Osteogenesis Imperfecta Federation Europe (OIFE)  
Strategy Plan 2018 - 2022

Introduction
Osteogenesis Imperfecta Federation Europe (OIFE) is an umbrella association for organizations dealing with the rare condition Osteogenesis Imperfecta (OI) also known as brittle bone disease. The non-profit organization was established in 1993 by six founding OI-organizations and is registered as a charity in the Netherlands.

We have more than 30 member organizations in three main categories:

• European OI-organizations (ordinary members)
• OI-organizations outside Europe (associate members)
• Supporting member organizations
  o Aid organizations
  o Research foundations

The OIFE does not have individual members. Our ordinary member organizations operate on a national level providing support to people with OI and their families through peer activities, awareness work and support for people with OI and their families.

OIFE is a member of EURORDIS – the umbrella organization for rare disease organizations in Europe.
Vision
Children and adults with OI living active and independent lives -
with access to competent healthcare and necessary social support

Mission
We connect and empower organizations, professionals and individuals
to improve lives of people with OI.

Goals
The goals of the OIFE are to

• **represent** our members on an international level and **be the voice** of people with OI
  and their families;
• grow an **international network** between professionals, organizations, individuals and other stakeholders;
• **advocate for** access to competent **healthcare and social support**;
• encourage scientific **research** on OI;
• **empower our** members by sharing information, knowledge and best practices;
• support **development** of OI organizations and local support in more countries;
• **guide individuals** towards information, healthcare and support.
Objectives
The objectives to achieve our strategy are to:

• represent our members on an international level and be the voice of people with OI and their families by
  • being an active member of Eurordis;
  • cooperating with the European Reference Network for Rare Bone Disorders
  • being connected to the European Medicines Agency (EMA);
  • being involved in European policy work for Rare Disorders;
  • participating in relevant international conferences related to OI
  • being involved in the planning of the international scientific conferences on OI;
  • making sure that the needs of both people with OI and their families are heard.

• grow an international network between professionals, organizations, individuals and other stakeholders by
  • maintaining an updated contact list of clinicians and researchers working with OI
  • connecting clinicians, researchers and representatives for organizations working with OI
  • developing a closer collaboration with industry when beneficial for the OI-community
  • contributing to travel support for volunteers, clinicians and researchers
  • developing a constructive relationship to OIFE’s Medical Advisory Board
  • actively recruiting new member organizations

• advocate for access to competent healthcare and social support by
  • promoting equal access to diagnosis, treatment, follow-up and social support
  • encouraging international collaboration between centres of expertise and healthcare providers
  • collecting information on access to treatment & social support for people with OI
  • being informed and updated about guidelines and best practices in OI

• encourage scientific research on OI by
  • encouraging more research in OI on different aspects
  • collecting and spreading information about ongoing or planned research
  • promoting priorities in research from people with OI and their families
  • strengthening our member’s capacity to be involved in research
  • promoting development of registries and databases on OI
  • sometimes partnering with or endorsing research projects or scientific initiatives with a broad international scope;

• empowering our members by sharing information, knowledge and best practices by
  • developing and updating efficient communication channels and tools
  • spreading information about and reporting from conferences and events
  • creating opportunities and promoting a culture for sharing of ideas and projects;
  • continuing to organise topical meetings
  • advising our members on organizational issues;
  • promoting awareness initiatives like Rare Disease Day and Wishbone day
  • supporting the organisation of youth events
• support development of OI organizations and local support in more countries by
  • helping individuals and groups in countries without an existing OI-organization to connect with local professionals and health care providers
  • assisting with establishment of new organizations
  • further developing guidelines on starting an OI-organization
  • supporting the spreading of knowledge through projects like Flying OI Experts

• guide individuals towards information, healthcare and support.
  • further developing the OIFE passport
  • providing peer support
  • helping individuals with OI to connect with each other;
  • guiding individuals to help them find information, organizations, health care providers and social support locally

Produced by: The Executive Committee
Draft developed date: July 31st 2018

Approved by: The Board of OIFE
Approved date: August 19th 2018