



**Care4BrittleBones**

**Beleidsplan / Policy (2025)**





# Together for a better quality of life

Many aspects are important when it comes to the “**Quality of Life**” for people with OI.

Most aspects are supported directly or indirectly by the country’s OI Community organisation (for example, VOI, Deutsche OI Gesellschaft, BBS, China Dolls, OIF of India...). There are ca. 40 countries with patient organisations for OI.

This makes sense! Patient organisations provide tremendous value “**HERE AND NOW**” through establishing and nourishing a strong local OI Community that

- supports each other
- inspires and challenges each other as to what is possible
- gets members access to the best possible healthcare available from hospitals and universities covered by insurance or subsidies where needed.



**Improving Health and Quality of Life for the FUTURE** requires **substantial levels of research over many years** based on strong **international collaboration**. This is what **Care4BrittleBones** is focussing on, working together with OI-researchers and the country OI-communities.





# Why collaborate for OI Research



OI is a complex and heterogeneous disorder which is rare.

The key reasons to collaborate for research are:

1. **Establish a sufficient size of cohorts** for **better** OI research
2. **Ability to compare** across different countries
3. **Access more funding available for larger projects** than the individual country could enable
4. **Ensure high quality management of Research proposals**
5. **Drive synergy from enhanced communication & network**
  - **amongst the OI-Community** after Research has been completed
  - **amongst OI – Researchers and healthcare providers** to learn from and build on each others work
  - **In between OI Community and OI Researchers**



**BETER RESEARCH**



**BETTER QUALITY OF LIFE  
OF PEOPLE WITH OI.**





# Overview Care4BrittleBones

## PARTNERS IN RESEARCH

- ERN (European Reference Network/EU)
- BBDC (BrittleBones Disease Consortium / USA + Canada)
- Pharmaceutical Industry
- 1100 Researchers and Clinicians with long term interest in OI
- High caliber international Advisory Board of Scientists and OI experts

## WHAT WE DO

### 1. Research

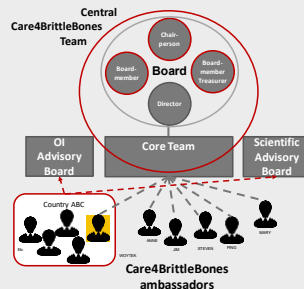
Funding

Coordination,  
Direction,  
Prioritization

### 2. Fundraising

### 3. Network & Org

## WHO WE ARE



Improving  
Quality of Life  
for people with

**Osteogenesis  
Imperfecta**

through  
**RESEARCH**



## HOW WE WORK

### Values

- Positive
- Inspirational
- Innovative

We work according to the highest standards as a charity. We are recognized as ANBI, members of Goede Doelen Nederland and certified by CBF

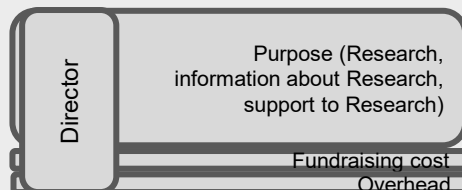
## PARTNERS IN OI COMMUNITY

- OIFE (European Federation Osteogenesis Imperfecta)
- OIF (USA/Canadian Patient organization)
- Ca. 40 national OI organizations
- People with OI & their family and friends

## COMMUNICATIONS

- Website
- E-mail / Newsletter
- Social media: Facebook, Instagram, twitter
- Zoom, teams
- Annual Report
- You Tube

## COST



## LONG TERM APPROACH: Multi year plan

- Research
- Fundraising
- Networks
- Operations
- Fundamentals





**Organisation & Network**





# Care4BrittleBones Organisation

The **Care4BrittleBones Board** and **Core Team** are working in an integrated way. Together they are forming the **Central Care4BrittleBones Team**.

