the time to highlight the programmes that the foundation had scheduled to mark the 1<sup>st</sup> International Albinism Awareness Day and requested that Nigeria Info be present to cover all these programmes. The Head of Station thanked all and promised that the station will continue to lend their support to the foundation.

### **9.5.2: Event Opening/Workshop – 12<sup>th</sup> of June**

The workshop which was part of the activities to mark the maiden edition of the International Albinism Awareness Day celebration scheduled for June 13 2015, started at about 10 am with prayers said by Christian and Moslem brothers. This was followed by the introduction of Special Guests of Honour at the high table. In his opening remark, the founder/CEO of the foundation,

Mr. Jake Epelle thanked the guests especially High Commissions present for honouring the foundation by creating time out of their busy schedules to come for this year's maiden edition of the International Albinism Awareness Day Celebration. He stated that this year's theme is Promoting and Protecting the Human Rights of Persons with Albinism. He stated that there was no consensus theme for this year's celebration, but each country had to formulate their respective themes.

In his opening remark, the Chairman of the occasion and a board member of the foundation, Prof. Anezi Okoro thanked all the participants for coming and re-iterated the need for more proactive action towards alleviating the plights of persons with albinism by governments at all levels and international communities.

#### **9.5.2.1 Goodwill messages**

In his goodwill message, the Chairman National Human Rights Commission, Prof Bem Angwe welcomed everyone to the Commission and stated that the Commission was saddled with the responsibility for the promotion, protection and enforcement of the fundamental human rights of all Nigerians irrespective of their sex, age, colour, circumstances of their birth or any other consideration. He added that these rights are guaranteed under the 1999 constitution of Nigeria, the African Charter and other regional and International Human Rights instruments. He stated that the Commission is gratified that the government of Nigeria has adopted the National Policy on Albinism and has equally set-up an implementation structure to take care of the unique needs of the albinism community. He stated that more needs to be done to ensure that states and local government across the country are involved urging that more enlightenment, publicity and strong partnership between the civil society and government agencies are required in achieving the objective.

In his goodwill message, the Director General, National Directorate of Employment, Mallam Abubakar Mohammed commended the leadership of the foundation for the doggedness in promoting and protecting the rights of persons with albinism and added that they are normal people and therefore deserve equal treatment and employment and other economic benefits without discrimination. He stated that NDE as an apex job creation agency of the government has an array of programmes and schemes strategically designed for persons with special needs especially the vulnerable groups.

In his goodwill message, the High Commissioner of Canada, Mr. Perry Calderwood, while commending the founder of TAF for creating awareness about challenges persons with albinism face pledged his country's support to work with the Nigerian government in alleviating the plight of persons with albinism in Nigeria. He stated that the Canadian Government is committed to promoting awareness in education around the world to ensure that persons with albinism are fully included in the society and should be treated like everyone else. He added that he was optimistic that when events like this are celebrated around the world they

will be effective in educating people that persons with albinism are like every other person irrespective of colour, race, gender and nationality.

In his goodwill message, Mr. Dirk Schulz, First Secretary, Attache for Economic and Development, Embassy of the Federal Republic of Germany said that "a country is judged by the way the minority in that country is treated". He said that most countries including Nigeria had deficiencies on how they treated their minorities. He called for a new push for tolerance in the way minority groups such as persons with albinism were treated, adding that the European Union and his country were ready to support The Albino Foundation in Nigeria.

In her goodwill message, Ms Fatma Rajab, Head of Chancery, High Commission of the United Republic of Tanzania said that her country was willing to collaborate with TAF and share experiences. She said that the Tanzanian government had taken major steps to fight discrimination and killings of albinos in the country. She added that their President has nominated a person with albinism to be a member of the parliament in order to bring awareness to members of the parliament. She stated that the government of Tanzania has executed so many persons who were charged with the killings of persons with albinism in the country. She added that the government has also created awareness to educate members of the public to stay together with persons with albinism.

