



Care4BrittleBones

Policy / Beleidsplan (2020)



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** (VOI, Deutsche OI Gesellschaft, BBS etc).

This makes sense! Progress in most areas happens through establishing and nourishing a strong local OI Support Community that

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



For any rare disorder or disease, **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.

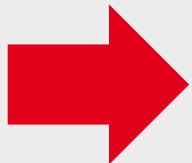


Why collaborate for OI Research

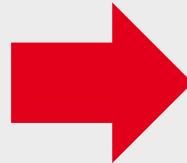


KEY REASONS TO COLLABORATE MORE FOR OI RESEARCH:

1. **Sufficient size of cohorts** for better OI Research
2. **Compare** across different countries
3. **More funding available for larger projects** than the individual country could enable
4. **High quality management of Research proposals**
5. **Synergy from enhanced communication & network**
 - **amongst the OI-Community** after Research has been completed
 - **amongst OI – Researchers** 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

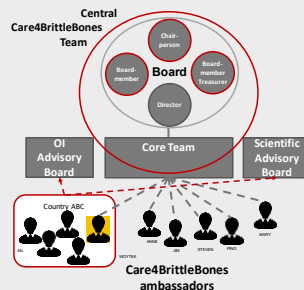
Funding

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

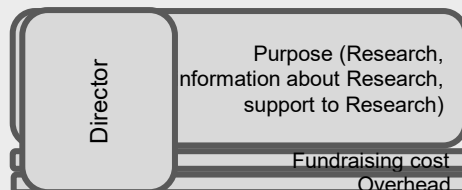
PARTNERS IN OI COMMUNITY

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

Communication channels

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

COST



LONG TERM APPROACH: Multi year plan

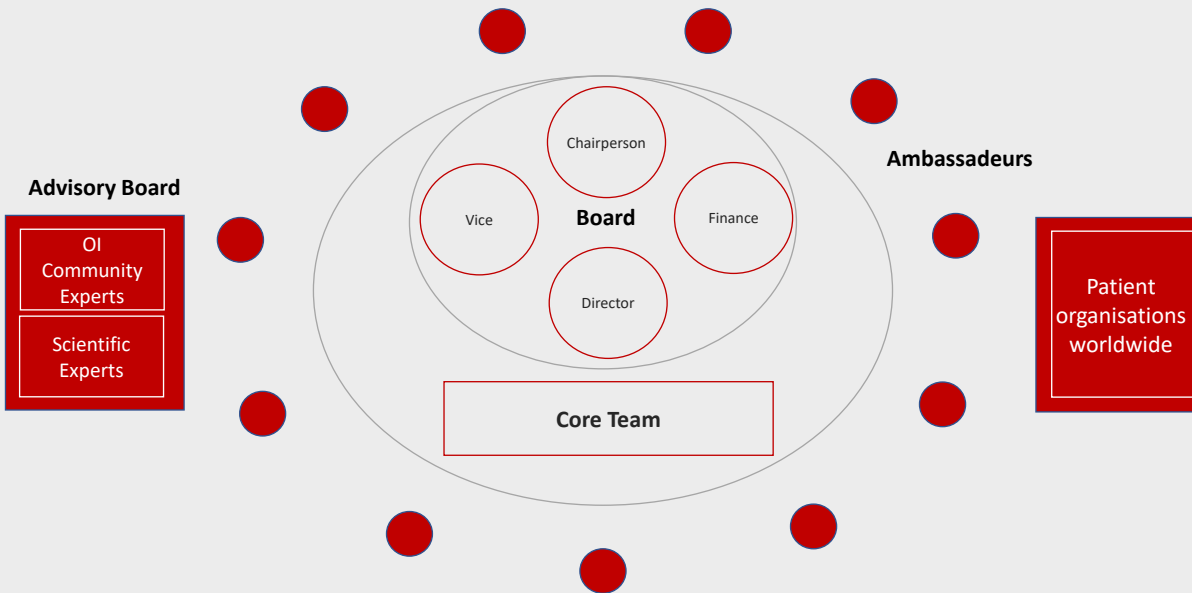
- Research
- Fundraising
- Networks
- Operations
- Fundamentals



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

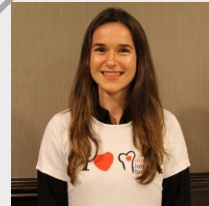


Central Care4BrittleBones Team

Board

Statutory body, formally accountable.

