

2024



**ANNUAL REPORT | 2024**  
Care4BrittleBones Foundation



## OI | IN NUMBERS

Some children break one of their bones

**10** TIMES A YEAR

**500.000** PEOPLE

Worldwide have OI

Germany: 5,000; UK, France and Italy: 4,000 each;  
Netherlands: 1,000; Belgium: 700; Switzerland: 500

People most affected with OI break over

**200** TIMES IN A LIFETIME

## OI IN THE WORLD

**0** MEDICATIONS

Have been developed specially for OI, but  
two are in progress

OI is one of

**7.000** RARE DISEASES

Together rare diseases are the 4<sup>th</sup> largest  
disease classification in the world.

**8.500** BABIES

Worldwide are born each year with OI

**25** VOLUNTEERS

**46.419** EUR

**30** %

Spent and/or allocated to our goals (research, information  
sharing, collaboration/ knowledge exchange for OI, including  
conference)

Overhead  
(The details are  
available in the  
Financial Report)

## REACHING OUT IN 2024

**37.229** EUR

Of funds raised in 2024 for much needed research for OI

**7.281** EUR

Fundraising Cost

**77** Speakers and Moderators

Involved in the Quality of Life 4 OI Conference 2024



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## 2024 | DELIVERING KEY MILESTONES ON OUR JOURNEY TOWARDS QUALITY OF LIFE 4 OI

2024 was a year of steady delivery and special achievements for the Care4BrittleBones Foundation, continuing our mission to improve the quality of life for people with Osteogenesis Imperfecta (OI). We started the year with another QualityofLife4OI Conference. It was the 4<sup>th</sup> Quality of Life Conference we organised. Three key milestones stood out this year:

### 1. Key4OI Registry Milestone

A significant accomplishment was the completion of the **Key4OI Registry** setup. Hosted by the **Netherlands Heart Institute**, the registry is powered by [REDCap](#) technology and has received **Medical Ethical Approval**. This marks a vital step forward in global OI data collaboration. The actual implementation will start in **2025 with first data shared at the 2025 Conference in HongKong**. The registry is designed to capture outcome data that matter most to people living with OI.

### 2. Energy4OI 2.0 – the fitness app for people with OI

The **Energy4OI** initiative was a big project with the goal to help the OI community to move more. Over **190 participants from 40+ countries** engaged in a **12-week program** via the **Trainerize app**, offered in **5 languages** (Dutch, English, German, Spanish, Italian). Key features included: 100+ instructional videos, 6 training levels for ambulant and wheelchair users, Adaptive, personalized workouts every 4 weeks, PROMIS tools for quality-of-life assessment and more. **Over 2,000 workouts** were logged, and many users gained **confidence to exercise safely** with OI.

### 3. Generous Art Donation

In a wonderful gesture of support, artist **Anke Labrie** donated **170 original paintings** to the foundation. These artworks will be used to raise funds and awareness for **OI research**, blending creativity and cause in a unique way.

### Conclusion

2024 was a year of **forward momentum and exciting milestones**: From pioneering research infrastructure to empowering individuals through exercise and receiving heartfelt contributions, the Care4BrittleBones Foundation continues its journey to improve lives for all those affected by OI. The board was strengthened in 2024 with a communications and fundraising team member. We have started the search for 2 new board members, replacing Vanja Zivkovic and Lydiia Zhytnik in 2025. We would like to thank everyone who has worked with the Care4BrittleBones in 2024 for their tremendous work.



**Vanja Zivkovic**  
(President)

**Dagmar Mekking**  
(CEO, Directeur-Bestuurder)



*“We have a single goal:  
to enable scientific  
research that improves  
the quality of life  
of people with OI.*

*We want the best  
possible health for  
everyone with OI and to  
find a cure.”*

## WHAT IS OSTEOGENESIS IMPERFECTA (OI)?

Brittle Bone Disease, also called OI, is a genetic bone condition that affects the connective tissue of the body. It is caused by insufficient production of collagen that normally ensures strong, healthy bones.

The main characteristic of OI is the fragility of the bones. People with OI can experience anything from “a few more fractures than normal” to more than 200 fractures in a lifetime. A small incident can have big consequences for people with OI. Other symptoms include physical deformities, chronic pain, scoliosis, short stature, hearing and dental problems as well as severe breathing and heart issues.

OI is a purely physical disorder but has broader consequences. People with OI have the same needs and hopes for their lives as everyone else but they need to realise their dreams with a very fragile body. Often OI-related physical challenges also lead to significant psychosocial challenges, like exclusion and the fear of experiencing yet another fracture. This can lead to people with OI feeling left out and alone.

There are five main types of OI. People with the disorder are affected in very different ways – those with a less severe form of OI can work and participate fully in study and social activities. Many people with OI, however, have to deal with frequent pain and mobility issues, which heavily influence how they live their lives. Some people with OI can have a significantly reduced life expectancy.

Children are the most affected group. Some children will have a fracture every few weeks, undergo 20 surgeries or more at a young age and spend half their childhood wearing a cast. This has a big impact on the child as well as the family around him/her.

Generally, the most important symptoms of OI we are looking to improve are:

| **Fractures** | **Pain** | **Anxiety** | **Isolation**

## | STATUS OF RESEARCH FOR OI TODAY

OI has been recognised for more than 100 years; however, there is no treatment that fundamentally addresses the condition. The key approaches used today are ‘hand-me-down medications’ from other related conditions such as Osteoporosis. These medications treat some of the symptoms for example, bisphosphonates which make bones harder. Whilst these medications clearly have benefits, they also come with potential adverse side effects. Moreover, their long-term effects are unclear. Most striking of all is that they don’t address the root cause. Simply put: this is not good enough.

Research for OI patients is not providing the right solutions today because it is a **rare disease** affecting relatively few people. There are about 500.000 people worldwide with this disorder (1 person out of 15.000 has OI). Like many other rare diseases, hardly any research funding is available to change the status quo.

It is time to address what is holding back progress. We are keen to put urgently needed support in place to address the challenges of OI in a strategic way. The key reasons for pushing forward now are:

1. **Promising new technologies** have become available, such as gene therapy or stem cell therapy, new medical treatment options, innovative materials and techniques for surgeries.



2. Modern **communication technology** is enabling collaboration and knowledge sharing between the world's top experts for rare diseases. Distributed around the world, they previously worked mostly in isolation.
3. **Big data** for small diseases is coming within reach. Genetic testing has become widely accessible and is cheaper than ever before. Over time this will allow us to look at 'scientific mysteries' like the discrepancy between genotype and phenotype. The largest research project ever completed in people with OI included fewer than 3,000 people. Significantly larger cohorts will soon be possible. This will enable new insights into patterns and stronger research as long as researchers are willing to work together and share data and/or patient organisations work together to collect data themselves.
4. There are significant questions to be addressed regarding bone metabolism, which is still, broadly speaking, unknown territory. A new trend in the last 2-3 years is to **look across related rare bone diseases** to understand the underlying biochemical processes. This has led to the formation of the European Reference Network for Rare Bone Diseases and the US-Canadian Brittle Bone Diseases Consortium. OI within both groups is standing out as the top priority research area amongst the nearly 450 rare bone diseases that exist.

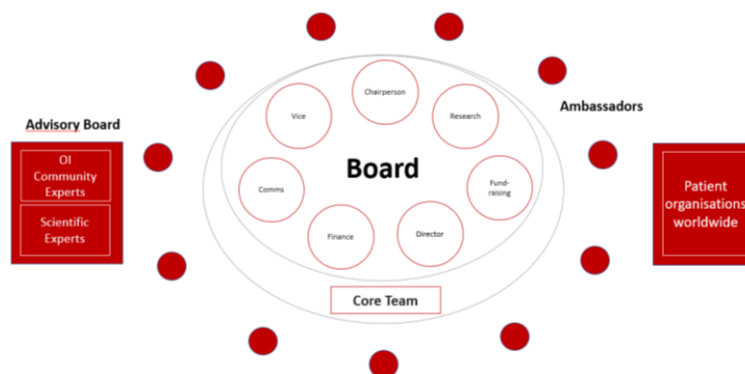
These circumstances create new opportunities for OI research. Care4BrittleBones has identified various short, mid, and long-term opportunities that have the potential to improve the quality of life of people with Osteogenesis Imperfecta and eventually to lead to a breakthrough therapy for OI.

## CARE4BRITTLEBONES | ORGANISATION

Care4BrittleBones consists of the board of the foundation and connects regularly with the following key stakeholders / stakeholder groups:

1. The Board
2. The Core Team
3. Two Advisory Boards
4. Patient Organisations

The composition of the Board and supporting groups remained the same in 2022, except for the Advisory Board which was refreshed and updated comprehensively.



### 1. | THE BOARD

At the end of 2024, Care4BrittleBones was officially governed by a board of 5 members, we had 1 vacancy (the role formerly held by Lidiia Zhytnik was vacated in December 2024).



We would like to thank everyone on the Care4BrittleBones Board for their continued dedication and leadership.