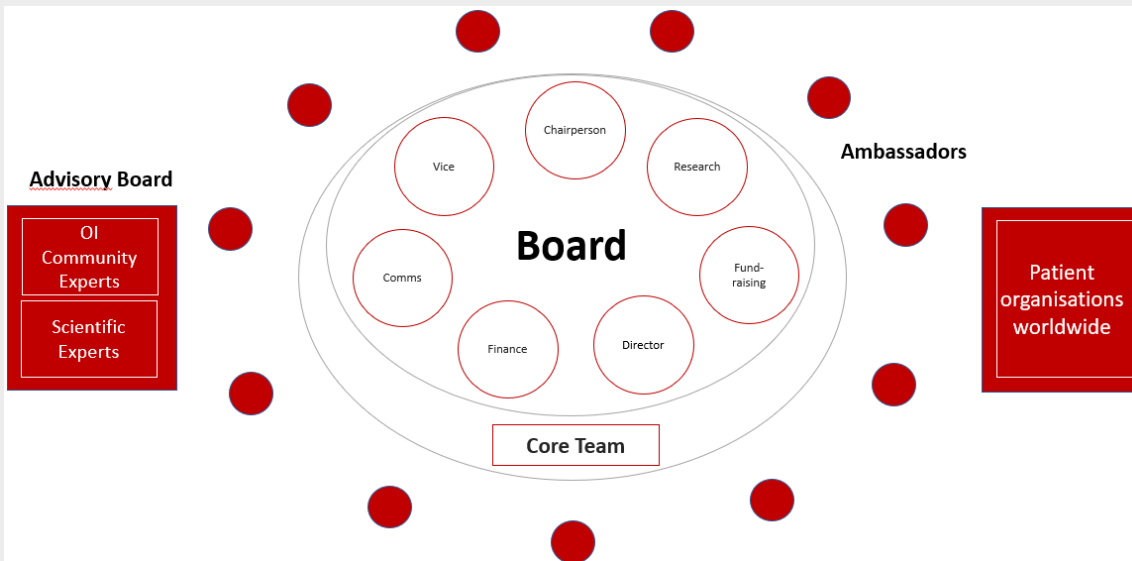
The Central Care4BrittleBones Team is accountable for:

- RESEARCH;
- FUNDRAISING
- NETWORKING / COMMUNICATIONS
- STRATEGY.

The **director** leads and manages the day to day activities of the foundation. The director is held accountable (and controlled) by the other board members. At least once a year the Boardmembers are meeting without the director to assess the performance of the director.

## Considerations:

1. COMPETENCIES
2. MORE TIME & IMPACT;
3. ORGANIC GROWTH;
4. CONTROL / TRANSPARANCY





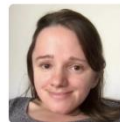


# Central Care4BrittleBones Team

## Board

Statutory body, formally accountable.

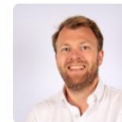
**Meetings integrated with Core Team**



Vanja Zivkovich  
President



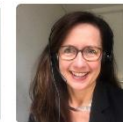
Celine Disch  
Vicepresident



Dirk-Jan Stegink  
Finance



Nicklas Teicke  
Fundraising



Dagmar Mekking  
Director

## Core Team

Defining Strategy and operational plans, setting standards for fundraising and research (contracts and contract management), PR to community and externally, financials, Project management, Coordination of fundraising and annual research proposal rounds

**Meeting once a month**

Finance  
Fundraising  
Communications  
IT / Data Privacy  
Research  
Collaboration

Dirk-Jan Stegink, Robert Brabander  
Nicklas Teicke, Dagmar Mekking  
Celine Disch, Lisette Puijk  
Henk Latour, Kees Mezouar  
Dagmar Mekking, Lieke Mekking,  
Dagmar Mekking





# Plan 2025

## 1. RESEARCH



- Key4OI Registry
  - Implemented in 6 hospitals
  - Key4OI Registry in place, working and robustly funded \* and supported (At least 1000 patient records in Database)
- Adult healthcare education \*
- Conference QualityofLife4All delivered
- Funding research from 3<sup>rd</sup> parties (consider other forms of funding, eg award scheme to restrict workload)
- OI2025 Hong Kong
- Strengthen Contract Management (proactive monitoring / mgt information)