Meetings integrated with Core Team



Celine Disch
Board member



Graham Marshall
Chairman



Dirk Jan Stegink
Treasurer



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	Dirk-Jan Stegink, Iwona Juzwa-Parfus,
Fundraising	Dagmar Mekking, Lieke Mekking, Graham Marshall
Communications	Celine Disch, Amy Hassett
IT / Data Privacy	Henk Latour, Kees Mezouar
Research	Graham Marshall, Dagmar Mekking, Lieke Mekking
Collaboration	Dagmar Mekking, Graham Marshall



Plan 2020

1. RESEARCH



- **Key4OI** - implement and create a path towards big data
- **2 Networks:** engaged and value adding Physical rehabilitation network and psychosocial network
- **Pilot Blockchain technology** – delivered. Delayed and kept momentum (not our cause)
- **Proposal Round (basic research)** - Q3 2020
- **Conference 2019 / 2021 (tbc)**
- **Support ongoing research projects** Vitamin K, Eat Breathe Sleep, Towards Therapy, OI Variant database (**tbc**)

2. COLLABORATION



- **Researchers:**
 - Sheffield 2020 fully utilized to advance Multiyear plan and research networks
 - Facilitate collaborative work and knowledge sharing across the OI researcher and healthcare provider community
- **OI Community:** Positive collaboration with all stakeholders (OIFE & OIF, national patient organisations)

3. FUNDRAISING



- Funding from **Public**
 - Funding from **Trustfunds**
 - Funding from **Companies**
 - Funding from **private donors with focus on Crowdfunding**
- } € 400.000

4. COMMUNICATION



- Sustainable **resourcing**
- **Social Media** impact
- Engage **broader OI Community**

5. OPERATIONS



- Multiyear plan development 2025
- Continue operational excellence in Finance and IT

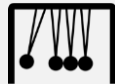


Our Ambassadors

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



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Research



OI Research Grants (annual)

1. Fundraising



2. Call4Proposals

Call 4 Proposals (mid 2014)

Call focus: Based on international expertise

Geographical focus: Global

Aim: The aim of this call is to fund projects that will generate a better treatment of Osteogenesis Imperfecta.

Scope: Researchers originating in the call can come from any country. A wide range of treatment or research strategies will be considered. No area will be excluded as long as the quality of life of people with OI can be improved in a longer and sustainable manner. All disciplines that are contributive to the well-being of people with OI are invited to join. Creation of networks and partnerships across national boundaries and medical institutions are explicitly welcomed.

Assessment Criteria - Points:

Application fee: Applicants for the international grant must complete:

- Project to Quality of Life of people with OI, especially how the negative impact of OI can effectively be prevented.
- Clarity of the objective and target group of the research (what will be different because of this research?)
- Scientific excellence of the topic (level of originality/innovation)
- Efficiency & Control (Project plan, Budget, Feasibility, Financial motivation, and expected outcomes)
- Fit with Core Values of Care4Osteogenesis: Patient & caregiver's involvement

The applications will be evaluated by a panel which is including professionals of various disciplines relevant for OI (Dentist, Radiologist and other specialists) as well as people with OI. The decision of Care4Osteogenesis is final.

Funding request / Award: We are looking for proposals that require funding of 40.000 - 80.000 Euros (max). In the first instance indirect funding. We will select 10 proposals for which we will try to find funding via our network. In some countries, complete info. The proposals are to be submitted by 1 October 2014. In the second instance: the next funding, we may decide at a later stage to fund 5 of the chosen proposals directly with Care4Osteogenesis - funds (between 1 & 2 November at the earliest). The next proposal round is expected for early 2015.