**Vanja Zivkovic**  
Chairman/Secretary



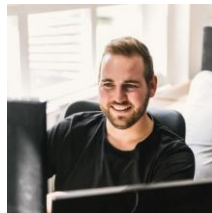
**Celine Disch**  
Vice-president



**Dagmar Mekking**  
Director



**Dirk-Jan Stegink**  
Treasurer



**Nicklas Teicke**  
Fundraising



**Lidiia Zhytnik**  
Research (until YE2024)

The Board is ultimately accountable for all aspects of the foundation, with a strong focus on strategy, finance, risk and governance.

**Governance of the foundation by the Board is organised as follows:**

The Board meets on an ad hoc basis and approves the annual budget, operational plan, strategy document and (re)appointment of the director and monitors the performance against the plans. The board meets on a monthly basis together with the Core Team to discuss all matters both strategic and operational. The director meets with most board members on a monthly basis to consult on key topics and work together. The Board formally reviews the performance of the director annually.

## 2. | THE CORE TEAM

The activities of the foundation are carried out by the Core Team, which acts as an extension of the Board. They define the strategy and operational plans, set and manage standards for fundraising and research, drive communications and PR, manage the financials and compliance, manage projects, develop relationships with funding institutions, support volunteers and manage the annual research proposal rounds.

The Core Team consists of highly skilled and motivated professionals from multiple industry sectors with significant experience working internationally and cross-culturally. They met on a monthly basis to discuss all matters concerning the foundation. These meetings are held with the extended team, consisting of ca. 12 highly engaged team members, all connected to one of the areas in our Operational plan.



Finance	Dirk-Jan Stegink, Robert Brabander,
Fundraising	Nicklas Teicke, Dagmar Mekking,
Communications	Lisette Puijk, Celine Disch
IT / Data Privacy	Henk Latour, Kees Mezouar
Research	Lidiia Zhytnik (until YE 2024), Dagmar Mekking, Lieke Mekking,
Collaboration	Vanja Zivkovic, Dagmar Mekking
General Support	Peter Mekking

In 2024 the team did not have a Face2Face team meeting. The aim is to have several team members travel in 2025 to the international OI Conference in 2025.

### 3. | ADVISORY BOARD

The Foundations' Advisory Board members are carefully chosen based on their expertise and reputation for collaboration. They are acting in the best interest of people with OI worldwide, irrespective of their own discipline or national background.

All **Scientific Advisory Board members** have an outstanding professional reputation and a proven track record of working closely with the OI-community over many years.

All **OI Advisory Board members** have OI themselves and have a good knowledge of the condition. They are taking a broad perspective and (informally) advise on behalf of the OI community (not from a personal perspective). Many of them have a qualified medical or scientific background in healthcare, others are leading national OI Organisations or hold another important role as networkers in the community.

The Advisory Board advises on which research projects we should prioritise and advise us in relation to our research strategy and communication. We usually deal with all Advisory Board members as "one group". The input from both Science and the OI Community are essential for the Care4BrittleBones Foundation to make the best decisions for the longer-term Quality of Life of people with OI.

#### Selection criteria for appointment

- Exceptional professional **expertise**
- Track record of close **collaboration** across professionals, internationally and with patients).
- Track record of acting **in the best interest** of people with OI worldwide, irrespective of their own discipline or national background
- Support to the **strategic direction** of the Care4BrittleBones Foundation (Multi Year Plan)

In addition, we are seeking to balance:

- **Clinical + Basic Science**
- **Geographical distribution**
- **Adult & Paediatric expertise**
- **Diversity**





## Advisory Board members

The Care4BrittleBones Advisory Board has been reconfirmed and refreshed in 2023. It remained in place in 2024, however 2 people have decided to step down from the board: Richard Kruse and Lars Folkestad. The Advisory Board is multidisciplinary, representing the global reach of Care4BrittleBones and includes some of the brightest people in science, healthcare, and the OI Community.



# Advisory Board 2024

### Scientific Advisory Board



### OI Community Advisory Board



1. Lars Folkestad, Odense University Hospital, Denmark (completed in 2024)
2. Antonella Forlino, University of Pavia/Dept of Molecular Medicine, Biochemistry Unit, Italy
3. Richard Kruse, Nemours Wilmington/Delaware, USA (completed in 2024)
4. Kathleen Montpetit, retired, former Shriners Hospitals for Children, Canada
5. Frank Rauch, Shriners Hospitals for Children, Canada
6. Marianne Rohrbach, Children's Hospital Zurich, Switzerland
7. Oliver Semler, Children's University Hospital Cologne, Germany
8. Michael To, University of Hong Kong, Shenzhen Hospital, China
9. Fleur Van Dijk, Northwest healthcare NHS University trust England, UK
10. Frank Zaucke, Goethe University Frankfurt/Main, Germany
11. Sander Colijn, OI Community, NL
12. Leonardo Panzeri, OI Community, Italy
13. Ute Wallentin, OI Community, Germany
14. Amy Hasset, OI Community, Ireland
15. Benedicte Alliot, OI Community, France
16. Ethel Aguirre, OI Community, United States
17. Sangeetha Ramdave, OI Community, Australia
18. Iqbal Munir, OI Community, Pakistan
19. Evianne Grosvenor, OI Community, Australia
20. Jasinth D, OI Community, India

## Ways or working

The Advisory Board and the Care4BrittleBones Foundation work together informally and openly. The multidisciplinary nature of the Advisory Board, the exceptional expertise, long term commitment to OI and the leadership qualities present in each individual member of the advisory board enable us to discuss all topics potentially relevant to quality of life for OI in an integrated way. The advisory board members may be requested to advise occasionally on an individual basis.

One of the most important roles of the Advisory board is support and challenge in the context of the **Proposal Rounds**, which are held every 1-2 years. In 2024 we didn't hold a



Proposal Round. The last round was in 2023. The aim is to hold proposal rounds again when sufficient financial means are available.

The Advisory Board members can also advise the foundation without request. In our Advisory Board everyone can advise on everything. We keep in mind that even though some people are not experts in a particular area, they may still have very important perspectives to offer on the topic. The advice of the OI community and the scientific Advisory Board members are considered on an equal level. The decision making takes place in the Care4BrittleBones Board after careful consideration of the input of the Advisory Board. In 2024 the Advisory Board convened once. On the agenda were general updates as well as the approach to communications when a well known person with OI deceases. The reason for this were the unexpected deaths of 2 people who were very active in the Care4BrittleBones Foundation and are very well known and much loved by the community: Rick Brink (11 May 2024) and Qusai Al Rifai (5 October 2024). We are very grateful for many years of connection and mutual support. May they rest in peace.

## 4. | PATIENTS AND PATIENT ORGANISATIONS

We believe that an active role for people with OI is an important aspect of a meaningful and impactful research agenda. Their willingness to advocate for research, articulate their needs and participate in research makes a major difference.

We also work closely with various patient organisations in all our activities. We maintain the relationship with OIFE (OI Federation Europe) and the OIF (OI Foundation based in the USA) and are inviting them to partner with us on events. We often partner with the Care4Bones Foundation due to their strong ability to engage the OI community and professionals worldwide with their enhanced means of communication and professional moderators and speakers from the OI community.

## STRATEGY | WAYS OF WORKING

### 1. | STATUTORY GOAL

The vision of our foundation as reflected in our statutes is unchanged. The foundation aims to promote scientific research into Osteogenesis Imperfecta with the intention of improving the quality of life of people with OI.

The Foundation seeks to achieve its objectives by:

1. Raising funds.
2. Funding research and activities enabling research.
3. Contributing to impactful research by developing priorities and strategies for improving Osteogenesis Imperfecta, supporting collaboration and knowledge sharing regarding Osteogenesis Imperfecta and providing support to research in the widest sense.
4. Informing stakeholders.

As opposed to many other foundations, we are not only a fundraising organisation but also a coordinator, strategic partner and thought leader in research for OI.



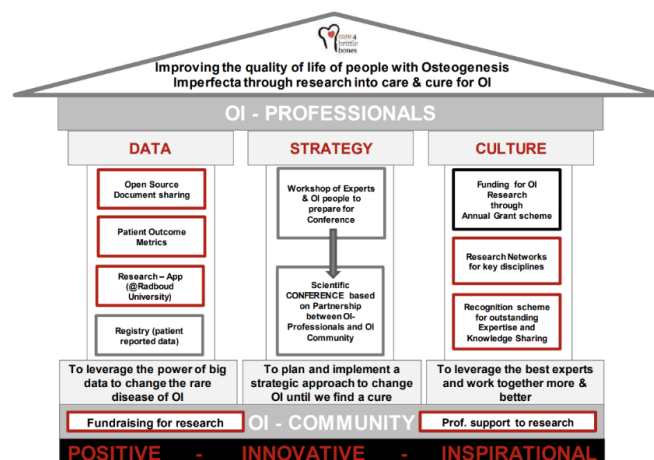
## Overview Care4BrittleBones



## 2. | OIKOS STRATEGY

We believe that a two-pronged approach is needed to improve the quality of life of people with OI. Our approach focuses on improving quality of life through short- and medium-term research, related to clinical interventions close to the patient (e.g., improved orthopaedic approach, physical rehabilitation, understanding scoliosis, etc.) and leveraging potential game-changing technologies, which may provide a cure for OI.