## 2. FUNDRAISING



- Professional support for fundraising delivers return on investment
  - Germany Fundraising Event / NL Fundraising Event
  - Funding from Public 10.000
  - Funding from Trustfunds 60.000
  - Funding from Companies 10.000
  - Funding from private donors 20.000
- € 150.000 Funding

## 3. COMMUNICATION



- Regular Social Media presence (once a week at least)
- Website update
- Annual Report finalized in April
- Keep constructive relationship with OIFE / OIF at all times

## 4. OPERATIONS



- Continue operational excellence in Finance
- IT review and update of tools / data privacy Q1
- Board successions and succession planning – urgently resource Chairman role, ideally at least one more board member.
- Team building
- Advisory board updated on the OI side



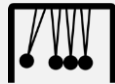


# Our Ambassadors

**BE AN ADVOCATE** for more  
and better OI-Research  
through Care4BrittleBones



**ACTIVELY PROMOTE**  
Care4BrittleBones as a  
fundraising goal for  
**OTHERS** (Companies,  
Service Clubs,  
Foundations)



Ambassadors



**FUNDRAISE**, in  
small or large ways,  
sticking to our values  
'Positive,  
Inspirational and  
Innovative'



**CONNECT** to support each other with ideas  
and network and to learn from others how to  
become even more effective

- Open to **anyone** who is willing to be active in support of OI-Research.
- Monthly optional calls with Chairperson Dagmar Mekking and other Ambassadors. No expectation for Fundraising success but expectation to speak up about OI, create awareness and be an advocate that more research is needed.
- Examples: Fundraising with Just giving – crowdfunding platform of Care4BrittleBones. Charity concerts/dinners. School-activity, Garage sale, internet-video-hypes, Fundraising by Rotary or Lions, etc

Current ambassadors:

1. NL: 16 Ambassadors
2. Germany: Patricia Knoetzsch, Andrea Kiel
3. Italy: Simona Paveri, Leonardo Panzeri
4. Finland: Eero Nevalainen
5. Denmark: Karsten Jensen
6. Malta: Chantal Stuiger
7. Switzerland: Therese Stutz-Steiger
8. France: Laura Marx
9. Austria: Arnold and Eva Seeber





**Research**





# OI Research Grants

Proposal Rounds are available as and when funding is available

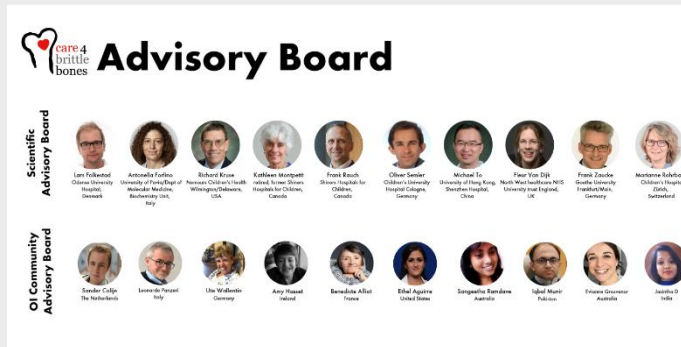
## 1. Fundraising



## 2. Call4Proposals



## 3. Advice



## 4. Decision / Impact



Care4BrittleBones Board





## Our Advisory Board



## Advisory Board

### Scientific Advisory Board



Antonella Forlino  
University of Pavia/Dept of  
Molecular Medicine,  
Biochemistry Unit,  
Italy



