

# 2025 Annual Report, Impact and Appreciation

## Osteogenesis Imperfecta Foundation Network (OIFN)

2025, Year in Review

### OIFN International Conference 2025 – *Breaking Boundaries*



In 2025, the Osteogenesis Imperfecta Foundation Network (OIFN) successfully hosted its scientific International Conference in Hertfordshire, United Kingdom, under the theme *Breaking Boundaries*. The conference convened a diverse global community of medical professionals, researchers, advocates, policymakers, individuals living with Osteogenesis Imperfecta (OI), and caregivers from the UK, Africa, and beyond.

The conference opened with a symbolic flag march that symbolised international unity and a shared commitment to inclusion, collaboration, and advocacy for people living with brittle bone disease. This decisive moment set the tone for a gathering rooted in trust-building, cultural diversity, and collective action.

Delegations from Kenya, Nigeria, and Nairobi shared messages of appreciation, highlighting the knowledge gained and the positive impact the conference will have within their communities. Participants described the conference as a transformative platform for learning, networking, and empowerment, supported by OIFN's welcoming and inclusive environment.

### Key Outcomes and Benefits

- Improved understanding of multidisciplinary OI care, including early diagnosis, physiotherapy, orthopaedics, nutrition, mental health, and audiology
- Increased insights into inclusive disability research, with a focus on underserved communities
- Strengthened advocacy skills to support policy engagement and inclusive healthcare reforms
- Expanded global networks, fostering collaboration and resource sharing
- Renewed motivation to raise awareness and support individuals and families living with OI

The conference also inspired pride and hope across African OI communities, who followed the event closely and celebrated the representation of African voices on a global platform.

More than a medical conference, the OIFN International Conference 2025 became a movement of solidarity, advocacy, and hope. As OIFN moves forward, it remains committed to expanding global partnerships, advocating for equitable healthcare policies, and amplifying the voices of people living with OI and their families.

**Together, we are stronger.**

## Organisational Impact and Progress in 2025



In 2025, the Osteogenesis Imperfecta Foundation Network made measurable progress and strengthened service delivery. Despite operational and systemic challenges, OIFN continued to advance its mission to improve the quality of life of persons living with Osteogenesis Imperfecta through advocacy, healthcare access, mobility support, awareness creation, and inclusive community engagement.

All interventions implemented during the year were aligned with the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)** and the **Sustainable Development Goals (SDGs)**—particularly:

- **SDG 3: Good Health and Well-being**
- **SDG 10: Reduced Inequalities**
- **SDG 17: Partnerships for the Goals**

## Advocacy, Awareness, and Networking Impact

Throughout the year, OIFN implemented advocacy and awareness initiatives that increased the visibility of Osteogenesis Imperfecta, promoted disability rights, and strengthened multi-stakeholder engagement. These programmes helped reduce stigma, improve access to accurate information, and strengthen referral and support networks.

## Access to Healthcare and Medication Support



OIFN extends deep appreciation to our treatment and medication sponsors, whose support significantly improved access to essential treatments and continuity of care for persons living with OI. This support contributed to:

- Improved health outcomes and reduced treatment interruptions



- Increased awareness of OI among healthcare professionals
- Expanded collaborations with hospitals across Nigeria

These efforts strengthened the healthcare ecosystem supporting persons living with OI.

## Mobility and Assistive Device Support

### mobility

In partnership with TTR, OIFN distributed **400 mobility aids** to persons living with OI, supporting independent living and participation. These interventions were implemented across **four (4) states** and **seven (7) Local Government Areas**, significantly enhancing mobility, autonomy, and inclusion in education, healthcare, and community life.

This initiative addressed critical barriers to inclusion and demonstrated the transformative role of assistive technology in improving the quality of life of persons with disabilities in Nigeria.

## Programme Reach and Geographic Coverage

In 2025, OIFN reached **over 1,500 direct and indirect beneficiaries**, including persons living with OI, caregivers, and healthcare providers, through integrated advocacy, awareness, medical support, and mobility-focused interventions.

Programme implementation spanned **four states in Nigeria**:

- Oyo State
- Ogun State
- Lagos State
- Delta State

Interventions were delivered across **seven Local Government Areas**, ensuring meaningful community-level engagement and impact, and the organisation hopes to expand its work into more states.