In 2021 Care4BrittleBones continued to build on its research strategy, which is called “OIKOS”. OIKOS is a holistic approach to driving change in research and improving the quality of life of people with OI. The three most important levers and associated strategic actions are: data, strategy, and culture.



Care4BrittleBones strives to be a ‘bridge builder’ to connect the three main groups active in the field of OI Research: the OI patient community, healthcare providers/researchers



and (pharmaceutical and other) industry. The [“QualityofLife4OI” Conferences](#) held in 2019, 2022, 2023 and 2024 exemplify this aspiration.

We actively work together with all communities, providing professional experience, tools and bandwidth to accelerate OI research projects and strategies with a clear link to the quality of life of people with OI in the short-, mid- and long term. Our aim is to contribute to the development of an ecosystem that continuously drives positive change for OI. We realise that we must reach out beyond OI networks to support related rare bone diseases where we can. Bone metabolism still has many ‘blind spots’ that are unknown territory for researchers worldwide. Therefore, supporting the research of one rare bone disease can potentially provide insight into others such as OI. This is important for all of us.



*Logos displayed are showing a selection of key stakeholders. There are many more!*

### 3. | MULTIYEAR PLAN (2021 – 2026)

In the first 5 years of its existence Care4BrittleBones worked based on annual plans only. In 2017, when Care4BrittleBones moved from a volunteer-based organisation to a professionalised organisation, it developed a first “Multi Year Plan 2018 – 2020”. It was a document that proved extremely valuable for our foundation. We delivered more than 90% of the plan.

In 2021 Care4BrittleBones developed its second Multi Year Plan, reflecting on our past performance and building on our strengths:

- the ability to orchestrate and support large scale research and healthcare improvement projects, working across many expertise centres in the world.
- the reputation and partnerships we have established across the entire ecosystem, resulting in collaboration of dedicated experts dedicated to improving quality of life for people with OI: healthcare providers, researchers, industry and people with OI.
- our “Future skills”: Healthcare innovation powered by data insight.

The Multi Year Plan (2021 – 2026) can be found on our website and on this [LINK](#).

### 4. | WAYS OF WORKING (COMPLIANCE AND TRANSPARENCY)

Foundation Care4BrittleBones is recognised as a charitable organisation in the Netherlands (**ANBI** status, Algemene Nut Beoogende Instelling).



As a charitable organisation, we are firmly committed to the highest standards of operation. This relates to every single process, but in particular to **compliance** with all applicable rules and procedures (including data privacy) and **transparency** (e.g., time writing of the CEO/directeur-bestuurder, regularly reviewing our performance against the goals and sharing our reflections on strengths and weaknesses with our stakeholders).

To demonstrate our standards and ensure we stay up to date on the latest developments in the charity sector we are a member/accredited by the following organisations:

- **Goede Doelen Nederland** – sector organisation for charities in The Netherlands. Through Goede Doelen Nederland we are participating in discussions with other stakeholders in the sector regarding topics relevant to all charities in the Netherlands. As a member, we are aligning with their standards and recommendations.
- **CBF – Centraal Beheer Fondsenwerving**. CBF will annually review all key processes of a foundation and carry out testing to decide if they are robust with regards to governance standards and transparency. This provides extra assurance to our donors that we are operating according with strong internal standards.

In 2024 we continued to adhere to the **EU-General Data Privacy Guideline** (GDPR). All relevant information including a complaints procedure have been published on our website and the changes have been implemented.

Key to our work are the values we have adopted when setting up Care4BrittleBones in 2012: three simple words guide everything we do: **positive, inspiring and innovative**. This applies to our research, fundraising activities and to the way we interact with each other and our stakeholders.







## 5. | FINANCIAL COMPENSATION

In 2024, none of the board members, core team or volunteers, ambassadors and advisory board members received financial or other compensation except for the director and funding in relation to project roles (eg Energy4OI Project).

The director's remuneration is explained in more detail in the financial report.





## OPERATIONAL DELIVERY | 2024

The year 2024 has been very productive across many areas with the Key4OI Registry, the Energy4OI 2.0 Project and the Donation of Anke Labrie as main highlights.

### Colour coding:

GREEN:	Accomplished fully.
AMBER:	Mixed delivery
RED:	Below plans
GREY:	Hold

### Plan 2024



<b>1. RESEARCH</b> 	<ul style="list-style-type: none"><li>Key4OI Registry<ul style="list-style-type: none"><li>Implemented in 7 hospitals</li><li>Key4OI Registry in place, working and robustly funded * and supported (At least 500 patient records in Database)</li></ul></li><li>Energy4OI No. 2 (International) delivered on time and on specs * Energy4OI No. 3 under consideration</li><li>Adult healthcare guideline project delivered on time and on specs (everything complete YE 2024, except for publication) *</li><li>Conference QualityofLife4OI delivered (400 participants, 20.000 income, abstract book)</li><li>Funding research from 3<sup>rd</sup> parties (consider other forms of funding, eg award scheme to restrict workload)</li><li>Strengthen Contract Management (proactive monitoring / mgt information)</li></ul>
<b>2. FUNDRAISING</b> 	<ul style="list-style-type: none"><li>Professional support for fundraising delivers return on investment</li><li>Berlin Fundraiser. Fundraising Goal: xxx</li><li>Funding from Public 10.000</li><li>Funding from Trustfunds 60.000</li><li>Funding from Companies 10.000</li><li>Funding from private donors 20.000</li></ul> <p>€ 100.000 (to be reviewed / aligned with budget) Funding for ****</p>
<b>3. COMMUNICATION</b> 	<ul style="list-style-type: none"><li>Regular Social Media presence (once a week at least)</li><li>Website update</li><li>Annual Report finalized in April</li><li>Keep constructive relationship with OIFE / OIF at all times</li></ul>
<b>4. OPERATIONS</b> 	<ul style="list-style-type: none"><li>Administrative Support from Danielle -&gt; strengthening of our operations -&gt; C4B</li><li>Continue operational excellence in Finance</li><li>IT review and update of tools / data privacy Q1</li><li>Board successions and succession planning – urgently resource Chairman role, ideally at least one more board member</li><li>Team building</li><li>Advisory Board updated on the OI side</li></ul>

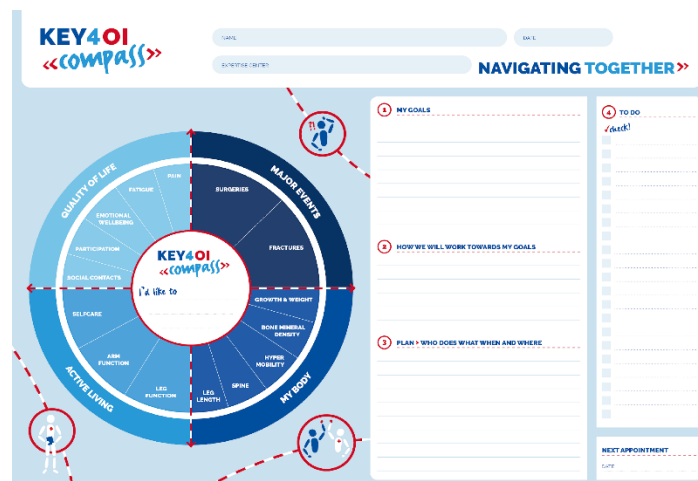
## RESEARCH

### Summary

We were very pleased by the progress of various research and healthcare improvement projects both conducted, as well as supported by Care4BrittleBones.

#### 1) Key4OI

In 2024 we continued to progress well on [Key4OI](#), our most ambitious project to develop and implement consistent outcome measures for OI. The aim of Key4OI is to improve quality of life on different levels:





- a) on the level of the individual (see Key4OI compass plan below)
- b) for multidisciplinary teams in hospitals to work better together
- c) for all stakeholders in the OI ecosystem to have better ways of learning together and working together.

The Key4OI Lead team continues to come together monthly and is working together to develop a registry in 2024 to bring the data collected locally together for research.

In 2024 the Key4OI Coreteam developed a draft consortium agreement and obtained medical ethical approval from the Leiden University Medical Center. Upon this approval the Registry Database was established using REDCap technology hosted by the Netherlands Heart Institute (<https://heart-institute.nl>), who is experienced with REDCap. With the support and advice the tailor-made Key4OI- REDCap database was set up, mirroring in every detail the Consortium Agreement and ensuring GDPR compliance. The participation of 6 hospitals has been secured. They will upload their own data into the data registry in 2025. Other expertise centers in the world have flagged their interest to join the registry. This will be possible starting 2026.

## 2) **Energy4OI 2.0**

An important project was expanded in 2024: “**Energy4OI 2.0**”. This project is based on various surveys conducted by Care4BrittleBones Foundation and others in the last few years. We know from these surveys, that physical wellbeing is a key priority for people with OI. Sufficient exercise plays an important role in this. For many reasons, regular exercise can be challenging for people with OI. The circumstances for them to engage in regular Fitness activity can rather discouraging and difficult. The aim of the Care4BrittleBones Foundation is to stimulate physical fitness for people with OI in a safe way. For this reason, it was decided to develop and test an app specifically by and for people with OI. The goal of the “Energy4OI” project is:

- a) To investigate whether a self-exercise app is suitable for making people with OI move more in a safe and responsible way.
- b) To see if people with OI feel better by participating in the exercise program.