In his goodwill message, the U.S. Ambassador to Nigeria, Mr. Entwistle represented by Dan Joyce, Political Counselor U.S Embassy in Nigeria commended the Founder/CEO of the foundation, Mr. Jake Epelle and the staff of the foundation for working diligently since 2006 to raise awareness about albinism and to empower persons with albinism in Nigeria. He stated that the United States government is committed to help end violence and discrimination against persons with albinism as well as ensure access to educational, economic and voting opportunities. He stated that the United States helped advocates for the establishment of the International Albinism Awareness Day and added persons with disabilities have been included as beneficiaries of the ongoing USAID civil society empowerment project. He added that U.S government is ready to further the cause of persons with albinism in Nigeria but stated real and sustained progress depends on the commitment and hard work of Nigerians. He encouraged the Nigerian Government and NGOs to remain sensitive and help address the challenges facing persons with albinism, including vision impairment and those with severe sensitivity to the sun's exposure.

In his goodwill message, the representative of Kenya High Commission, Mr. Linus Ogola thanked the foundation for inviting the commission and added that in order to fight discrimination against persons with albinism in Kenya; the country's legislation has passed a bill on albinism. He stated that the government has equally appointed a person with albinism as a judge to treat all cases involving abuse of persons with albinism in Kenya. He therefore commended the foundation for their commitment in uplifting the plight of persons with albinism in Nigeria.

In his goodwill message, the Chairman Nigerian Electricity Regulatory Commission, Dr. Sam Amadi apologized for coming late and stated that he had to forgo other engagements and

meetings irrespective of his ill health to be in the event. He commended the foundation for being one of the best NGOs in Nigeria and for the advocacy drive in producing the only National Policy on Albinism globally. He reiterated the need for continuous support by the government and promised that NERC will continue to partner and support the foundation.

### **9.5.2.2 Paper presentations**

The first paper for the day was presented by the Director General, Institute of Peace and Conflict Resolution, Prof. Oshita Oshita. His paper was on Strategies for Developing the Mindset of an Entrepreneur in persons with albinism. He laid emphasis on the objectives of the Institute, which he said seeks to enhance the inclusion of persons with albinism and other vulnerable groups and added that persons with albinism have every rights to be part of the socio-economic development of the country. He added that for total economic development of every nation, its minority should be part of that economic development. He stated that the institute will continue to protect the minority, especially persons with albinism. For economic empowerment of persons with albinism, he proffered the following solutions:

- Preference should be given to vulnerable groups in government's policies and programmes
- Scholarships should be given to vulnerable groups especially persons with albinism and other disabilities in skill development programmes
- The foundation should continue to research more on skill development programmes and other preventive measures of affecting the social challenges of persons with albinism
- Government should not short-change persons with albinism since so doing will affect the country's man-power development

The second presentation was done by Prof. Douglas Anele of the University of Lagos. His paper was on Building Self Confidence; Discovering and Building Inherent Values within Persons with Albinism. He started by saying that the essence of being human is to face challenges. He talked extensively on the following areas:

- Cultivating self-confidence by persons with albinism
- Psychological attributes of oneself
- Albinism as a model
- Self-knowledge as the best knowledge
- Albinism as a way of being courageous
- Success as a means of fighting discrimination

The third paper was on coping with vision in albinism presented by Dr. Edi Onyinye. Her paper dealt extensively on general conditions of persons with albinism; common complaints in albinism;

features in albinism; low vision; common challenges of low vision in persons with albinism; principles of improving vision; low vision aids; tips for better mobility; classroom adaptations; home adaptations; computer use in low vision; and educational considerations to be given to people with low vision

The fourth presentation was on Preventing and Mitigating the Impact of Skin Cancer in Persons with Albinism presented by Prof. Ifeoma Okoye. Her paper was able to answer the following questions as highlighted below:

- Prevalence or incidence of skin cancer in persons with albinism ... What is the incidence of Skin Cancer in persons with albinism....Globally and in Africa?
- What are the socio-cultural economic factors that drive this high prevalence?
- How can we prevent skin cancer in Albinos ... Best practices for preventing skin cancer in Albinos
- How will you mitigate the impact of skin cancer on persons with albinism or what kind of interventions will you need to put in place that will impact skin cancer prevention
- Management of those who receive a diagnosis of skin cancer
- The challenges associated with the care of persons living with albinism are numerous and there is a need to proffer solutions for improved outcome.

