

GENERAL REPORT ON THE ANNUAL WORK PLAN

Below is a report on the progress of the organization based on the various activities undertaken on achieving its organizational goals and objectives:

CLIMB FOR ALBINISM (OSIEA funding)

The Climb for Albinism is an awareness and empowerment initiative which saw six women with albinism from across Africa scale up Mount Kilimanjaro, Africa's highest mountain, from 1st to 7th October 2018. The aim of the climb was to shift public perceptions on persons with albinism from victimization to empowerment by displaying their capabilities, while consciously raising awareness about challenges persons with albinism often face.

The movement, "Climb for Albinism" was co-created in February 2016 by human rights activist, speaker and change agent, Jane Waithera and adventure filmmaker, speaker and high-altitude climber Elia Saikaly. In February 2018, creative strategist and educational consultant Nodumo Nkomazi was included as social media manager to maintain the movement's online presence, and generalist to assist in coordination efforts.

The Climb would then culminate in a final documentary would be released on the next International Albinism Awareness Day; June 13th, 2019. The team's ascent was documented by filmmakers; Garry Tutte and Anthony Gordon, both commissioned by Saikaly. In May, the whole team met for the first time and climbed Mount Kenya, as a warm up. From February 2018 to September 2018, Elia Saikaly travelled to Kenya, Tanzania, South Africa, Senegal and Nigeria, to film pre-climb footage, including each climber's story, as told by the climber and her family and friends. In October, the team climbed Mount Kilimanjaro with the aim of sharing their lived experiences which spoke out on the macro-aggressive prejudice and discrimination which culminate to the serious and fatal attacks that

persons with albinism in Africa face. The stories of the participants were put together in a documentary which will be released and shared to contribute to changing the narrative around albinism. The movement #ClimbForAlbinism gave the six a safe space to speak on the various challenges that face the albinism community while showcasing their strength and abilities in a quest to creating a regional push for the enjoyment of rights by persons with albinism.

This activity marked a major milestone for which the organization on its goals of utilizing art and innovation to advocate and awareness creation for persons and especially women with albinism and created a lasting impact in the following ways:

- Equipping and building the capacity of the climbers and providing a safe platform for women across different African countries to share their courage stories which greatly created awareness on the diverse and apparently similar issues that affect women with albinism across the continent. These stories were inspirational and encouraging to the albinism community to stand strong.
- Establishment of both a broad and confidential network of women with albinism and mothers of children with albinism which stems from the first activity of the project which bringing together of six women with albinism from different countries to raise and be the voice of women with albinism through their lived experience which represent the stories of other hundreds of persons with albinism in this country. Under this program, we have formed strong support network of women with albinism and mothers of CWA and provided a safe space for their healing from past trauma from their past experiences with stigma and stereotype and transformed them to advocates for either self or their children
- Heightened awareness of the ongoing attacks on persons with albinism

within the region and different forms of discrimination and exclusion that make PWA highly vulnerable. Such issues include blame and abandonment, sexual violence, poverty confinement, displacement, reprisals and non-inclusive learning institutions that continuously lower the levels of meaningful education and professionals in the albinism community.

- Elevating the level of women with albinism in the society to a position they are not often seen in by summiting the tallest mountain in Africa for a noble cause as that of raising the voices of the albinism community itself took the continent's attention on the magnitude of change in policy and empowerment that remains undone in the journey of achieving the SDGS and leaving no one behind, starting with the furthest behind where PWA demographically lie in.

AWARENESS AND ADVOCACY

The following activities have been carried out in creating public education and sensitization on understanding albinism and in bringing out the plight of PWAs.

- Dissemination of vital information related to albinism and the work of the organization through creation of weekly posts on different topics and distribution of the same on Facebook and P.E WhatsApp group from mid-December. To date the following topics have been covered and received immense feedback and impact based on the responses and improved visibility attained.

ALBINISM AND THE KENYAN EDUCATION SYSTEM

The posts done for the week generated engagement with a wide scope of social media consumers, ranging from parents of CWA, to persons with Albinism and the general public.