In 2023 the ENERGY4OI App was successfully tested and evaluated for 50 participants from the Netherlands. In 2024 this project was followed up with an international project, stepping up this successful project. The so called “Energy4OI 2.0” brought inclusive fitness to the global OI community. Over 190 participants from 40+ countries engaged in a 12-week program via the Trainerize app, offered in 5 languages (Dutch, English, German, Spanish, Italian). Key features included:

- 100+ instructional videos
- 6 training levels for ambulant and wheelchair users
- Adaptive, personalized workouts every 4 weeks
- PROMIS tools for quality-of-life assessment
- App usage tracked via a custom API

Despite limited statistically significant results due to data attrition, two-thirds of participants reported subjective improvement in strength, balance, energy, and emotional well-being. Over 2,000 workouts were logged, and many users gained confidence to exercise safely with OI. The Key findings will be subject to two publications.

## c) **CONFERENCE QUALITYOFLIFE4OI 2024**

In 2024 we held the fourth online version of the QualityofLife4OI Conference.

The event featured 77 speakers and moderators and 356 attendees, which is again a ca.





10% increase from the previous year.

The event was carefully evaluated and provided overwhelmingly positive feedback as well as some improvement opportunities. The decision was taken soon after to make the conference an annual online event, making knowledge as accessible as possible for any healthcare provider, any researcher, and any person with OI worldwide.

## Conference 2024: Key Metrics

QUALITY OF  
LIFE4OI



**356 live attendees**  
• 59% healthcare providers  
• 41% OI community



**Time spent on  
conference platform:**  
52 days, 3 hour



**494 Chat messages**



**77 moderators and  
speakers**



**1 day  
40 hours of programme**



**5 Themes**  
(Children, Adults, Basic  
Science, Oral Health,  
Healthcare Innovation)



**Audience from 48  
different countries**



**Posters**  
84 posters



**8 different types of  
sessions** (presentations,  
panel discussions,  
livestreaming, video's,  
workshops, 1:1, community  
sessions, Virtual Booths)

## Conference 2024: Participant feedback

QUALITY OF  
LIFE4OI

**100%**

of participants found the conference overall  
(very) good

**85%**

of participants indicated that the formats used during  
the conference were suitable

**70%**

Will keep the connection  
through CARE4BONES

**100%**

of participants said that speakers were (very)  
knowledgeable

**97%**

of participants said the event was  
(very) useful for them

**85%**

Is working or is interested  
to work with Key4OI

**95%**

of participants said that the organization of the  
conference was excellent / good

**9,2 ★ out of 10**

is the average rating participants gave to our Conference overall.

### e) Adult Health

New in 2024 was the focus on Adult Health. Focusing on adult health in OI is essential because this area has significantly less specialists and data insights compared to pediatric care. Adults face unique health challenges such as chronic pain, fatigue, joint degeneration, cardiovascular issues, and mental health concerns that are often under-researched and poorly addressed. Unlike in childhood, where growth and fracture management are primary concerns, adult care requires long-term strategies for maintaining mobility, independence, and quality of life. Without adequate adult-focused care, there is a risk of increased disability, social isolation, and reduced participation in



work or community life. Moreover, a lifespan approach to OI helps ensure continuity of care and empowers individuals to manage their condition proactively throughout life. Addressing adult health in OI is not just an extension of pediatric care—it is a critical step toward holistic, lifelong well-being.

In 2024 we started to develop educational content for various areas mentioned above. The topic will remain core to our foundation for the years to come.

#### **f) CONTRACT MANAGEMENT**

We actively managed our research contracts. The status of all running contracts is part of a regular review process. Two research project supported by the Care4BrittleBones Foundation were funded in 2024 and will lead to publications in 2025 to share the findings:

- Prof. Dr. Bank: “Sweet Bones”
- Prof Dr. Docquier et al “OI Tendon and ligament study
- Another study is ongoing and delayed: “Osteogenesis Imperfecta - Bone strength, Osteoarthritis and Soft Tissue Complication in Adult OI / Jannie Hald”. The committed funding has been set aside

#### **g) RESEARCH SPENT**

We spent €46.419 on our statutory goals: research, information sharing and collaboration for knowledge exchange (excluding exceptional items, see fin. report for details). This is significantly below 2023 levels and due to our focus on delivering the Key4OI project.

#### **Improvement opportunities, risks and uncertainties in this area:**

As the Key4OI Registry enters its implementation phase in 2025, successful data collection will depend on sustained engagement from participating hospitals and the ability to address potential delays in onboarding additional international centers. Ensuring data completeness, consistent quality, and adherence to GDPR standards will also require ongoing oversight and support.

For Energy4OI 2.0 and other patient participation projects, maintaining participant engagement over time and improving data collection (especially PROMIS responses) remain key challenges to achieving statistically robust outcomes. Additionally, the development of new educational content on adult health must navigate limited existing research and specialist availability, posing risks to timely and comprehensive delivery. Continued contract management and coordination across multiple projects will be critical to maintaining momentum and accountability.

## **| FUNDRAISING**

In 2024, the Care4BrittleBones Foundation successfully raised funds through various channels to support its mission of improving the lives of individuals with OI.

Fundraising was successful in 2024: The foundation continued to work with a professional fundraiser who helped to understand the fundraising landscape and successfully apply to various funds for the Adult Health Education projects and beyond. Also the foundation received 170 paintings as a unique gift from one of the Care4BrittleBones friends in the OI



Community. The objective of her donation is to support the work of the foundation and research into OI.

**Crowdfunding:** Individual donations amounted to a total of €7.690 raised in 2024, a small increase compared to 2023 levels. Whilst it is clear that a stronger basis of local financial supporters would help the foundation a lot, it is not easy to build that: Families affected with OI often also experience challenges on the financial front due to the impactful nature of the condition. General public is often more interested in diseases like cancer or other life threatening diseases. OI remains a “niche interest”. We are particularly grateful to the long term supporters of our foundation.

**Company Donations:** We are grateful for the support received from various companies. Through our collaborative activities, we raised €22.584 in corporate donations during 2024, which is similar to the previous year.

**Governmental Grants:** In 2024, no government grants or public funding was received by the Care4BrittleBones Foundation. While this fell short of our expectations, we are actively working to enhance our grant application strategy. More information can be found in the section under “Improvement Opportunities, Risks, and Uncertainties”.

**Donations from other non-profit organizations:** Care4BrittleBones received just under €6.000 in donations from non-profit organizations, reflecting our collective commitment to improving the lives of individuals with brittle bones. The amount is significantly lower than in the previous year. The reason for this was that the foundation was prioritising the delivery of existing commitments to NGOs with 2 year projects like the Adult Health Project over generating new projects and new funding for projects.

**Donation of paintings by Anke Labrie:** We received 170 paintings from the Amsterdam artist Anke Labrie. They were all picked up from the Atelier, photographed and classified and published on a dedicated website: [www.art4oi.org](http://www.art4oi.org). Preparation has started to organise 2 Fundraising events in 2025 to try to monetize the gift.

#### **Improvement opportunities, risks, and uncertainties:**

In 2025, fundraising for Care4BrittleBones may face uncertainties due to broader economic pressures such as inflation, shifting donor priorities, and increased competition in the non-profit sector. Donors may become more cautious, favouring high-profile causes or limiting unrestricted funding, which can challenge the foundation’s flexibility and long-term planning. The move toward digital engagement also requires continued investment in technology and communications to effectively reach and retain supporters. Additionally, reliance on project-based funding can leave core operational needs underfunded. Community engagement and volunteer-driven campaigns may also fluctuate, affecting grassroots fundraising efforts. To navigate these risks, the foundation will focus on maintaining strong donor relationships, diversifying income streams, and demonstrating clear, measurable impact.



## | COLLABORATION AND REACH

Collaboration is key for everything we are trying to achieve. We maintained strong and very positive relationships within the foundation, which can be seen from stability of the board members as well as delivery in busy times. This can only be achieved with strong commitment to the goals of the foundation on an individual and collective level.

Collaboration with stakeholders outside of the foundation is also critical. We have strong positive relationships with most national patient organisations. Very few national patient organisations are a bit reserved. We are mindful to respect their lead role in the country. The collaboration between Care4BrittleBones, OIFE and OIF continues to be constructive. Whenever there is a need, the organisations will support each other. Care4BrittleBones continues to lobby for a strong collaboration as it is in everyone's interest to not duplicate and use the volunteer time and resources in the research and healthcare space as efficiently and effectively as possible. We will need to continue building trust and collaboration also in 2024.

Since the CARE4BONES Foundation started in 2021, most engagements are left to CARE4BONES, who has superior ways to connect and grow the community of people with OI and professionals supporting OI. The communication of the Care4BrittleBones Foundation was centred around the QualityofLife4OI Conference. Currently, our newsletter is sent out to 1,800 individuals/professionals, which is similar to previous years. The website [www.care4brittlebones.org](http://www.care4brittlebones.org) reflects the key information required for transparency. An in-depth update is recommended to take place to ensure the latest developments are reflected fully.