Timeline: Submission deadline: 1 August 2014. Decision on proposals to be used for indirect funding: 1 October 2014. Decision on proposals to be used for direct funding: 15 December 2014.

Submission of proposal:

Format requirements: Max. 8 pages, English language

Content requirements: To specify the proposal has to cover:

- Goal: Research, scientific or social aims
- Short description of the project and method used
- Fit between: a) appropriate or required and if they have been provided (e.g. from ethical committees)
- Benefits for quality of life for people with OI
- Measurement of success
- Risks: What will happen as a result of the study? How will this impact on Quality of life?
- References (e.g. numbers of patients involved)
- Budget and describe other sources of funding
- Team: English name and all project related expertise (not running operational units)
- Study plan including project timeline
- The project's timeline should not exceed 24 months
- Link to Care4Osteogenesis Core values (Patient & caregiver's involvement)
- What has already been completed (e.g. grant money)

Information for proposal and review:

- Cover sheet and title, Chemistry, logo of the institution, location, topic
- CV of applicant and participants
- A single summary for use with potential funding organizations (scientific, non-scientific) (maximum 3000 characters) for non-scientific audience. A second, scientific summary is optional for scientific use only (a maximum of 1000 characters) (maximum 1000 characters). In 8000 characters max. No additional data or other information should be included. E-mail: info@care4osteogenesis.org

Contacts for questions / Requests to be addressed to:
 Organization: info@care4osteogenesis.org | e-mail: info@care4osteogenesis.org | internet: www.care4osteogenesis.org



3. Advice

THE SCIENTIFIC ADVISORY BOARD MEMBERS

Fleur van Dijk Genetics UK	Oliver Semler Pediatrics Germany	Lena Lande Wekre Rehabilitation Norway	Lars Folkestad (*) Endocrinology Denmark	Marianne Rohrbach Endocrinology Switzerland	Antonella Forlino (*) Research Italy	Frank Zeucke Research Germany <small>(for this round only)</small>

THE OI ADVISORY BOARD MEMBERS

Margriet Creze Netherlands	Ute Vollenin Germany	Eero Nevo-Jainen (*) Finland	Kevin Van-antwerpen Belgium	Therese Stutz-Stieger (*) Switzerland	Leonardo Panzeri Italy	Benedicte Alliot France

Also, Taco van Welzenis participated in the proposal round on behalf of OIF.



4. Decision / Impact

Celine Disch Board member	Graham Marshall Chairman	Dirk Jan Stegink Treasurer
Dagmar Mekking Director		



Our Advisory Board

THE SCIENTIFIC ADVISORY BOARD MEMBERS



Fleur van Dijk
Genetics
UK



Oliver Semler
Pediatrics
Germany



Lena Lande Wekre
Rehabilitation
Norway



Lars Folkestad (*)
Endocrinology
Denmark



Marianne Rohrbach
Endocrinology
Switzerland



Antonella Forlino (*)
Research
Italy



Frank Zaucke
Research
Germany
(for this round only)