The organization had a post reach of 1,857 and a post responsiveness of 60%

REPORT ON THE MALAWI INCIDENT

Posts were done in response to this incident that involved the attack and consequent brutal murder of a man with albinism in the presence of his son elicited a lot of emotions and further highlighted the huge task that remains undone at a regional level in prevention and protection of PWA and basic awareness on human rights of PWA.

BURSTING MYTHS AND BELIEFS ON ALBINISM

A campaign on understanding albinism, its occurrence and its unique needs was carried out with a bigger picture of bursting the weird myths and beliefs that exist in our African culture and which form the basis of attacks and assault on the albinism community. There was great success in replacing myths with facts around the social media.

SKIN CANCER AWARENESS

Real facts on what skin cancer is, its cause and occurrence among PWA, its prevention and treatment were disseminated in very innovative ways that utilized photography to illustrate all this. To sum it up, there was a display of different ways of ensuring use of protective clothing while remaining fashionable.

Direct dialogues were also conducted with PWA and parents of CWA who have visited the office over the last one month. We successfully collected and documented their stories with their consent for the organization to use them in inspiring others (available on the organization's database)

1. Beatrice Wanja (PWA) and her parents whom P.E-Kenya assisted to get an opportunity in a tertiary college in Thika where she is now studying psychology and referred her to DR. Choksey Albinism Foundation for scholarship.

2. Esther Wambui parent to Hope Nyambura (CWA) who has met the P.E-Kenya Team severally and received mentorship and training on how to bring up a child with albinism. We have also engaged her as the office cleaning

lady to enable her supplement her income to cater for the needs of the baby as well as her entire family.

3. Winnie Akoth a parent to Octavia Achieng a CWA. She was trained on the care and needs of a child with albinism and especially the need for ensuring her child goes to school and ensure the child is secure. The organization did manage to get her some employment as a house help and liaised with her new employer to have her enrolled on the NHIF platform for her own sake and the child's health care.

4. Parents of Angela Wangari (CWA), who is a form 1 student who were taken through a session on understanding albinism which was very helpful because her mother didn't quite understand that the recessive gene that causes albinism is carried by both parents and had been blaming herself all along for bearing a child with albinism the more reason her family had acceptance issues with Angela. They were also added to our Nairobi support group and made future beneficiaries of our future activities.

5. Rusinga Family, Erastus Ochieng (CWA) who were engaged on phone by the team and enlightened the mother on how to care for a child with albinism by always having sunscreen which is available in government hospitals, the importance of protective clothing and eye care. The family also expressed a desire for financial support in transferring the child to a school which they felt was safer.

PARTNESHIP DEVELOPMENTS

In a bid to seek helpful and resourceful partnerships in realizing our objectives and goals, P.E has established some important networks with relevant stakeholders in this space including donors and policy makers;

- Participation in the Trust conference in the UK (14th -15th November 2018) an annual event that brings together global corporations, lawyers,

government representatives, and pioneers in the field of anti-slavery and women's rights. The organization's ED (Jane Waithera) was invited to speak on the panel as an advocate for the rights of women with albinism in Africa and as someone who has experienced stigma and prejudice. Her insight was an invaluable addition to the panel discussion based on the topic of violence against women.