The last topic for the day was presented by Prof. Kate Nwufu of Nigeria Educational Research and Development Council (NERDC) on Education: A Tool to Fighting Social Discrimination Against Persons with Albinism. She extensively talked about the concept of education; albinism as a genetic condition; prevalence rate of albinism; myths and misconceptions about albinism; social discrimination against persons with albinism; impediments to education of persons with albinism; and the way forward for the comprehensive education of persons with albinism.

After the presentations, there were questions and answers from the participants.

### **9.5.3: Albinism Walk – 13<sup>th</sup> of June**

Members, staff, stakeholders, members of the public and the media started converging at the venue of take-off, Millennium Park-Abuja as early as 6am. The aim of the albinism walk was to further sensitize the public on the plights of persons with albinism. By 8am all the participants took off from the park through Transcorp Hilton to National Human Rights Commission, Maitama, venue of the International Press Briefing. Participants, including children defied the early morning showers to make it to National Human Rights Commission. One hundred and fifty persons participated in the walk including children with albinism.

#### **9.5.4 Press briefing – 13<sup>th</sup> of June**

The press briefing which started immediately after the Albinism Walk at National Human Rights Commission commenced at exactly 10:30am with virtually all the media houses in Nigeria in attendance (18). Prayers were said by Christian and Muslim brothers.

In his opening remark the Chairman of the press briefing and board member of the foundation, Prof. Anezi Okoro called on the government at all levels to support albinism cause in Nigeria and ensure that persons with albinism are mainstreamed into the socio-economic development of the country.

In his remark, Vice Chairman of the board of the foundation, Prof Douglas Anele and also a person with albinism stated that he was a fulfilled person for being part of this year's maiden edition of International Albinism Awareness Day Celebration. He said that persons with albinism do not have problems; rather it is members of the public who see problems in persons with albinism. He added that it was as a result of these problems that members of the public tend to discriminate against persons with albinism. He added that the discrimination against persons with albinism cannot stop until PWAs themselves take laws into their own hands and stop it. He concluded by saying that persons with albinism should not make excuses but come out and make their voice heard.

In her goodwill message, Hajia Suwaiba Jubrin of Actionaid, one of the supporters of the event stated that ActionAid supported the programme as a result of stigmatization and discrimination meted to persons with albinism by members of the public. She re-iterated the need for the government to continuously support the foundation and the albinism cause in Nigeria. He added that persons with albinism should be confident in themselves in order to fight societies' discrimination and other myths associated with albinism. He added that the organization will continue to support the foundation in order to achieve its objectives.

A message from the UN Secretary General Ban Ki Moon on this year's International Albinism Awareness Day celebration was read by the Founder/CEO of the foundation, Jake Epelle which centred on the need for the Nigerian government to take proactive steps that would ensure better lives for persons with albinism.

After the message, Mr. Epelle appealed to the Nigerian government to implement a free education programme for persons with albinism in the country. He stated that a programme such as this is presently being practiced in Malawi. He said that such a policy would encourage persons with albinism get quality education which would enable them maximise their potentials.

He also appealed to the new administration to continue the free skin cancer treatment for persons with albinism, saying that it should be carried out in all Teaching Hospitals across the

country. He added that the management of the foundation is working towards setting up a cooperative society that would help meet the financial needs of members. The founder also appealed to the Federal Ministry of Finance to pay for the sunscreen that had been shipped into the country so that persons with albinism could get them for free.

#### **9.5.5 Gala Night – 13<sup>th</sup> of June**

The International Albinism Awareness Day Celebration culminated with a Gala Night. It started by 4:00 pm with Nigeria's National Anthem followed by opening prayers said by Christian and Muslim brothers. The Gala Night was primarily aimed at creating albinism awareness as well as honoring individuals and organizations that have supported not only the foundation but the albinism cause in Nigeria. It was equally an opportunity to showcase the rich talents in persons with albinism. Highlights of the activities included a Fashion Show by the African Fashion Hall of Fame chaired by Dr Fati Ibrahim and consisted of a bevy of representatives from different countries present such as Liberia, Pakistan, Ethiopia, Tanzania and different cultures and tribes in Nigeria. Songs and renditions from children with albinism, the foundation's presentation by the Assistant National Project Specialist of the foundation, Oluchi Iwuoha and presentation of awards formed the highlights of the evening.

