

2019 ANNUAL REPORT OF OSTEOGENESIS IMPERFECTA FOUNDATION

GHANA (OIFGHANA)

INTRODUCTION

Osteogenesis Imperfecta Foundation is an organization that exists to help people living with Osteogenesis Imperfecta (OI) with care, management and support within Ghana.

OI also known as brittle bone condition is a rare genetic bone condition, which causes the bones of some individuals to be brittle and break easily with or without any apparent reason. This condition makes individuals with such conditions to be physically challenged and thus need assistance and support from society.

OBJECTIVES

The objectives of the organization are;

- To educate and create awareness of OI in Ghana.
- To help people understand, respect, accept and improve the quality of life for people living with Osteogenesis Imperfecta.
- To advocate for quality health care and treatment for OI patients.
- To help solicit for adoptive aids and mobility equipment for people living with OI.

The organization's vision is to advocate for the establishment of Osteogenesis Imperfecta treatment Centre in Ghana since there is none in the country.

OFFICE

The foundation operates from its office at house number 2 at Pedu, Abrewa Gyimisiwa close in the Cape Coast metropolis.

COMPOSITION OF THE EXECUTIVE COMMITTEE

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| a. Director | Mr. Harold Stewards Amonoo-koufi |
| b. Director | Nicole Ama Abrahm |
| c. Director | Justina Yiadom-Boakye |

ORGANIZATIONAL AFFILIATION

The foundation is affiliated to Heart to Heart foundation- USA, OIF Europe and OI parents Group

STAFFING

The foundation has nine (9) voluntary staff members.

The organization though very young was able to undertake some activities during the year under review.

ACTIVITIES FOR 2019

- On the 23rd of January, the organization made a visit to Kolebu Teaching Hospital to visit an abandoned OI child. The foundation was then officially introduced to the hospital, specifically its ICU designated for children. Health officers at the unit were also trained on how to handle OI children, especially with issues bothering on their bathing, feeding and dressing.
- In the month of May, Wish bone day celebration witnessed series of awareness creation programs. These included sharing of tracts that educates the masses on the condition. These distributions were mainly done at shops, supermarkets and several other places where people gather. ATL FM in Cape Coast also hosted officials from OIFGhana to speak on the condition. This was followed by the **'#A Touch of Yellow'** challenge lunched on social media platforms. This online campaign went beyond the shores of Ghana to touch the hearts of many.
- The ambassador of OIFGhana, Afia Ayeyi Yiadom -Boakye, featured in a documentary filmed by TV3 in June which went viral in a matter of weeks. This created an opportunity for Ayeyi to meet the First Lady of Ghana, Mrs. Rebecca Akuffo Addo.
- In September, the President of OIFG, Justina Yiadom Boakye was invited to grace the year's Special Needs Parenting Summit to speak.
- OIFGhana engaged MTN Ghana Foundation for possible sponsorship and assistance for mothers of children living with OI. This was a fruitful discussion awaiting further deliberations in the coming months.
- In order to help empower mothers of children with OI to become self-reliant, management of OIFGhana organized a skill training workshop for participants to be trained on how to produce liquid soap. All participants received donations and other packages as their Christmas gifts. Participants expressed their profound gratitude for both the training and gifts received.
- Thankfully, all children under the care of the organization received their quarterly Pamidronate treatments at the Cape Coast Teaching Hospital accordingly.

FUND RAISING

The organization was able to raise meagre funds through donations received through our Social media interactions –WhatsApp, YouTube and Facebook

CHALLENGE

The organization's major challenge is funding as the OI condition requires huge financial resources to treat.

FUTURE PLANS

The organization's future plan is to bring all parents and people living with OI to form a formidable Association to advocate for quality treatment and Centre for OI patients.

COMMENDATION

We would like to thank our social media friends, donors, volunteers and partners who in diverse ways supported the foundation.

CONCLUSION

We are pleased with the progress we have been able to see the past year, and look forward to continuing to see reached with our advocacy and programs. Above all we thank the Lord for the strength He has given us to do the work and His hand of blessing in the work