- The African Union Commission workshop held in Addis Ababa (26th November to 1st December 2018) where the organizations Executive Director participated in the validation workshop on the Draft Protocol to the African charter on Human and People's Rights on the Rights of citizens to Social Protection and Social security and the Draft AU Social Agenda 2063. The organization's major contribution was based on the ED's rich knowledge and expertise in disability and inclusion.
- Participation on the panel of persons with albinism at the 63rd Ordinary session of the African Commission of Human and Peoples Rights (ACHPR) on 27th October 2018, at Banjul, Gambia. The objective was to present a progress report (challenges, advancements and ways forward) on the implementation of the Regional Action Plan one year after endorsement by the ACHPR mainly from the perspective of the Independent Expert and from civil societies from different countries. The Regional Action Plan is the result of broad consultation undertaken in the region under the auspices of the United Nations Independent Expert on the enjoyment of human rights by persons with albinism. This cooperation between the ACHPR and the Independent Expert was facilitated by previous exchanges and collaborative work between the ACHPR and the Office of the United Nations High Commissioner for Human Rights (OHCHR) on the issue as well as by the framework of the Addis Ababa Road Map. The Regional Action Plan is the first regional initiative in Africa to comprehensively address discrimination and stigmatization leading to ritual attacks and trafficking of body parts owing to myths and witchcraft misbeliefs. It is the pinnacle of previous work on the issue including the work of the Working Group on Rights of Older Persons and People with Disabilities of the African Commission on Human and Peoples' Rights and the African Committee of Experts on the Rights and Welfare of children.
- The Australian HC meeting which was attended by Jane and Patricia This was on 3rd December 2018 which is International Day of Persons With Disabilities (IDPD) held at the Australian High Commissioner's residence

whose theme was empowering persons with disabilities and ensuring inclusiveness and equality. As a key stakeholder organization on advocacy for PWA the team took the opportunity to share and express the plight of PWA with the different stakeholders present and also sensitized the audience on our current initiatives and projects on Albinism Awareness and Advocacy under the OSIEA Grant

- On 6th December 2018 P.E team (Jane, Patricia & Nodumo) attended a HIVOS (donor organization supporting organizations in the advocacy space under VOICE) meeting on establishing a future basis of working together which was followed by a submission of a concept note for fund seeking.
- Meeting with the Nyeri Governor (Patrick, Jane and Joseph) on 18TH December 2018

The meeting was set up as a follow-up of the Need Analysis Forum in Nyeri in preparation for the upcoming trainings on understanding albinism and awareness under this project. The main reason was liaising with the county government for data mapping (data on PWA and stakeholder identification at rural areas (health care givers, educators, social workers and administrative assistants. We also got linked up with the Chief Officer in charge of Youth, Gender and Persons with disability department.

- The P.E Team (Jane, Patricia, Joseph and Faith) attended an event on 23rd January 2019 dubbed ‘learning Indaba’ hosted by Voice –HIVOS whose aim was to create a platform in which organizations share and sensitize the society and partners on their current projects innovatively. This will be a great opportunity to learn what other groups are doing on albinism and established links on working together in achieving coordinated efforts.
- P. E-Kenya and AMPA meeting on 24th January 2019. As a team we hosted three officials from AMPA (Aminata Traore, Abdul Toure and Djouma Djisi) in the office for a partnership meeting. On this several issues on possible regional future projects were addressed as documented in the minutes. In addition, P.E also supported the AMPA team with 60 pcs of sunscreen lotion. (AMPA is the Association for Mali for Persons With Albinism).

STRATEGIC PLAN

Progress has been made in working towards having a solid strategic plan for P.E-Kenya for the next three years. The first session on the same took place

in mid –December where the whole P.E team met and engaged an external expert on strategic planning and a general framework on the contents laid down as follows:

1. Chapter one: Background of the organization
2. Chapter two: Linkage to other plans / policy documents (SDGs, RAP)
3. Chapter three: Situational analysis (SWOT and PEST)
4. Chapter four: Strategic pillars/priority areas
5. Chapter five: Implementation Framework
6. Chapter six: Monitoring and Evaluation

The vision, mission and core values describe the rationale of the organization. The concept of albinism incidence has been brought out at a global, regional and national level. The SP has also been linked to other plans like the UN Sustainable Development Goals, Regional Action Plan on Albinism, the Convention on the Rights of Persons with Disability and other disability Acts.