Among those who were given awards were the Federal Ministries of Education and Health, German and Canadian Embassies, The Nigerian Television Authority, Federal Radio Corporation of Nigeria, British Broadcasting Commission, National Hospital, Abuja and some worthy Nigerians that have supported the foundation and the albinism cause over the years.

The Founder/CEO of the foundation used the occasion to appeal to the present government and National Hospital, Abuja to continue the free skin cancer treatment for persons with albinism. He said that the foundation and Federal Government owe the National Hospital more than Fifty Million Naira (**N50M**) and appealed to the management of the National Hospital not to discontinue the free treatment as a result of the debt.

In his response, the Chief Medical Director of National Hospital Dr. J.A.F Momoh, while receiving an award from the foundation on behalf of the hospital, said that the hospital would continue to partner with the foundation and would not stop rendering treatment to patients with albinism affected by skin cancer. He said that over 1000 persons with albinism had benefited from the free skin cancer treatment carried out in the hospital. Speaking on the over N50 million debt owned the hospital by the federal government for the free cancer treatment for albino patients; he called on philanthropists to help foot the bills rather than waiting for government.

## **9.6 Press briefing on a suicide committed by Ugochukwu Ekwe, an albino over discrimination meted to him by the society, held on the 21<sup>st</sup> of August, 2015.**

The press briefing, which was organised by the foundation to address members of the press and the general public on the death of Ugochukwu Ekwe who committed suicide on Sunday, 16<sup>th</sup> of August, 2015 as a result of discrimination was held on the 21<sup>st</sup> of August, 2015 at the foundation's conference room.

The press briefing was organised by the foundation in order to state its position towards the suicide and inform members of the public on what the foundation has done since the incidence took place.

The founder/CEO of the foundation, Jake Epelle stated that the foundation and the albinism community in Nigeria condemns in its entirety someone taken his/her life as a result of discrimination. He stated that the society is largely responsible due to the manner persons with albinism are being treated within the society, which is discriminatory, derogatory and dehumanising. He equally stated that the government is insensitive to the plights of persons with albinism in Nigeria and urged the Lagos state government to take proactive steps to ensuring that such incidence does not repeat especially in Lagos where there are large population of persons with albinism.

The founder/CEO of the foundation added that the foundation would not like to lose any of its members as a result of discrimination or any other form of inhuman treatment to persons with albinism. He stated that the foundation was in contact with the family members and the security agencies to get to the root of the case. He added that an autopsy of the body will be carried out and necessary investigations conducted before the burial.

He equally added that the foundation will keep the press informed on the outcome of the investigation.

He stated that discrimination starts from the home and therefore, re-iterated the need for families of persons with albinism to treat their family member living with albinism just like any other person within the family. He added that when a person with albinism feel discriminated within the family he tends to withdraw from the general public and the resultant effects is emotional and psychological trauma.

A human rights advocate and a friend of the foundation, Mr. Kelvin Fine Face, whose two of his siblings are living with albinism in his brief comment stated that albinism is not a disease but a condition that not does not affect the brain or any other parts of the body. He added that though persons with albinism have their basic challenges such as visual and skin cancer, but with adequate care these challenges can be managed.

A total of 32 media organisations attended the press briefing including foreign media houses.



### **9.7 TAF Participates at the Lunch of The Year of Action to End Violence Against Children, September 15, 2015.**

The Federal Government of Nigeria, led by the National Population Commission (and supported by UNICEF Nigeria, US Presidential Emergency Plan for AIDS Relief and US Centers for Disease Controls and Prevention) carried out the first comprehensive and national representative survey on violence against children (VACS) in 2014, covering all the states in Nigeria.

To mobilise Nigerians to take action in response to the findings of the survey, the President of the Federal Republic of Nigeria, represented by the Head of Service, launched The Year of Action to End Violence Against Children on 15<sup>th</sup> of September 2015. The ceremony, which took place at International Conference Center Abuja, was well attended by so many Ministries, Departments and Agencies as well as NGOs.

The Albino Foundation was represented by The Assistant National Program/Project Specialist, Oluchi Iwuoha and the Head Media/Communication, Afam Kasim. The foundation is committed to fighting violence against children through her programs and projects and through active networking with groups of like minds.