Kathleen Montpetit  
retired, former Shiners  
Hospitals for Children,  
Canada



Frank Rauch  
Shiners Hospitals for  
Children,  
Canada



Oliver Semler  
Children's University  
Hospital Cologne,  
Germany



Michael To  
University of Hong Kong,  
Shenzhen Hospital,  
China



Fleur Van Dijk  
North West healthcare NHS  
University trust England,  
UK



Frank Zaucke  
Goethe University  
Frankfurt/Main,  
Germany



Marianne Rohrbach  
Children's Hospital  
Zürich,  
Switzerland

### Community Advisory Board



Sander Colijn  
The Netherlands



Leonardo Panzeri  
Italy



Ute Wallentin  
Germany



Amy Hassett  
Ireland



Christine Coppin  
Belgium



Ethel Aguirre  
United States



Sangeetha Ramdave  
Australia



Iqbal Munir  
Pakistan



Evianne Grosvenor  
Australia

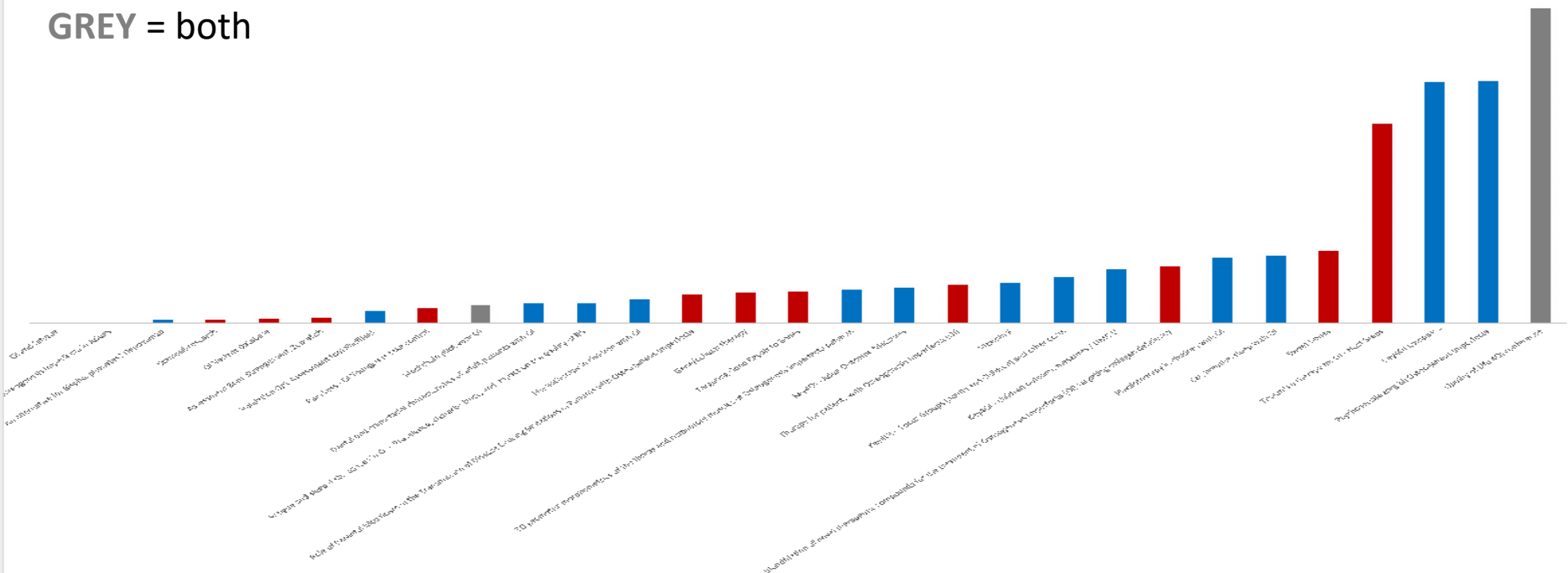


Jasinth D  
India





- RED** = Basic research.  
**BLUE** = Clinical research.  
**GREY** = both







**Fundraising**



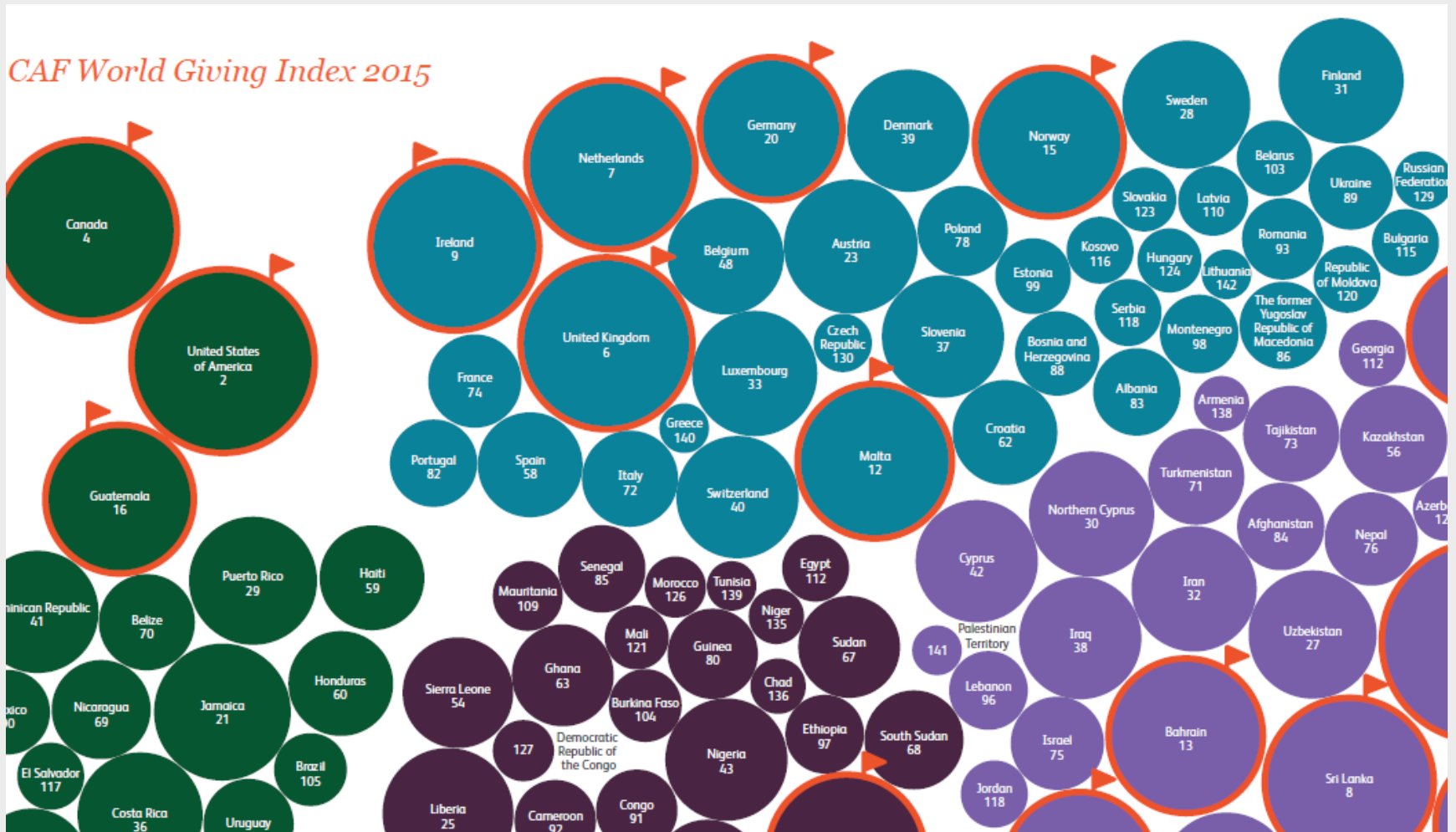






# Fundraising for OI is possible everywhere

Check out your own country's position in the CAF World Giving Index. Look [HERE!](#)







# Our Fundraising toolbox



Please connect to discuss ([info@care4brittlebones.org](mailto:info@care4brittlebones.org))