### **Improvement opportunities, risks and uncertainties in this area**

Our focus is on keeping the relationships with the big OI umbrella organisations OIF and OIFE as good as possible, for everyone's benefit. A friendly and mutually supportive relationship will generate the best synergy and minimize overlap or other "noise". This requires continued attention and focus.



## IT | OUR SYSTEMS AND TOOLS

Foundation Care4BrittleBones believes in innovation and technology. We therefore need to lead by example, ensuring we work to the highest standards with regards to the data we process. We make use of the following systems and tools:

- **Policies and procedures:** We developed a data management plan in line with the new GDPR rules introduced in 2019, published our approach on data privacy and implemented a complaints policy and procedure. No formal complaints have been raised through this policy in 2024. Informally we noticed some sensitivities with regard to the communication around the death of 2 community members who were formally on the coreteam of Care4BrittleBones. These were addressed with 2 meetings: One meeting of the Board reflecting and discussing together and one meeting of the board with the Advisory Board of the foundation.
- **E-bookkeeping tool:** The financial administration is maintained in an online bookkeeping environment called “e-boekhouden”.
- **Document management:** All Foundation documents are kept in Google Workspace since December 2022, which is accessible for everyone in the Coreteam.
- **Website Care4BrittleBones ([www.care4brittlebones.org](http://www.care4brittlebones.org)):** All key information about Care4BrittleBones is available on our website which is updated on a regular basis (hosted at Vimexx).
- **Website Conference QualityofLife4OI ([www.qualityoflife4oi.org](http://www.qualityoflife4oi.org)):** This website is used each year to update the global community about the conference programme, speakers and how to join.
- **Website Key4OI ([www.key4oi.org](http://www.key4oi.org)):** This website enables “brand neutral” sharing of information about Key4OI. All measures are available for free for everyone interested to work with Key4OI. The aim is to develop a Key4OI Registry in 2024, which will be a major new step in the development of Key4OI and our foundation.
- **Formdesk for surveys:** We conducted several anonymous Delphi surveys, facilitated by ourselves, supported by a user-friendly web based tool (Formdesk), which fully protects the privacy of people participating in our surveys.
- **Mailchimp:** Our newsletter provider is Mailchimp. We continue to watch data privacy compliance.
- We are working with various **social media channels and other platforms such as YouTube and SoundCloud, where we have dedicated channels**
- **Crowdfunding platform Research4OI (<https://research4oi.kentaa.com/>)** continued to run in 2024.





## COMMUNICATIONS | NETWORKS

### | OI COMMUNITY NETWORKS

In 2024, more than 25 people have been involved as volunteers of Foundation Care4BrittleBones. They are active in raising awareness, in supporting research (e.g. researchers and OI community in Key4OI plus and many other projects), in raising funds and last - but not least – running the activities of our foundation (e.g. our Core Team, the QualityofLife4OI Conference). Also, we interact with patient organisations in various countries and work together with them to achieve shared objectives. Our OI-world is a small world. We strongly believe we need to work together to improve the quality of life for people with OI.

#### **VOI – Dutch OI Association**

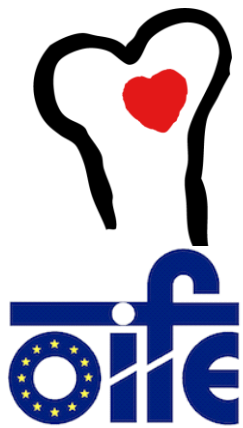


Foundation Care4BrittleBones originally started due to a call of the Dutch OI organisation VOI (Vereniging OI). In 2011, the VOI urged its members to consider what they could personally do to improve the lives of people with OI. The founders of Care4BrittleBones, parents of a daughter with OI and members of the VOI, volunteered to support research. Quickly it turned out that the VOI's statutory objectives did not include research. The VOI therefore suggested setting up a separate organisation and working together! And this is exactly what happened: The VOI and Foundation Care4BrittleBones serve complementary goals and support each other in various ways. While the VOI focuses on "making the best of today" by working with the healthcare providers in the Netherlands and organising meetings between people with OI, Care4BrittleBones aims to contribute to a better quality of life "tomorrow" by enabling research and working around the globe. Care4BrittleBones is present at all formal meetings of the VOI and is regularly invited to address VOI members during plenary meetings with a presentation about the activities of the foundation. Likewise, the VOI is kept up to date about the foundation and they are invited to attend the monthly meetings of Care4BrittleBones whenever they want. The connection is positive and strong, and we will continue to support each other in topics of shared interest.

In 2022 the VOI and Foundation Care4BrittleBones developed a Collaboration Agreement which describes transparently how the organisations support one another and work together. The agreement was endorsed by the annual VOI association meeting. The partnership works very well also in 2024 and contributes to the positive climate for research into OI in the Netherlands.

#### **Other National Patient organisations**

We continue to engage with many national Patient organisations and with representatives in countries where there is no patient organisation yet.



## OIFE

For many years Foundation Care4BrittleBones has been a supporting member of the OIFE (OI Federation of Europe). The OIFE is an umbrella association for organizations dealing with OI in Europe and beyond. They were established in 1993 and have 20 European member organisations (with voting rights) and various associated and supporting members (both not entitled to a vote). Foundation Care4BrittleBones and the OIFE work together on specific projects, such as the conference QualityofLife4OI (the OIFE was part of the Steering Committee). Also, the foundation frequently connects to president Ingunn Westerheim as a sounding board and advisor for strategic initiatives of the Foundation.

## OIF Osteogenesis Imperfecta Foundation

The Osteogenesis Imperfecta Foundation is the most important OI association in the USA and is strongly linked to the Canadian COIS. With a very successful track record of 50 years of dedicated work by volunteers and strong support from their healthcare providers and researchers, they are a thriving and empowering network that we learn a lot from. Foundation Care4BrittleBones and the OIF work together on specific projects, such as the conference QualityofLife4OI (the OIF was part of the Steering Committee and sponsored many speakers with a US/Canadian background). Also, the foundation connects with CEO Tracy Hart as a sounding board and advisor for strategic initiatives of the Foundation.



## | SCIENTIFIC NETWORKS

Collaboration in the medical world is paramount for achieving progress in OI research and ultimately a better quality of life for people with OI. In 2024, Care4BrittleBones engaged with the following scientific professional contacts:

1. **ERN-BOND:** The European Reference Networks, coordinated by the European Union, advocate for increased collaboration across the member states to support and address rare diseases. OI is part of the ERN-BOND, which covers more than 400 rare bone diseases. OI is one of the major rare bone diseases, which is why it has been selected as one of the key focus areas of ERN-BOND. More information can be found on <http://ernbond.eu/>.
2. **BBDC:** The BrittleBonesDiseases Consortium is one of the most important networks in the US/Canadian region for research into OI. More information can be found on <https://www.rarediseasesnetwork.org/cms/BBDC>
3. **Dutch OI Group:** The Care4BrittleBones Foundation is informally connected to the Dutch OI Group, a group of medical specialists who support OI in the Netherlands. The experts of this group are associated with the Wilhelmina Children's Hospital Utrecht (specialising in children with OI), Isala Hospital Zwolle (specialising in adults with IO), and several other hospitals. Together they ensure that they regularly share knowledge with each other and relevant stakeholders, including Care4BrittleBones.
4. **Meetings and Conferences:** In 2024 Care4BrittleBones Board members attended several virtual meetings and conferences (eg OIF meeting, OIFE Young Investigator meetings), all national meetings of the Dutch OI Organisation VOI.
5. Over the course of the last 11 years, we have established a worldwide **database of about 1100 OI researchers and health care providers across all disciplines**





supporting people with OI. This includes, for example, orthopaedics, endocrinologists, geneticists, physiotherapists, and dental, hearing and breathing experts. We are in contact with **all leading researchers** in the world. We know them and they know us.



## | COMMUNICATION

Since 2021 the engagement of the OI community and professional community is increasingly left to CARE4BONES to handle as they think is best. Care4BrittleBones continues to communicate on research projects, e.g. Key4OI and the QUALITYOFLIFE4OI Conference.

**Website C4BB** <http://www.care4brittlebones.org/en/>

Our website contains information about OI, provides an overview of the projects we are conducting and provides information on the foundation and its processes. On top of this “internal” information, it also supports an information platform catering for the needs of researchers, clinicians, healthcare professionals, OI communities and industry supporting OI. It is possible to donate in support research or help in other (non-monetary) ways. Our website is currently showing the basic information about the foundation. It needs to be updated to reflect the latest developments.

### **Newsletter**

During 2024 we have sent out 4 newsletters, many of them in relation to the QUALITYOFLIFE4OI Conference. They reached 1.800 healthcare providers, researchers and people in the OI community. The open rate is about 40% which is high compared to newsletters in general and a good sign for an engaged and interested audience.

### **Social Media:**

We share information through LinkedIn, Instagram, Facebook and Youtube. The variety in channels gives us the opportunity to target different audiences. We also have ca. 10 podcasts available on soundcloud.