### **9.8 TAF attends a one day stakeholders meeting on the Development of a Policy Framework on Sexual and Reproductive Health and Rights of Women and Girls with Disability: September 16, 2015**

A one day Stakeholder's meeting, organised by Disability Rights Advocacy Center (DRAC), was attended by various NGOs, Disability Partner Organisations (DPO), Development Partners and Ministries. This meeting focused on developing a policy framework on Sexual and Reproductive Health and Rights of Woman and Girls with Disability. The need for this framework was facilitated by the findings of a baseline survey by DRAC (with support from United States Agency for International Development) which revealed the difficulties Women and Girls with disability face in trying to access reproductive health services and information. TAF was represented by the Assistant National Programme/Project Specialist, Oluchi Iwuoha.

### **9.9 TAF Participates at the two day training on Disability-Inclusive Gender Programming: September 29 – 30, 2015**

A two day training, organised by Christian Blind Mission (CBM), was well attended by representatives of various organisations: DPO, NGO and Media. The focus of the training was to educate participating organisation how to strategically design disability projects and programmes

to be gender inclusive and vice versa. Sessions during the training centered on Concept of Disability as well as Gender and Disability. Interactive sessions which included group works was also employed in driving home the objectives of the training. Oluchi Iwuoha Represented TAF at this training.

#### **9.10 Report On The 7<sup>th</sup> International Cancer Week Held At Sheraton Hotel, Abuja, 5<sup>th</sup> To 9<sup>th</sup> October 2015**

International Cancer Week Initiative (ICWI), in collaboration with Federal Ministry of Health, were the major players at this year's Cancer week. The theme for the 2015 International Cancer Week was ***Lighten the Path: Making Late Detection of Cancer History***. The Albino Foundation, being a partner to ICWI, was there to give support via organising media coverage for the programme. Participants were drawn from various facets of the Society; NGOs, Medical Practitioners, MDAs, Media, Students from teaching Hospitals and Development Partners.

The programme was kicked-off on October 5 with a Nationwide "Go Pink Day". Screening centers were staged all over the nation to give free cancer-detection test. In Abuja, screening center was staged at Wuse Market where people were given access to free cancer test. Again to make this more significant, Nigerians were sensitized through the various media outfits, to wear a touch of pink signifying fight against breast cancer which is a more predominant kind of cancer especially among women.

October 6<sup>th</sup> – 7<sup>th</sup>, 2015: Various Paper presentations and Symposiums were held with various topics delivered by Cancer focused NGOs as well as Medical Personnel. Mr Jake Epelle of TAF, Delivered a power point presentation on ALBINISM AND SKIN CANCER. In his presentation, he outlined the various challenges that Persons with Albinism encounter due to their susceptibility to skin cancer, He urged Government and Development Partners to key into the free cancer treatment presently being enjoyed by Persons with Albinism at the National Hospital Abuja. He equally enjoined all to be advocates in their capacity so as to create the needed awareness of the prevention of skin cancer in Persons with Albinism.

Other topics presented at the conference includes:

- Symposium on Childhood cancers
- Surgical Oncology
- Oncology in Diagnostic Radiation/ Nuclear Medicine
- New Trends in Radiotherapy and Brachytherapy
- Palliative Care

The conference came to an end on October 9, 2015 with the departure of participants

### **9.11 Press Conference on the suspension of the free skin cancer treatment by National Hospital, Abuja**

A press conference was organised on the 5<sup>th</sup> of November at the foundation's office to address the issue of free skin cancer treatment for PWA which National Hospital Abuja put on hold due to the accumulated bill of N50,000,000. The CEO expressed his displeasure at the sudden decision of the National Hospital to cease treatment which resulted to the death of a member of the foundation who was on admission in the hospital.

He further urged the federal government to look into the matter and also allocate funds to pay of the bill. Although the press briefing was not part of the original plan for the strategic meeting, the necessity for organising it was prompted by the sudden death of a member due to negligence of staff at the national hospital Abuja.