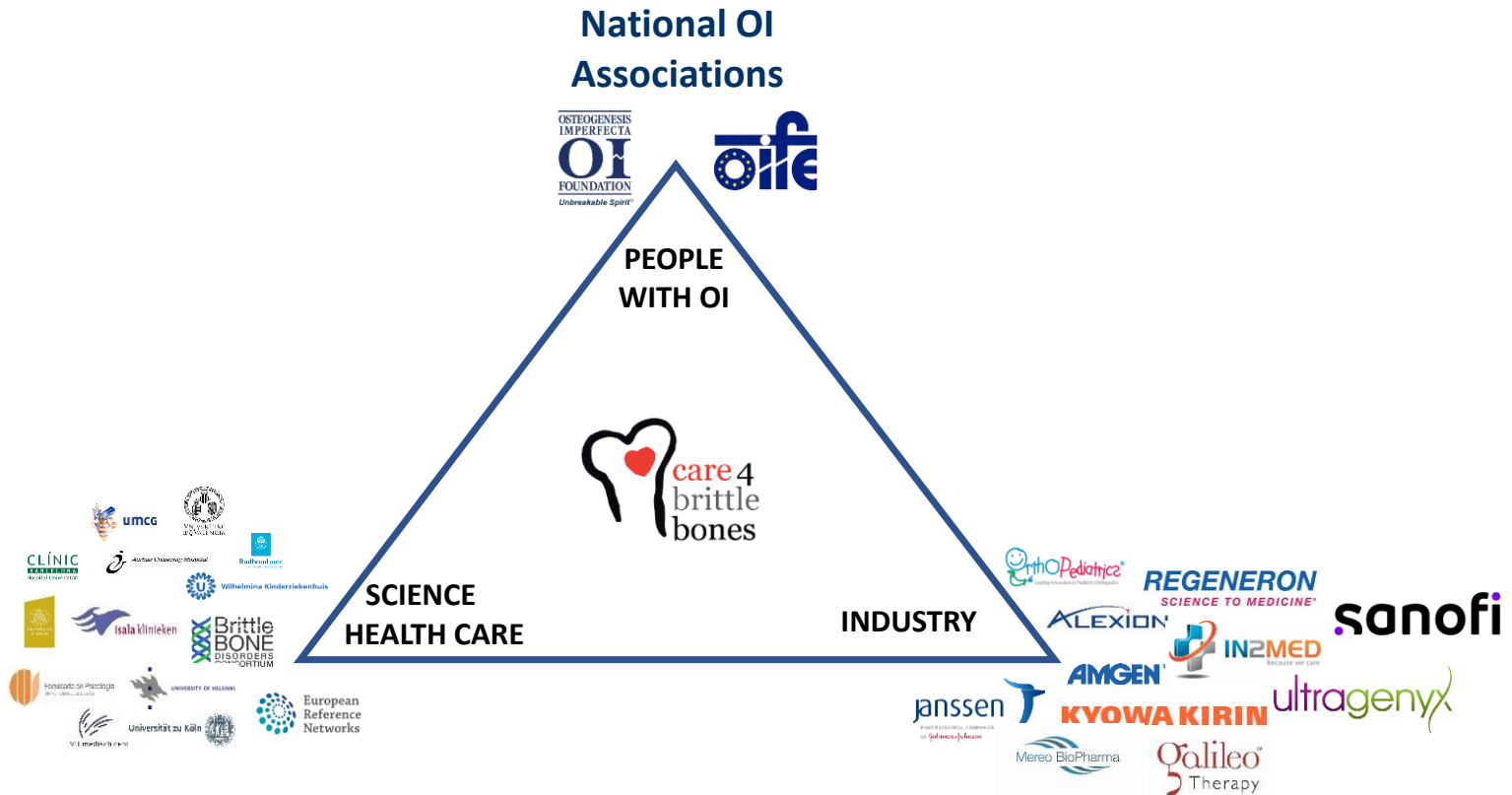


**Long term thinking...**





# Partnerships







# Long term thinking

OIKOS Strategy & 2021 – 2026 Multi Year Plan