THE OI ADVISORY BOARD MEMBERS



Margriet Crezee
Netherlands



Ute Wallentin
Germany



Eero Nevalainen (*)
Finland



Kevin Vanantwerpen
Belgium



Therese Stutz-Steiger (*)
Switzerland



Leonardo Panzeri
Italy



Benedicte Alliot
France

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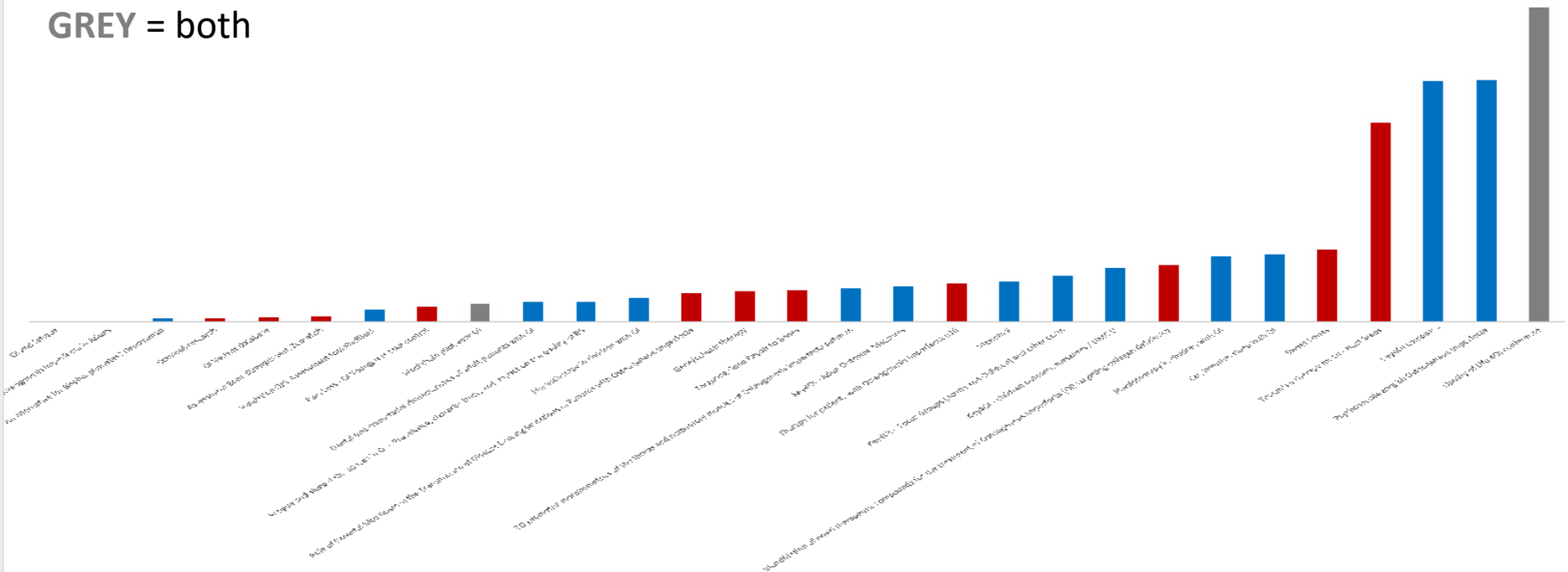
Research enabled by Care4BrittleBones

- €1,5 Mio spent 2012 - 2021
- 32 projects across basic science and clinical research

RED = Basic research.

BLUE = Clinical research.