### **9.12 Five Year Strategic plan document review and validation meeting by TAF state coordinators**

#### **9.12.1 Review of Accounting and Operational Manual**

In order to ensure that all stakeholders were carried along in developing TAF five year strategic plan, the foundation invited all its 42 state coordinators across the states for the review and validation of the strategic plan document and its operational manual. However, due to the absence of the resource person, Prof. Emeka Eneh, this did not hold. However, the coordinators complained that a copy of this document was not made available to them for a pre assessment before the meeting and hence also requested that the review of the document be placed on hold.

#### **9.12.2 Building Self Confidence by Dr. Samuel Jinadu**

A 45 minutes presentation was delivered by one of the resource persons, Dr. Samuel Jinadu. Dr. Samuel is a Clinical psychologist working with Karu General Hospital Abuja. Dr. Samuel described persons with albinism as people who have high tendency of developing anxiety and depression because of the attitude of the society towards them and how PWA see themselves. He described depression as when an individual is sad most of the day, more than 4 days in a week and for 2 weeks in a roll.

He described building confidence as being contented with one's self. He advised all to learn how to overcome the barriers that society possess to them and also to discover value-adding activities. He further voiced that gaining mastery in what one does is a stepping stone to focusing on one's strength rather than weakness.

#### **9.12.3 Transformational Leadership Presentation by Barr. Chukwuemeka Okoli**

Barr. Chukwuemeks Okoli took on a presentation on Transformational Leadership. His presentation was focused on four cardinal points: Power of the mind; Concept of transformational Leadership; Values and principles; Importance of effective time management

In his presentation, Barr. Chukwuemeka highlighted the need for a transformational leader to show sincere love for those he is leading and also to have a vision without which a leader cannot effectively plan. In summary, he opined that life will not be worth living if one is not continually impacting positively on other people's lives.

#### **9.12.4 Review of Strategic Plan Document**

The review of TAF 5 Year Strategic Plan document was broken down into three presentations for better understanding:

- TAF Management Quest to repositioning the foundation
- The Strategic Action Plan
- The Strategic Action Plan ; Expected output/target

##### **9.12.4.1 TAF Management Quest to repositioning the foundation**

This presentation was delivered by the foundation's Programme/Project Specialist, Damian Ivom. His presentation focused on the foundation's vision, mission, values, Board of Directors and contact details. During the course of this presentation, Mr Damian went through the aim and objectives of the strategic plan as well as the organizational structure. He also went through the reason behind the foundation's decision to come up with a five year strategic plan.

##### **9.12.4.2 The strategic action plan**

This presentation was made by the foundation's Assistant National Programme / Project Specialist, Oluchi Iwuoha. She spoke extensively on the foundation's five thematic programme areas and highlighted the projects the foundation intends to execute in the next five years.

Under each project she highlighted the goals, expected outcomes and the activities scheduled to achieve these goals as well those responsible for performing these activities.

Contributions made and issues raised

- There should be a clear indication of who funds the International Albinism Awareness Day as the last celebration Coordinators were expected to raise their own funds to attend
- Coordinators wanted to know whether Coordinators roles were indicated on the foundation's constitution

- It was observed that the celebration for National Albinism Awareness day have been turned down due to its closeness to the International Albinism Awareness Day. Suggestion was made to shift one of those days so that optimal attention can be paid to each.
- It was advised that the foundation work with National Identity Management Council (NIMC) to get them to add albinism as one of the disability options so as to aid in the foundation's National Survey Project
- The issue of content validity was raised as regards the Strategic plan document draft as the time frame was not consistent. Attention was drawn to the fact that the cover of the document indicates the five year plan to cover 2015 - 2019 whereas the content of the document indicates 2016 - 2020.

#### **9.12.4.3 TAF Back-To-School Project**

Mr Damian Ivom briefed all the coordinators on the TAF Back-To-School Project that is currently funded by TOTAL Corporative, which will be commencing second term of 2016. A total number of 100 indigent children are proposed to benefit from the present funds from TOTAL Corporative. The selection will be drawn from chapters. To that effect, forms were shared to coordinators at the meeting for onward distribution to qualified members of the chapters that collected. Chapters that were not opportuned to get the forms at the meeting got them through emails. All the coordinators were advised to return the filled forms latest second week in January. Below is a table of distributed forms.