## Medical and Professional Contributions

OIFN expresses profound gratitude to the doctors, orthopaedic specialists, paediatricians, physiotherapists, nurses, and allied healthcare professionals who worked tirelessly throughout 2025 to provide life-saving and long-term care for individuals living with OI. Their dedication and expertise remain central to improved survival outcomes and holistic care.

## Regional Collaboration



OIFN values its continued partnership with our sister Osteogenesis Imperfecta community in Kenya, and Clevenard Media, which strengthened regional collaboration, peer learning, and cross-border advocacy throughout the year.

## **Lives Touched: Care, Training, and Lasting Impact**

### **Hope and Healing for Dee**

Dee was referred to us by the Brittle Bone Society. At just five years old, she was living with brittle bone disease and facing profound emotional and social challenges. Having been abandoned by her mother, Dee was residing in a care home in Ogun State that felt ill-equipped to meet her complex medical needs and was considering asking her to leave.

After assessing her situation, we implemented a multidisciplinary approach to address her medical, psychological, and social needs. Dee was taken to Lagos State, where she received her first treatment with **Zoledronic Acid**, a bone-strengthening therapy, alongside a complete medical assessment. We also provided her with a wheelchair—an essential mobility aid—as she had previously relied on bottom-shuffling to move around.

Through these interventions and ongoing support, the care home reversed its decision and committed to continuing her care. We remain actively involved to ensure Dee receives ongoing medical attention and holistic support. Her story is one of hope, advocacy, and the power of compassionate intervention, with reports from her dad and the home where she resides attesting to improved bone strength since her first dose intake of Zoledronic acid.

### **Roofbreaker Training – February 2025**

In February 2025, we hosted **Roofbreaker Training**, with over 150 participants across the four-day programme. The training focused on equipping participants with Church leadership and disability-inclusive practices within the church and society, while fostering collaboration, personal growth, and the spread of God’s word and love.

Beyond inclusivity building, the training also had a spiritual impact and was committed to ongoing collaboration with the **ECWA Church**, underscoring the programme's far-reaching influence.

### **Participant Testimonials**

*“The Roofbreaker Training was eye-opening and deeply practical. I gained tools I can immediately apply in my community, and the sessions challenged me to think differently about collaboration and service.”*

— **Training Participant (Moses)**

*“This training strengthened both my skills and my faith. The atmosphere of learning and unity was powerful, and I am grateful for the opportunity to connect with others who share a heart for impact.”*

— **Training Participant (Clare)**

*Thank you for standing with us as we continue to bring care, training, and transformation to lives and communities.*

## Donor and Stakeholder Appreciation



The achievements outlined in this report were made possible through the trust, commitment, and partnership of our donors, sponsors, volunteers, advocates, and community members. Every programme delivered, every mobility aid distributed, and every life impacted reflects your invaluable contribution.

We extend special appreciation to **Through The Roof. (TTR), Bethany Community Church, National Youth Council of Nigeria, Europe Region, Tolexars Therapy and Services, and** all our volunteers, donors and partners, for their unwavering support throughout 2025.

## Financial Overview and Support



In 2025, the organisation experienced notable financial challenges that constrained the scale of our programming and limited our overall reach. Despite these limitations, we are proud of the meaningful impact achieved throughout the year. Our continued operations and program delivery were made possible through the generous support of our community. A grant of under £1800 from Bethany Community Church, together with funds raised through dedicated

fundraising efforts and the generous contributions of individual donors, provided critical financial support that sustained our work. Their commitment and generosity enabled us to continue advancing our mission and serving those in need, even during a period of reduced funding.

## Looking Ahead to 2026



As OIFN transitions into 2026, we remain committed to scaling impact, continuing and strengthening partnerships, and enhancing transparency and accountability in programme delivery. Our priorities include:

- Expanding geographic reach
- Increasing access to healthcare services and assistive devices
- Advancing inclusive policies aligned with global disability frameworks
- Better funding

Because of your continued commitment, we have raised awareness, fostered inclusion, and provided meaningful support to individuals and families affected by Osteogenesis Imperfecta. Together, we move forward with renewed purpose—stronger, united, and steadfast in our shared commitment to a future where inclusion is fully realised for all.

**Thank you.**

Admin Team

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