## FINANCIAL REPORT

### SUMMARY OF FINANCIAL RESULTS INCLUDING EXPLANATION

For 2024 we had planned a sizeable increase in our efforts in fundraising. We did indeed step up our efforts and made some expenses associated with this increase. The planned events all slipped into 2025 though. This meant that we did not yet see income from the charity event in Germany, the very generous donation of paintings that the Foundation received and the gala fundraiser in The Netherlands.

Keeping in mind that we started the year with negative Contingent reserves (also called 'Other reserves'), postponing the fundraising events meant that we had to drastically adjust expenses. Thanks to very efficient (also virtual) ways of working, we were able to continue our work on Key4OI, Adult Health and Energy4OI, as well as organise the QualityofLife4OI conference. We also continued to fund the research projects we committed to in previous Research proposal rounds. This funding does not run through our Income & Expenses accounts though, since we already accounted for the expenses in 2023. This is in line with Guideline 650 Fundraising Organizations (RJ650) that stipulate commitments need to be recognised in full as costs in the year they are made.

Overall, we were not able to balance reductions in planned income with reduction in spend. This ultimately led to a more negative balance, compared to plan, of income and expenses. On the one hand this result weighted further on our financial position. On the other hand, thanks to the closing out of the two research projects we committed funding to, we were able to release Earmarked Reserves related to these projects. Combining these two effects, we saw a marked – and needed – improvement in our other reserves position from € -16.709 to (positive) € 12.096.

We consider our current balance sheet position healthy. In 2025, we will look to further improve this. This should be a realistic goal, considering that the fundraising activities that were postponed will take place in the first half of 2025.

At the same time, we continued to have strong liquidity, despite another year of negative cashflow. As remarked in our previous annual report, a negative cashflow in itself is not an issue. This would only come into play if our Foundation would have low liquidity. At the end of 2024, this was not the case since our liquid means (bank, PayPal accounts) were more than sufficient to cover the cash paid for the full year. On top of this, stripping out the payment for previously committed funds to research would have led to a positive cashflow for the year.

As in previous years, we continued to ensure that most of our (financial) resources were spent on research support and research projects. The Foundation aims to spend 75% or more of its expenses on its purpose, meaning that we aim to keep our 'overhead' spend (the total of fundraising and management costs) below 25% of total costs. As per the plan for 2024, we deviated from this norm for the first time in many years. However, much less than planned in both absolute and relative terms. We ended the year with 70% spend on purpose against a budget of 64%.



## Income

Our income generated in 2024 was much lower than planned and also fell significantly short of previous years' income. As mentioned above, this is largely due to the postponement of fundraising activities to 2025. On the other hand, we also reduced the activities of the professional freelance fundraiser who previously helped generate additional income from governments and non-profit organisations, mostly for research related activities.

In total, our income was down from €106.059 in 2023 to €37.229 in 2024. The difference is mainly found in income from governments and non-profit organisations. The biggest gap versus plan is from income from individuals. As mentioned, this was expected to increase thanks to fundraisers, but instead remained roughly flat against 2023 due to the postponement of these activities.

Although the level of income is not at the level of our ambition, we continue to appreciate all contributions and are very happy to have the continued support from individuals, institutions, and companies for our foundation.

## Spend on Purpose

The ratio of spend on purpose vs total expenses decreased to 70% from 85% in 2023. Total spend was €66.482, significantly less than previous years. Underlying spend of €46.419 on Research projects and other purpose-related activities (e.g. providing information about research and supporting knowledge sharing) was lower than budgeted.

This was mainly driven by lower income to which we adjusted our spending. This resulted amongst others in less time spent on our Foundation by our (freelance) director and the cancellation of the proposal round for research grants for early career scientists due to insufficient other reserves. The main expenses related to our purpose we did incur came from spend on (in order of decreasing spend) the QualityofLife4OI conference, Energy4OI, Adult Health, and Key4OI related activities.

## Fundraising

The cost of fundraising of €12.781 decreased from 2023 when we spent €16.165 on these activities. As mentioned earlier, more importantly, we did not reach the aspired level of activities and associated spend, since activities were postponed to 2025. We still expect to incur these costs in the next year. Approximately half of the costs we incurred though were related to preparation of these fundraising activities. This is one of the key drivers for our higher relative spend on 'overheads'.

## Management & Admin

In 2024 we spent €7.281 on management and administration related activities. This is well below both our budget of €29.820 and also less than our spent in 2023, which was €9.886. The decrease against 2023 was mainly thanks to a further reduction in hours from our director and hours spent on IT related activities.

Compared to the 2024 plan, we mainly reduced spend in IT, with over €10.000 lower spend, in fact pausing all planned improvements. We also managed to stop or keep costs low for communications, team activities, and travel and accommodation.



## Financial Position

We ended 2023 with negative other reserves and noted that this level was too low to be sustainable in the mid-term. The Board has a longstanding prudent aim to have sufficient Contingent Reserve to cover 6 months of costs for our Foundation.

In 2024 we closed out two of our key commitments to fund external research, namely the OI Tendon and ligament study by Prof. dr. Docquier et al. and the Sweet bones study led by Prof. dr. Bank. The final payments on these projects have been made and as a result we released the Earmarked Reserves, strongly contributing to the improvement in our overall financial position and leading to a positive Other reserve position.

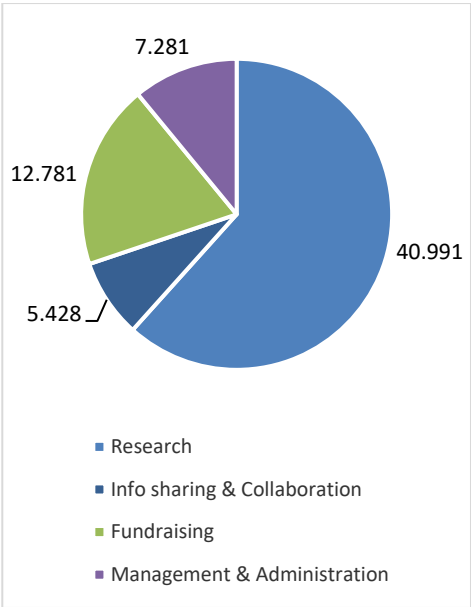
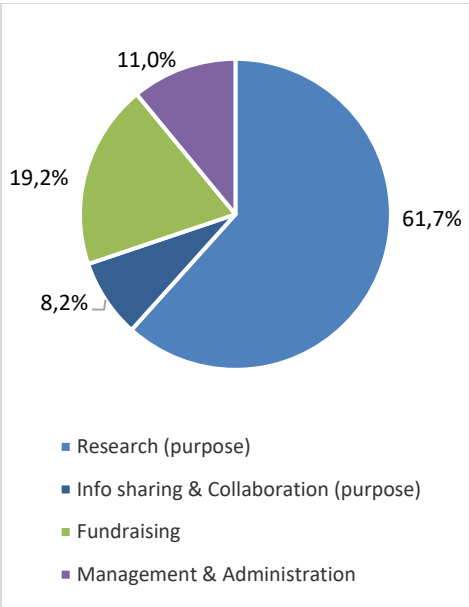
The current level of Other Reserve remains below the threshold set by our Board, for which a minimum of €22.813 would be required. It should be reminded that we expect to see a further improvement in this position as the results of the postponed fundraising activities come in in 2025. We will continue to monitor our reserves position and spend on overhead activities very carefully in 2025.



## KEY NUMBERS

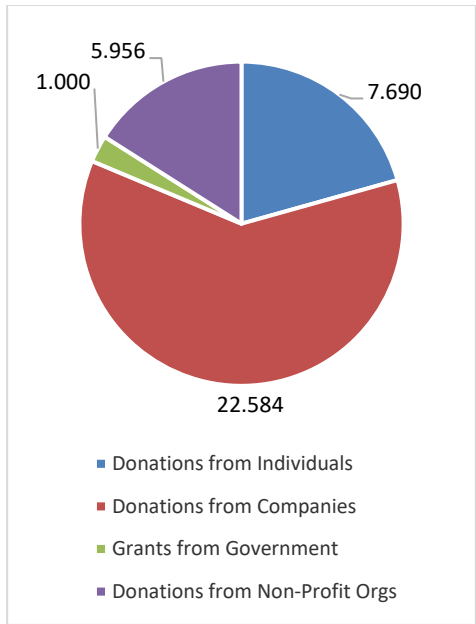
### How did we spend your contribution?

Spend in 2024: €66.482



### What are our sources of income?

Income in 2023: €37.229





## BUDGET 2025

The Care4BrittleBones budget for the following year is approved annually by the Board. Normally, this is based on a balanced operation, i.e. with a change of the Contingent Reserve of zero. There could be balances on designated reserves and funds. These are balance sheet transactions that arise from timing differences in income and expenses. Often the Foundation first receives the benefits and then only spends the funds and / or incurs them.

## Income

As mentioned above, for 2025 we expect several fundraising activities will help deliver a significantly higher level of income. Given a lot of the preparation work has been done in 2024, we mainly expect the effects to be on the income side, with relatively modest expenses related to these activities.