GREY = both





Fundraising



Our approach to Fundraising



Absolutely **EVERYTHING** is allowed
as long as

positive
inspiring
Innovative

THE VOICE OF 

FAMILY


I  I

Cheque
€ 8.500,-

I  I
RUN



Our Fundraising toolbox

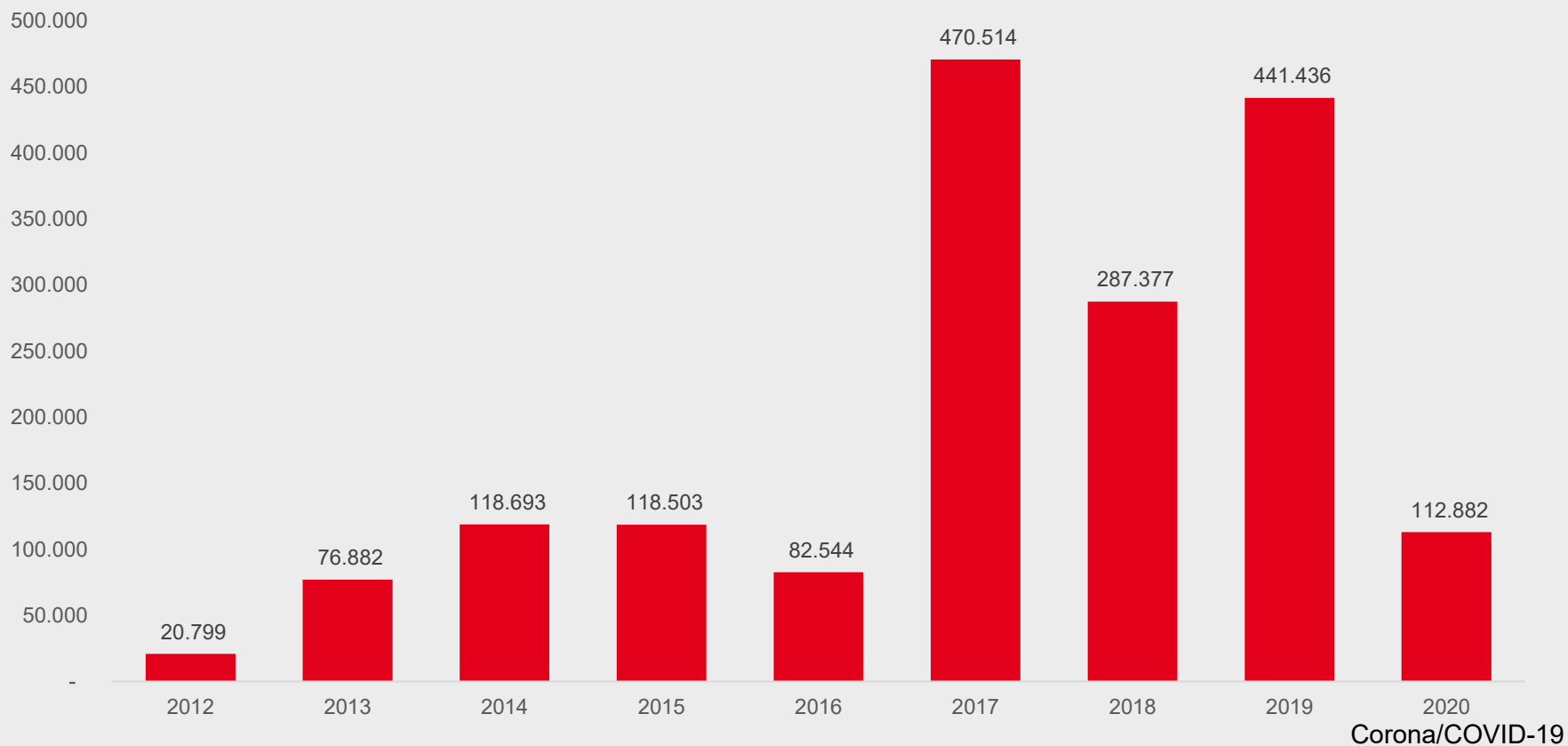


Please connect to discuss (info@care4brittlebones.org)



Funds raised 2012 - 2020

- €1,7 Mio funds raised (2012 – 2020)
- Fundraising cost: 11,3% (2020)
- Admin/overhead: 9,4% (2020)





Long term thinking...



Partnerships

National OI
Associations



PEOPLE
WITH OI



SCIENCE
HEALTH CARE

INDUSTRY





OIKOS - Strategy



Improving the quality of life of people with Osteogenesis Imperfecta through research into care & cure for OI

DATA

Open Acces (incl registries)

Innovation through data (eg Blockchain, big data, benchmarking)

Patient outcome focus

To leverage the power of big data to change OI

RESEARCH PRIORITIES

Healthcare improvement (Key4OI, Key4OI Plus)

Innovative Treatment strategies

Basic Science for OI

To actually improve QoL for everyone with OI

COLLABORATIVE CULTURE

Knowledge exchange and collaboration in research (networks, consortia, Quality of Life 4 OI Conference, CARE4BONES)

Partnering culture

Strong role of OI community in Research (eg. CARE4BONES for education, collaboration and peer support, funding)

To work collaboratively across research, healthcare, people with OI and industry

POSITIVE - INNOVATIVE - INSPIRATIONAL