



**REPORT ON OUR COUNTRY PROGRAM  
AND HOW IT HAS CONTRIBUTED TO  
THE R.A.P. TARGET SINCE 2017**

**SUBMITTED TO  
UNITED NATIONS INDEPENDENT  
EXPERT**

**12<sup>TH</sup> OCTOBER, 2020**

# **TABLE OF CONTENT**

INTRODUCTION

1. OUR PROGRAMMES AND PROJECTS

2. ROLL OF GOVERNMENT AND MAJOR STAKEHOLDERS

3. COUNTING OUR SUCCESSES

4. OUR CHALLENGES

CONCLUSION

## **INTRODUCTION**

The number of Albinism has grown rapidly since the report by Statistics Sierra Leone in 2015 that there are only 501 PWA in the country. Albinism in Sierra Leone still crippling to take a reasonable position in society. Many people still believe that PWA is not part of disability. They also believe PWA never dies and be buried, they just disappear, and others will liken the cause of Albinism to having sex during menstruation the story goes on and on. Much sensitization has not yet commenced in our country rather people use PWA as an opportunity to make money.

While we still awaits better conditions of PWA in our country of which the government is still silent, we are happy to see that the action plan for PWA meets its goal in our country with the little resources we have. We believe that one day thing will turn around for PWA in our country. Frankly, there is nothing to write home about from here on PWA (I mean government intervention).

## **1. OUR PROGRAMMES AND PROJECTS**

Since registration with the government, our road map to carry out this noble task in making PWA productive. We have expanded our operational area from Freetown to the five regions of our country. We can boast of having 11 districts out of 16 districts. We do have our core programs as follows:

- **Education and Skill Training:** During our visibility studies, we noticed that PWA have the highest number of drop outs from schools and other learning institutions due to:
  - (a) myopic problem
  - (b) Provocation
  - (c) Little attention for them
  - (d) Poverty
  - (e) Illness
  - (f) Rejection etc.

As education is the key to inclusion, we have introduced a project called “Send a Child Living with Albinism to School”. This project is implemented every academic year to see that we send both ongoing students, those who left for any reason and new students to school.

- **Health:** This is very challenging to our organization as the common problem of health is the SUN versus the SKIN. Our approach to our government has been very robust to tackle this problem but all to no avail. We have lost 4 to cancer and still have increase in cancer related illness especially in the provinces. Countless number of efforts and meetings with the Ministry of Health and Sanitation has proved worthless.

We have a project to tackle this health hazard called “Early Detection against Skin Cancer” which usually implemented every May which is cancer month.

## **2. ROLL OF GOVERNMENT AND MAJOR STAKEHOLDERS**

Issues on Albinism seems to be the list or rather a forgotten one in the hands of government. Other stakeholder can only fit in to the picture when government other source will issue out money for PWA. This has been the norm since Albinism was not integrated into disability.

For PWA in this part of the world there is nothing to write home about especially for government and other players; less attention, no effort towards PWA is taken seriously in all areas of life. It is very discouraging and frustrating.

We really need the intervention of the United Nations to come with policies to the government to set aside a budget allocated for PWA because we do have destitute, orphans and the abandoned.

## **3. COUNTING OUR SUCCESSES**

Over the years, the Albinism Royal Foundation was able to identify many issues ranging from Albino child birth, Reasons why mothers lose their marriages, rejection of Albino child, drop outs from schools, and poverty etc.

Since we started raising awareness on our own, we can boast of having about 65% which is enough for government to help. Our approach with the issue of human right abuse was on top of our priorities. Many now have access to legal justice both in the court of law, the police and the local chiefdom policing.

Out of 501 PWA since 2015, we were able to register over 350 PWA in 11 districts out of 16 districts with a total number of 139 PWA students.

Health intervention for PWA was very robust in that out of 11 cancer cases only 3 died because they fail to tell someone beforehand and fail to access the hospital.

#### **4. OUR CHALLENGES**

Problems and Challenges of Albinism vary from different aspects ranging from Education, Health, and Social Exclusion. Addressing Challenges of such diverse nature needs a swift and systematic approach.

Drafting policies may, however, be an important national step towards providing the support and care needed by people with albinism in Sierra Leone

Considering the challenges around albinism, there should be an Educational, Societal and health care policy for it. Despite relatively low total numbers, a policy is warranted for this particular vulnerable, at-risk group given the high incidence rates of albinism in the country.

Policy-supported efforts should include health care support for eye and skin care. It should also stress the importance of protection from the sun with clothing, hats, sunglasses, shade and sunscreen. And information as well as educational material needs to reach people who suffer from albinism and their families, health care providers and educators. Stringent laws to protect Person's with Albinism from discrimination, abduction, trafficking and violence.

#### **CONCLUSION**

To complement the Regional Action on Albinism, we need to advocate for funds to handle two areas (Education/skills Training and Health). With proper monitoring in place, our society will respect and include us socially and educationally.

Therefore, we are calling on the government and other major stakeholders to extend their hand of help and save our race. Government should establish a Secretariat for and headed by Person's with Albinism.