ORGANIZATION OPERATIONS

The following activities that relate to routine operation and smooth running of the organization have been undertaken but some are still work in progress:

- A tentative work plan for the awareness and advocacy on albinism project (OSIEA) has been developed, approved by the team and also shared with the fiscal agent.
- A weekly reporting template was developed and shared with the team and has successfully been used for presenting weekly reports by all
- Based on the need to have a reporting system on the organizational activities, projects and program events in response to the Regional Action Plan on albinism, a general work plan for the next one year has been developed and approved by the team. It includes future projections on proposals that the organization may seek funding for.
- A staff meeting was conducted on 3rd January 2019 in which several issues were addressed in the spirit to grow the organization and ensure its strategic goals are met. (minutes of the meeting available)
- The development of digital communication platforms such as the Slack. Joseph developed this and also trained the team on its use and how

documents are shared. In building the P.E-Kenya database, he also trained the team on the use of MS Access in developing a wide database of PWA within our target areas.

- A proper filing system both physically and digitally has been put in place to ensure information safeguarded for easier retrievals and reference in book-keeping activities

IMPLIMENTED ACTIVITIES (OSIEA PROJECT)

Three major activities in reference to the tentative working plan have been executed within the second phase of the OSIEA-PE Kenya project and their respective successes and challenges are as described below:

- **NEED ANALYSIS;**

This was carried out in 3 phases; through an online need analysis form that was distributed and is still on our social media platform, a ‘Hear Me Too’ forum involving young ladies with albinism in Nairobi (10th December 2018) and a focus group discussion involving PWA, CWA and their parents in Nyeri and Kirinyaga (13th December 2018). The three activities yielded immense feedback on the real issues facing PWA as follows;

From a vibrant group young ladies with albinism and in a closed door meeting in which we engaged them in candid conversations on issues that relate to them as women with albinism, we received the following feedback:

- **SELF AWARENESS AND SELF LOVE**

Almost all of the participants have had experiences both in childhood and adulthood that blurred their self-awareness. Most of these experiences revolved around parents mistreating and misunderstanding them, which evidently damaged their capacity to love themselves.

Most of the ladies showed tendencies of self-blame for the mistakes and/or misfortunes of their families and for the fact that they were born with Albinism.

- **ACCEPTANCE AND INCLUSSION IN SOCIAL CIRCLES**

Some of the participants have encountered incidents of discrimination from family members and their communities as a result of having Albinism.

In the case of one participant, a teacher intentionally excluded her in any form of participation in class.

- **BLAME AND ABANDONMENT**

Mothers to some of the participants were accused of infidelity after having children with Albinism.

- **MOTHERHOOD AND MARRIAGE**

It was evident from what the participants shared that society has an absurd set of expectations for women with Albinism, with regards to marriage and motherhood.

In marriage, they are expected to be grateful that they even got a spouse and silently accept any mistreatment therein.

In motherhood women with Albinism are seen as being incompetent.

- **ACCESS TO SEXUAL AND REPRODUCTIVE HEALTHCARE**

There arose an evident gap in the comprehension of reproductive healthcare.

In one particular utterance a participant made an innuendo on their linkage of reproductive health issues to witchcraft.

LEARNINGS:

Notably there was a genuine need to create a safe space and platform where ladies with albinism could share their lived experiences and form a strong network where they would work together and build each other's capacity through their stories of courage.

It was also noted that a training skewed towards trauma healing, mental health, self –awareness/ acceptance/love /advocacy and capacity building would be a necessary intervention measure. This largely informed our forthcoming training and adequate preparation of training material in this context has been made.

NYERI-KIRINYAGA FOCUS GROUP DISCUSSION:

From this focus group discussion, a meeting that was attended by 30 persons (PWA, CWA& their parents), we collected the following data and feedback:

- **UNDERSTANDING ALBINISM**

From the participants' contribution, it is clear that there is a significant gap in understanding Albinism and its genetic cause and most people do not understand Albinism. Public awareness and acceptance of PWA is very low among different stakeholders (parents, caregivers, health care providers, teachers). The need to foster understanding and spread the truths about albinism including its genetic information and end myths and stereotypes that contribute to human rights violations is of great importance. One parent of CWA complained of having been completely neglected in hospital after having a CWA by the health officers and received no support or advise on intervention measures necessary in taking care of the child.