Given our financial position at the end of 2024, we are planning a positive balance of income and expenses. We have built in flexibility and the necessary buffer to improve the financial position of our Foundation.

## Expenses

For 2025, we expect to focus on the continuation and expansion of the work on Key4OI, Adult Health and Energy4OI. We also plan to host the 2025 QualityofLife conference.

Following on a year where we overshot our norm of spend on 'Overheads', we expect to bring this spend back in line in 2025. The percentage of spend covering Management and admin expenses and Fundraising costs is expected to decrease from 30% in 2024 to 22% in 2025.

This means the percentage of spend on Foundation Goals is expected to be 78%, bringing us back in line with the CBF-based guideline we set.

## Budget 2025

Income & Expenses	Budget 2025		Actuals 2024		Budget 2024	
	EURO	EURO	EURO	EURO	EURO	EURO
<b>Income</b>						
Income from Individuals		60.000		7.690		135.000
Income from Companies		25.000		22.584		25.000
Income from Lottery Organizations				0		
Income from Grants from Government		2.000		1.000		
Income from Associated (international) Organizations						
Income from other Non-Profit Organizations		50.000		5.956		70.000
Total Acquired Income		137.000		37.229		230.000
Income as compensation for the delivery of:						
- Products and/or Services						
- Other income						
<b>Total Income</b>		<b>137.000</b>		<b>37.229</b>		<b>230.000</b>
<b>Expenses</b>						
<b>Spent on Goals</b>						
- Research	75.000		41.175		111.038	
- Information sharing & Collaboration	15.500		5.428		20.000	
- Other			0			
		90.500		46.603		131.038
<b>Fundraising costs</b>		8.677		12.781		45.500
<b>Management &amp; Administration costs</b>		16.115		7.281		29.820
<b>Total Expenses</b>		<b>115.292</b>		<b>66.665</b>		<b>206.358</b>
<b>Balance before Financial Income &amp; Expenses</b>		21.708		-29.436		23.642
<b>Balance Financial Income &amp; Expenses</b>						
<b>Balance Income &amp; Expenses</b>		<b>21.708</b>		<b>-29.436</b>		<b>23.642</b>



## FINANCIAL STATEMENTS 2024

### Income Statement

Income & Expenses	Actual 2024		Budget 2024	
	EURO	EURO	EURO	EURO
<b>Income</b>				
Income from Individuals		7.690		135.000
Income from Companies		22.584		25.000
Income from Lottery Organizations		0		0
Income from Grants from Government		1.000		0
Income from Associated (international) Organizations		0		0
Income from other Non-Profit Organizations		5.956		70.000
Total Acquired Income		37.229		230.000
Income as compensation for the delivery of:				
- Products and/or Services				0
- Other income				
<b>Total Income</b>		37.229		230.000
<b>Expenses</b>				
<b>Spent on Goals</b>				
- Research		41.175		111.038
- Information sharing & Collaboration		5.428		20.000
- Other		-184		
		46.419		131.038
<b>Fundraising costs</b>		12.781		45.500
<b>Management &amp; Administration costs</b>		7.281		29.820
<b>Total Expenses</b>		66.482		206.358
<b>Balance before Financial Income &amp; Expenses</b>		-29.252		23.642
Balance Financial Income & Expenses		1.261		0
<b>Balance Income &amp; Expenses</b>		-27.992		23.642
<b>Assignment Balance Income &amp; Expenses</b>				
<b>Addition to / Withdrawal from:</b>				
- Other Reserves		28.804		
- Earmarked Reserves		-43.702		
- Earmarked Funds		-13.093		
		-27.992		

### Balance Sheet

	Notes	31/Dec/24		31/Dec/23	
		EURO	EURO	EURO	EURO
<b>Assets</b>					
Receivables & Accrued Assets	1	4.990		40.358	
Cash & Cash Equivalents	2	130.591		171.634	
			135.581		211.992
			135.581		211.992
<b>Liabilities</b>					
<b>Reserves &amp; Funds</b>					
- Reserves					
- Earmarked Reserves	3	29.398		73.100	
- Other Reserves	4	12.095		-16.709	
			41.493		56.391
- Funds					
- Earmarked Funds	5		51.867		64.960
			93.360		121.351
Long Term Debt	6		0		0
Short Term Debt	7		42.588		90.641
			123.853		228.701



## CASHFLOW STATEMENT

	2024	2023
<i>Cash collected from:</i>		
donations	30.275	55.496
Income from Grants from Government	1.000	21.745
Income from other Non-Profit Organizations	40.956	21.205
Products & Services	0	0
Interest received	1.261	868
Total cash collected	73.492	99.314
<i>Cash paid for:</i>		
Research projects	94.472	89.195
Sponsoring events		
Governance costs	7.281	9.886
Fundraising activities	12.781	16.165
Interest paid	0	0
Total cash paid	114.535	115.246
Net cash from operations	-41.043	-15.932
<i>Cash Balance:</i>	2024	2023
Opening balance ABN AMRO, SNS & Paypal	171.634	187.566
Closing balance ABN AMRO, SNS & Paypal	130.591	171.634
Net cash from operations	-41.043	-15.932



## NOTES TO THE ACCOUNTS

### General

The financial statements for 2024 have been prepared in accordance with Part 9, Book 2 of the Netherlands Civil Code and in particular the regulations of the Guideline 650 Fundraising Organizations (RJ650). The purpose of this annual account is to provide insight into income and expenditure, and in the financial position of Care4BrittleBones.

#### ***Accounting policies for valuation and determination of results***

Unless stated otherwise, the assets and liabilities are valued at the acquisition price, the manufacturing price or the current value. If no specific valuation principle is stated, valuation takes place at the acquisition price.

The accounting policies used for valuation and determination of results have remained unchanged compared to the previous year.

In order to be able to apply the principles and rules for the preparation of the annual accounts, it is necessary for the management of Care4BrittleBones to form an opinion on various matters, and to make the directives that can be essential for the amounts included in the financial statements. If it is necessary to provide the insight required in article 2: 362 paragraph 1 of the Dutch Civil Code, the nature of these judgments and assessments, including the associated assumptions, has been included in the notes to the relevant financial statements.

### Cash flow statement

The cash flow statement has been prepared according to the direct method. The cash in the cash flow statement consists of cash and cash equivalents.

### Receivables and Accrued Assets

Debtors and other receivables are initially valued at fair value. Subsequently, these receivables are valued at the amortized cost price subject to a deferral of provisions deemed necessary.

### Cash & Cash Equivalents

Cash and cash equivalents consist of current - and saving account bank balances and Paypal balance. Cash and cash equivalents are valued at nominal value.

### Project obligations

Contractually committed contributions to third parties are recognized as project obligations, split into long-term and short-term obligations. These are defined obligations, which are therefore recognized as expenses, but not yet implemented or for which no reports have yet been received.

### Statement of income and expenses

Accounting principles for the determination of the result:





Income is recognized for the amounts received or promised without deducting the costs incurred by the own organization. Income is in principle recognized in the year in which it is unconditionally committed to or, when the former is not possible, when it is ultimately received.

## Charges

Projects are often carried out together with research institutions. Defined contributions in the context of research projects are charged to the year in which the contribution was unconditionally contractually agreed. Other expenses are allocated to the year to which they relate.

## Cost allocation

The recommendation 'Costs of allocation of Management and Administration' of Goede Doelen Nederland is followed.

By making use of projects in the administration, which are categorized according to the objectives (Research and Information & Collaboration), costs are recorded as much as possible directly.

The remuneration costs of the director are allocated to the goals, fundraising and management and administration on the basis of time writing.

## Reserves and funds

The Care4BrittleBones's assets must be subdivided into reserves and funds on the basis of the Reporting on Fundraising Institutions. The Reserves include the contingent reserve and part of the reserves that are further earmarked by the association's board for special spending purposes (so-called "Earmarked Reserves"). Funds include those funds that have been given a specific destination by a third party, called "Earmarked Funds", as a result of which Care4BrittleBones can only spend these funds on this specific project.

The contingent reserve, reported under "Other Reserves", is intended as a buffer for disappointing income or unexpected expenses. With this reserve, Care4BrittleBones can continue its activities in financially difficult times.

As a CBF (Centraal Bureau Fondsenwerving) accredited organisation, Care4BrittleBones is bound by the rules for holding or building up reserves by fundraising institutions, as well as the instructions for how the asset management policy should be accounted for in the annual report. In accordance with the Financial Management Guidelines for Charities of Goede Doelen Nederland, the Association Board of Care4BrittleBones decided to set the standard for the reserve for Care4BrittleBones as a whole at a minimum of 6 months and a maximum of 1 time the annual costs of the organization. Based on the 2025 budget, a contingent reserve of a maximum of €45.625 will follow as of 31 December 2024. The realized balance Other Reserves of €12.095 is significantly below this threshold set by the Association Board. It is also below the minimum threshold of 6 months of normal expenses, €22.813 for 2025. In 2025 we expect to continue the improving trend from 2024. Following that trend, we aim to bring these reserves back to a healthy level by end of 2025, in line with the standard, as described above.