#### **9.12.4.4 Conclusion**

The Review meeting came to an end with Damian Ivom requesting that further contributions as regards the Strategic Plan Document can be sent in via email. Electronic copies of TAF constitution will also be emailed to coordinators.

### **9.13 Pan African Albinism Alliance (PAAA) Held In Dar Es Salaam Tanzania 19<sup>th</sup> To 22<sup>nd</sup> November, 2015.**

The first Pan African Albinism Conference was held on the 19<sup>th</sup> to 22<sup>nd</sup> November, 2015 in Dar Es Salaam, Tanzania. The conference organized by Under The Same Sun [UTSS], a Canadian based Non-Governmental Organization [NGO] was aimed at bringing albinism into the front burner to the society in Africa, especially in Tanzania where the killing of persons with albinism in on the increase. The foundation were represented at the conference by her Founder/CEO and its Media and Communication Officer.

The conference which was declared open officially by a representative of Tanzania President, John Magufuli, outlined various actions and supports of the government of Tanzania to persons with albinism in that country. He noted that one of the major achievement of the government is

the establishment of a local sunscreen production factory to help reduce the number of persons with albinism affected with skin cancer in Tanzania.

The four day programme witnessed series of activities such as free eye test, skin cancer screening by team of dermatologist, paper presentations by medical professionals on skin cancer prevention and treatment, strategies for advocacy for the mainstreaming of albinism in government policies and programmes, teachers training to ensuring an effective teaching and learning for children with albinism

The issue of mutilating and killing albinos in Tanzania and other countries in east Africa in particular and Africa in general for money ritual was discussed at the conference and it has made albinos a danger species in the hand of witch doctors and the buyers of their body parts. With the life testimony from some of the surviving victims it was discovered that it is an organized crime carried out by their fathers and members of their families believing that the body parts of PWAs will give them riches. Victims who survived attacks from witch doctors and ritualists shared their experiences.

The conference also afforded participants the opportunities to share ideas and experiences in their various countries. There was a video documentary recording where each of the participants had a section at a studio specifically provided for the event to tell their story as a person with albinism.

A certificate of honour was presented to Foundation at the conference for her numerous advocacy roles in champion the cause of albinism in Nigeria and Africa.

The high point of the conference was the establishment of Pan African Albinism Alliance (PAAA) by 39 African countries that attended the programme. The aim of PAAA is to strengthen the voice of persons with albinism and the albinism community in advocating for the mainstreaming of albinism in UN conventions and treaties and also to ensure that state parties adhered to such. The Pan African Albinism Alliance Conference will be inaugurated in Abuja, Nigeria to be hosted by The Albino Foundation in February, 2016.

#### **9.14 TAF/AMEMUSO Joint Press Conference, November 12, 2015**

TAF in Partnership with Abuja Metro-Politan Musical Society (AMEMUSO) organised a press conference towards the Annual Yearly Musical Concert "OPERA ABUJA". This concert, being an annual event organised by AMEMUSO, was tagged "ARISE". Present at the meeting were Maria Cecilia Toledo de Schmillen, the Artistic Director of the group AMEMUSO. In her welcome speech she thanked the members of the press for honouring the invitation and also thanked TAF for partnering with AMEMUSO to create the needed awareness of the 2015 OPERA ABUJA which was to hold on November 15, 2015. She further emphasised the vision between hosting this event every year. AMEMUSO with this annual event, works to raise awareness of the richness of

talent that Nigerians possess in terms of performing arts and the group wish to tap and train these talents by building a music Center in, AMAC.

Also present at the conference was the three times Grammy Award winner and former Minister of Culture Peru, Susana Baca who was a guest performer at the event. She expressed her delight at the warm reception she had received on her three visits to Nigeria. She also recognised the richness in the Nigerian Culture and also her willingness to work with TAF in creating awareness to the plights of Persons with Albinism in Nigeria

Mr Jake Epelle, who commented via skype call from London, also expressed his delight at the growing partnership between the foundation and AMEMUSO. He also encouraged the organisers of the annual OPERA ABUJA event to use the platform to be advocates for Persons with Albinism. He thanked Susana Baca for her preparedness to work with the foundation and promised to keep in touch.