- **BLAME AND ABANDONMENT**

most women participants complained of being blamed by their husbands and family to an extent of being abandoned for bearing children with Albinism. Others have faced great hostility from the extended family and mothers in law specifically. This calls for fierce advocacy to demystify the blame that is heavily imposed on a mother when a CWA is born. There was a case of one lady who has since been separated from her husband from the day she bore a CWA who is now eight years old.

- **SELF-ACCEPTANCE AND SELF-ADVOCACY**

Notably, PWA are still facing social stigmatization and discrimination in the communities they live in with a major outcry from social institutions such as schools, work places, hospitals and even largely at family levels. This results to a greater need for psychological and social empowerment to PWA to enable them develop self-worth and learn better ways to effectively advocate for their own rights. For instance, the PWD cards are supposed to enable them access free treatment from public hospitals but most PWA are not aware and therefore this waiver is never implemented in most cases.

- **PARENTING AND ALBINISM**

Reportedly parents of CWA face two major issues when raising up a child with Albinism. The first challenge comes with the amount of stigmatization and discrimination that parents of CWA receive from the society. This brings out the need for an inclusive public education involving all stakeholders from the society that include mid wives, caregivers, family members and teachers on understanding Albinism. The second issue is poverty confinement among mothers of CWA because in most cases they end up quitting their jobs to take care of a CWA. This often comes with an additional financial burden associated with meeting the special needs of a CWA basically the skin care and eye care. There was also a report of discrimination

- **ACCESSIBILITY TO EDUCATION OPPORTUNITIES**

Currently CWA are encouraged to enroll in mainstream schools for social and psychological empowerment as opposed to special need schools. This approach enables a CWA to fully utilize their residual vision however it becomes a greater challenge when the child finds a school community that is not accommodative and irresponsive to the needs if a CWA. The solution is to create massive awareness and advocacy for CWA in schools for a more accommodative learning environment with understanding and kindness from both students and teachers.

- **SOCIAL ECONOMIC EMPOWERMENT**

Notably four major issues came up strongly from PWA and parents of CWA on empowerment:

- Inaccessibility of employment opportunities

PWA often face direct discrimination and denial of existing job opportunities while searching for employment. Non –recognition of PWA in online application forms specifically with government jobs is significant and participants felt that the 5%of jobs that is supposedly reserved for PWD at county levels never recognizes PWA as PWD and this issue needs re-address with relevant stakeholders. In the case of one participant, she was directly discriminated and denied the chance to take part in an interview in the scheduled day.

- Need for vocational training, development of entrepreneurial skills and mentorship to equip PWA and parents of CWA to with business skills that will enable them to fully develop and exploit their business potential and create sustainable business and become self-reliant
- Social schemes
There is a notable need to empower and enlighten PWA on existing resources such as affirmative action funds basically the Uwezo Fund and Youth Fund on how to access and benefit from them

SUCCESS

The team used the data and information gathered in developing training materials below:

- TRAINING MATERIALS ON UNDERSTANDING ALBINISM

In developing content on what to train with and on in our forth coming public awareness and trainings on albinism, we analyzed and classified the feedback under the following subjects and developed content based on the same:

- Understanding albinism
- Self-awareness and self-advocacy
- Parenting and albinism
- Education and albinism
- Sexual education and health rights
- Economic empowerment and entrepreneurship

- DESIGNING AND PREPARATION OF TRAINING MATERIAL

This activity involved finding a designer who would convert the training literature into understanding albinism tool kits or brochures, stickers and posters that utilize art in display. We believe this would be easy to understand and create long lasting imagery and memory even after the trainings.

This activity has been stalled financial issues and requirements and is therefore behind schedule in reference to the tentative project work plan.

1. RESOURCE MOBILIZATION

Efforts to increase the financial base and the capacity of the organization have been put forward with several funding opportunities being sought and updated in a donor scoping matrix indicating priority areas and submission deadlines. So far, three proposals have been developed; ‘Ceasing the Opportunity’ Grant under VOICE whose concept note was submitted on 23rd December 2018, the UN Women Trust Fund and the UNDEF Grants whose concept notes were developed but could not be subjected due to key eligibility criteria requirements that the organization lacks at the moment.

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