



OIFN ANUNAL REPORT 2024. WWW.OIFN.ORG



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Our Mission & Vision:

The Osteogenesis Imperfecta Foundation Network (OIFN) aims to guarantee that the demands of those who have osteogenesis imperfecta (OI) in the UK and across Africa are recognised, appreciated, and completely satisfied.

In addition to continually supporting the provision of wheelchairs and other mobility aids and raising awareness of the condition, OIFN will work to improve the quality of life of individuals with OI in the UK and Africa by offering guidance, information, and signposting.

We will also support and collaborate with other pertinent organisations and stakeholders to advance our efforts to realise our organisation's goals and objectives. We sincerely care about the empowerment, well-being, and dignity of vulnerable groups, including those with brittle bone disease, also known as OI, and disabilities, and work to build a more inclusive and equitable society.

Our Aim and Objectives:

Set up educational institutions that would give OI children the ability and confidence to communicate effectively.

To develop in each OI child self-esteem and a feeling of self-worth

We will encourage strong connectivity and effective partnerships between parents and their OI organisations, professionals, and stakeholders and create networking opportunities.

Organise conferences or seminars where specialist doctors are invited from home and abroad to discuss the latest medical discoveries on OI.

To be able to recognise their capabilities and maximise their potential.

Show respect to individuals but work collaboratively towards common goals with shared learning outcomes.

Signposting, information dissemination, etc.

To create a 'feel good' factor so that each OI child feels good about themselves and what they do.

To provide mobility for independent or assisted movement.

To continuously raise awareness of osteogenesis Imperfecta, also known as brittle bone disease.

OUR PROJECTS

Osteogenesis Imperfecta, commonly known as Brittle Bone Disease, is a genetic condition affecting approximately 5,000 individuals in the UK, as noted by Brittlebone.org. Our charity is dedicated to raising awareness, enhancing the quality of life, extending life expectancy, and fostering greater inclusion while reducing isolation for those affected by this condition.

Our project spanned nine months, during which the outcomes and progress achieved have consistently met and exceeded our expectations. At the project's inception, we conducted a series of seminars (located in Hertfordshire) and webinars, each lasting approximately two hours, focusing on wellness for individuals living with Osteogenesis Imperfecta (OI).

One of the key seminar topics was starting a business for people with disabilities. This session aimed to empower participants, offering them a sense of purpose and an alternative to idleness and isolation. Another important seminar addressed housing issues, providing valuable insights and resources. Additionally, we held a workshop dedicated to mental health for individuals with disabilities. This session explored strategies for maintaining mental well-being amidst the daily challenges and pain associated with OI. This event had 40 people in attendance and garnered significant positive feedback; one stated that "the information was desperately needed".

Our webinar series included a session on managing pain, offering practical advice and support for those dealing with chronic discomfort. Another webinar focused on corrective surgery for OI, providing participants with crucial information and hope for improved quality of life. Our webinars attracted a substantial audience, with 70 participants in attendance. This impressive turnout was achieved by live-streaming the sessions on Facebook, thereby reaching an international audience. Given the high attendance from our global audience, our webinars featured approximately six distinguished speakers.

Furthermore, we hosted a "Partners Get Together" event to foster partnerships and raise funds. This event served a dual purpose: to increase awareness of our

organisation and to solicit potential partners for support and fundraising. Each partner was encouraged to invite a friend who could become a partner.

Our International Event in Nigeria (Delta and Lagos State).



The event was a resounding success, resulting in two new partners who committed to supporting us with their expertise and sponsoring our events in Africa. One of our notable initiatives includes a wheelchair distribution in Nigeria, where we plan to deliver 300 wheelchairs. We actively support and collaborate with other OI organizations across Africa, using our events to raise awareness and generate support for our African projects. Although the Lottery funding was designated for our UK project, we strategically used our events as a platform to create awareness and raise funds for our international work in Africa.

Vision 6060 Project



The OI Vision 6060 project is a new project we started in 2023, and it is aimed at supporting oiers and other disabled people with their vision, where they were assessed by a trained and qualified optician and given the appropriate glasses to them. These glasses were donated by individuals here in the UK and the USA. This is a new project by the organisation. We had the Vision 60 60 project, which was held on the 13th of March 2024, at the same time as the OI wheelchair distribution at the same venue. We had 65 individuals who came for the eye assessment, and more than 50 people benefited from the programme, with others given referrals as their cases needed the consultation of an eye consultant.

At the Harpenden Carnival, we had a stand which allowed us to actively engage with the community, raising awareness about brittle bone disease. We interacted with individuals affected by the condition and provided guidance on accessing additional support services. Moreover, we made valuable connections with volunteers from L&D Hospital, who were previously unfamiliar with the condition.



This has led to an invitation for continued dialogue to enhance awareness and foster greater engagement among hospital staff. On Saturday, February 8th, 2024, we were at the Harpenden Carnival talking and engaging with people across Hertfordshire and the London region about brittle bones, educating them on the condition and how they can support it.

We had fun, and meeting new people and making friends gave us all the satisfaction.



Thank you to everyone who stopped by our stall to ask questions, donate, or chat. It was great to meet everyone.

Thank you to all our volunteers and team at OIF Network UK; you are all fantastic.

Thank you to the Community Fund, National Lottery, and Awards for making this a reality. It's worth the cause.

The OIFN were fully represented at the OIFE Capacity Building Conference held in Valencia, Spain @oioife "Stronger Together, " from 5th – 8th September 2024.

[#Valencia](#) [#oife](#) [#strongertogether](#) [#oi](#) [#italiandelegation](#)
[#UnbreakableSpirit](#)





We OIFN secured £2000 from the Scouter Foundation to support the international work of wheelchair distribution in Lagos and Delta State and £1000 from Bethany Community Church Harpenden, including donations from generous individuals.



OUR THANK YOU's AND SUMMARY

Testimonial



"Being a part of the conference has given me the confidence and resources to pursue my objectives tenaciously. It has given me the confidence to take charge of my life and trust my skills and inner self, knowing I have the strength to push myself further."

Jane Cox

"It was a life-changing experience to attend the recent conference Knowledge is Power in Redbourn. It was a worthwhile investment of my time and energy because the enlightening lectures and stimulating networking opportunities offered priceless knowledge and contacts. I want to say thank you so much, and please do contact me when you are planning another session.

Bree xxx



As we all know, there is no climbing up without difficulties, and this year was no different. We had problems with the volunteering role, and one of our trustees left; even though we scaled through the year, it was not at a cost, as the other trustees had to put in extra time to fill the gap to ensure the smooth running of the organisation, for that we say a huge thank you to all our trustees and volunteers, we very much appreciate all your effort and hard work.

Our organisations faced challenges, technology adaptation, and a lack of awareness of brittle bone (OI) disease within our community. We have committed to attending the outdoor communities' event to enable us to reach more audiences to raise awareness.

Thank You!

We are grateful to our funders, the Scouter Foundation, Bethany Community Church Harpenden, and generous individuals who donated to our cause. To all our trustees and volunteers who have worked tirelessly

We thank our partners Through The Roof (TTR) and all the individuals who have donated and partnered and with us directly or indirectly to help us achieve our goal in 2024.

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