Short-term debts have a duration of less than 1 year. The project obligations and commitments to (research) organizations to the financing of projects have a remaining duration of less than 1 year.

## NOTES TO THE BALANCE SHEET

### Note 1

	2024 EURO	2023 EURO
<b>Receivables &amp; Accrued Assets</b>		
Receivables from Individuals	-	-
Receivables from Companies	-	368
Grants from Government	368	4.990
Interest		
Receivables from Non-Profit Organizations	4.990	35.000
<b>Total</b>	<b>5.358</b>	<b>40.358</b>

### Note 2

	2024 EURO	2023 EURO
<b>Cash &amp; Cash Equivalents</b>		
ABN AMRO Current Account	3.106	25.328
ABN AMRO Savings Account	24.322	44.322
SNS Bank Savings Account	101.626	100.409
PayPal	1.871	1.837
<b>Total</b>	<b>130.926</b>	<b>171.895</b>

### Note 3

	2024 EURO	2023 EURO
<b>Earmarked Reserves</b>		
balance 1/1	73.100	25.000
Additions	0	48.100
Withdrawals	-43.702	0
<b>Balance 31/12</b>	<b>29.398</b>	<b>73.100</b>

*The withdrawals relate to the payments for OI Tendon and ligament and the Sweet bones studies*

### Note 4

Note 4

	2024 EURO	2023 EURO
<b>Other Reserves</b>		
balance 1/1	-16.709	152.686
Additions	61.795	8.700
Withdrawals	-32.992	-178.094
<b>Balance 31/12</b>	<b>12.095</b>	<b>-16.709</b>

*The additions relate to the release of commitments from both Earmarked reserves and Earmarked funds. The withdrawals are the addition of Earmarked funds and the balance of the income and expense accounts.*

### Note 5

	2024 EURO	2023 EURO
<b>Earmarked Funds</b>		
balance 1/1	64.960	8.700
Additions	5.000	64.960
Withdrawals	-18.093	-8.700
<b>Balance 31/12</b>	<b>51.867</b>	<b>64.960</b>

*The withdrawal are Energy4OI related activities. The additions are new funding for Energy4OI.*



#### Note 6

	2024	2023
Long Term Debt	EURO	EURO
Project Commitments	0	0

*Project commitments concern commitments to research organizations for the funding of projects with a remaining duration of more than 1 year.*

#### Note 7

	2024	2023
Short Term Debt	EURO	EURO
Project Commitments	29.398	73.508
Creditors	13.190	17.133
Total	42.588	90.641

*Project commitments concern commitments to research organizations for the funding of projects with a remaining duration of less than 1 year.*



## NOTES TO THE INCOME STATEMENT

### Explanation of Spending

	Spent on objectives Information sharing & Research      Collaboration		Fundraising costs	Management & Admin	Total Actual 2024	Budget 2024	Total Actual 2023
Project contributions	17.657	0			17.657	15.194	76.434 0
Outsourced work	0	0	10.421	0	10.421	20.000	12.391
Remuneration of director	23.518	5.428	2.361	2.124	33.430	67.351	76.346
Office and general costs				5.157	5.157	22.499	6.790
Buitengewone lasten	-184				-184		0
<b>Total</b>	<b>40.991</b>	<b>5.428</b>	<b>12.781</b>	<b>7.281</b>	<b>66.482</b>	<b>125.044</b>	<b>171.961</b>



PROJECT OVERVIEW– SPENT ON GOALS

	Year	Project Title	Lead Country	Institution	Lead researcher	Status	Originally Committed pre 2023	movement in commitment 2024	Total ITD Commitment 31/12/2024	PY Paid	Outstanding payment on 31/12/2024	CY Paid	Directors' remuneration 2024 (included in Paid)	Outstanding to be paid (to be received) 31/12/2024
2020	2020-023	Sweet bones		UINCG		committed	60,000	0	60,000	35,000	25,000	25,000	0	0
2022	2022-029	Energy 4CI		ZonMw		committed	0	0	0	0	0	0	0	0
2023	2023-027	Adult health		Stichting Aanmoedigingsfonds van de Koninklijke Faculteitieve & v M De Hoop Stichting & Versteeg Lity		committed	40,000	0	40,000	35,000	5,000	5,000	4,916	0
2023	2023-024	2023-024 Study UCLouain				committed	19,100	0	19,100	0	19,100	19,702	0	398
2023	2023-26	2023-026 ENERGY4CI- Purpose> Projects 2		Care4BB ZonMw		committed	24,960	0	24,960	19,970	4,990	0	907	-4,990
2023	2023-029	023-029 CI – Bone strength. Other research projects		Jannie Held		committed	23,000	0	23,000	0	23,000	0	0	29,000
			Netherlands			Ongoing	0	0	0	0	0	0	13,424	0
Total Projects		Total Projects					173,060	0	173,060	96,270	91,790	48,702	19,247	24,408
Overall Total		Overall Total					173,060	0	173,060	96,270	91,790	48,702	28,946	24,408



## NOTES ON THE ROLE AND REMUNERATION OF THE DIRECTOR

2024	
Notes on the role and remuneration of Management	
Name	Dagmar Mekking
Position	Director
Line of work	Contract (2 years)
Hours	ca. 11/week
Parttime percentage	ca. 32%
Period	1/1/2024 - 31/12/2024
Annual remuneration (gross)	85.419
Vacation payment	-
Year-end payment	-
Compensation holidays not utilised	-
<b>Total</b>	<b>85.419</b>
Taxable reimbursement	-
Pension payments (Foundation)	-
Pension compensation	-
Other long term remuneration	-
End of Service payment	-
<b>Total</b>	<b>85.419</b>

*In setting the remuneration policy and the actual director's remuneration Care4BrittleBones follows the "Regeling belonging directeuren van goededoelenorganisaties" (ref. [www.goededoelennederland.nl](http://www.goededoelennederland.nl)). This guideline provides maximum thresholds for the director's annual income based on specific weighing criteria.*

*The assessment of the circumstances of C4BB is done annually by the Board. The assessment over 2024 led to a so-called BSD-score of 305 points with a maximum annual income of € 89.738,- for our director. On a self-employed basis, i.e. including pension payments that would otherwise fall to the Foundation as an employer, this translates to a maximum of € 110.852 (1 FTE/12 months). The total remuneration of the Director (self employed) on a full-time basis of € 104.108,- excl VAT (or € 125.970,68,- incl VAT) remains within this maximum.*

*The allocation of remuneration costs of the director is based on time writing, see 'Explanation of spending' (page 59).*

*\*including 21% VAT (is not recoverable as our foundation is exempt from VAT).*



## 2025 ACCOUNTING CONTROL STATEMENT

### Accounting Control Statement

The Auditing Committee in the person of Mrs. I. Parfus and Mr. R. Le Grand have on Friday 20 June 2025, in the presence of Treasurer Mr. D.J. Stegink and Mr. R. Brabander, checked the books of the Care4BrittleBones foundation for the financial year 2024.

The Committee states that:

- The Annuals Accounts give a correct representation of the income and expenses for the year 2024
- The balance sheet as at 31 December 2024 give a true and fair view of the Reserves.

Den Haag, 27 June 2025

The Auditing Committee

I. Parfus

R. Le Grand





## THANK YOU!

We would like to thank everyone who directly supported Care4BrittleBones in the last year – our generous donors, fundraisers and ambassadors and other volunteers. The achievements of Care4BrittleBones are enabled by this group of people, working relentlessly together to make a difference for people with OI. A wholehearted thank you to the core team for the numerous brainstorming sessions, discussions, challenges and huge effort committed to our cause. The power and passion of this team makes our organization move forward.

We also would like to thank our partners in the OI “ecosystem”: Our partners in universities and academic institutions, hospitals and other health related institutions and the life science and health industry. Your deep expertise and true dedication to improve the lives of people with OI and other rare bone diseases are an inspiration to us. We admire your innovative ideas and your courage to try out new approaches in responsible ways to address the many different symptoms of OI. Your work gives us hope for a better future.

And of course – a big thank you everyone who supports us and worked with us in the wider OI Community network, people with OI, their families and friends as well as the OI associations on a regional, national and international level! We are extremely proud to serve you all and thankful for the opportunity to work together to improve quality of life for people with OI!

**We stand strong together!**





## CARE4BRITTLEBONES | FOUNDATION

Care4BrittleBones (statutory name 'Stichting Care4BrittleBones') is located in Wassenaar. It is registered as a foundation (Dutch: 'Stichting') at the Chamber of Commerce of The Hague Nr. 54665256.

Established as a foundation in February 2012, Care4BrittleBones is recognised as a charitable organisation in the Netherlands since 12 June 2012 (RSIN 851392854; [www.kennisbankfilantropie.nl/anbi/care4brittlebones](http://www.kennisbankfilantropie.nl/anbi/care4brittlebones)).

Based on a ruling of the European Court of Justice, the recognition as charitable institution in one member state is sufficient to establish beneficial tax treatment for donations from donors based in any country of the European Union.



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 LinkedIn	<a href="https://www.linkedin.com/company/10639515">www.linkedin.com/company/10639515</a>