Also present at the conference were Samuel Ezugwu - Music Director of AMEMUSO, Barbara Magi - PA to the Artistic Director of AMEMUSO, Damian Ivom – National Program/Project Specialist TAF, Oluchi Iwuoha – Assistant National Program/Project Specialist TAF and 13 media houses.

### **9.15 Advocacy visit to Nigeria Education Research and Development Council (NERDC)**

The meeting, which was attended by staff and management of the foundation was held on the 7<sup>th</sup> of December, 2015.

In his speech, the founder/CEO of the foundation thanked NERDC for all their support to the foundation and also for sending a representative during the Inclusive Education policy drafting that was held in Enugu. He pleaded with the management of NERDC to fulfil all the promises made to the foundation especially provision of accommodation for the foundation's Lagos chapter and also the albinism desk in the council.

He also stated how the albinism policy is being sorted after by other countries in Africa. And added that it will be necessary if such is duplicated to other countries by Nigeria. He equally made mention of the upcoming NOAH conference coming up in Pittsburgh, USA in July, and urged the council to send representatives to attend the conference in order to showcase its achievements to other albinism communities.

In his introductory speech, the Executive Secretary of NERDC, Prof. Ismail Junaidu represented by Prof Kate Nwufo, who is also a registered member of the foundation thanked the foundation and the CEO particularly for the effort put in place for the recognition accorded to persons with albinism and the albinism community in Nigeria. She stated that the CEO has left all he was doing for the cause of albinism in Nigeria and the world. She added that the Executive Secretary would have loved to be in the meeting if not for an urgent engagement in Lagos. She stated that albinism have been integrated into NERDC basic education curriculum. On issue of accommodation in Lagos, she stated that the Abuja office will write to Lagos office in order to make provision of the accommodation for the foundation's meetings and operations in Lagos state.

On the global conference on albinism taken place in July at Pittsburgh, USA, she stated that NERDC would like to be part of the conference in order to showcase what the council was able to achieve in albinism education in Nigeria to the outside world.

On the issue of establishing a desk office for the foundation in NERDC, she stated that she will discuss the issue with Executive Secretary and get back to the foundation.

In her own remark, the Director Special Programme Centre of NEDRC stated that she was happy with the level of work done by the foundation especially the CEO in touching other people's lives. She particularly made reference to the National Hospital free skin cancer treatment for persons with albinism that have been suspended. She added that NERDC will continue to sensitise the public on albinism education through its publications. She also advised the foundation to continuously advocate and sensitise the public on the developed materials that will aid members of the public to understand the challenges faced by persons with albinism.

The Director of procurement of NERDC in his remark stated that the issue of albinism is mainstreamed into the council's 2016 budget and added that as soon as the budget is released the council will contact the foundation for planning and programme implementation.



A presentation of all the developed informational materials by NERDC were presented to the foundation. These materials include albinism core messages, frequently asked questions on albinism and the albinism blue print.

### **9.16 IHVN OVC Education Project**

The Institute of Human virology of Nigeria (IHVN) Project is a renewable one year project aimed at ensuring that orphans and vulnerable children in FCT have access to quality education. It was in view of this that in 2013/2014 when the programme started, the foundation was able to enrol 112 (62 males and 60 females) children into the programme and pay 25 (16 males and 9 females) indigent children with albinism's school fees, uniform, sandals and books. In the 2014/2015 calendar year, the foundation was able to cater for the school fees, uniforms, books and sandals of 20 children (10 males and 10 females) while 12 care givers (mothers) were economically empowered with the sum of N10,000 to N18,000 to enable them sustain their small businesses and take adequate care of the albino/indigent children. At the end of 2014/2015 calendar year 74 children (30 males and 44 females) were enrolled into the IHVN OVC project. With this number, a total of 186 children (92 males and 94 females) were enrolled for the year 2013/2014 and 2014/2015 calendar years.

### **9.17 Free skin cancer project at the National hospital**

The free skin cancer project with National Hospital, Abuja was aimed at ensuring that persons with albinism affected with skin cancer is treated free of charge. In the 2015 calendar year, the foundation was able to refer 52 persons with albinism (28 males and 24 females) affected with skin cancer for treatment. Out of this number, three lost their lives. Unfortunately, the project has been suspended following the N50 million owed the hospital by the federal government.