

2023



**ANNUAL REPORT | 2023**  
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

**145.910** EUR

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

**17** %

Overhead

## REACHING OUT IN 2023

**106.059** EUR

Of funds raised in 2023 for much needed research for OI

**14.0** %

Fundraising Cost

**100** Speakers and Moderators

Involved in the Quality of Life 4 OI Conference 2023



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## 2023 | A YEAR OF STEADY DELIVERY IN BUSY TIMES

We are looking back on a year with solid delivery against our statutory goal: “to support Quality of Life for people with OI by supporting research in the widest sense”.

1. We funded research of others through a proposal round.
2. We successfully moved our own research projects forward, in particular the ENERGY4OI Fitness app and Key4OI.
3. We continued our dialogue with Researchers, Clinicians and the OI Community.
4. We ensured our foundation board is fully resourced to deliver on its mission. Whilst everyone else remained in position, Andreas Matsangos transitioned from his role as President of the Care4BrittleBones Foundation into the role of Core Team member. Dr. Vanja Zivkovic has taken the role as new president of the foundation. With her medical professional background and personal connection to OI she is ideally equipped to help the foundation deliver on its goals in the coming years.

Our Foundation is a learning organisation. As such we continue to evolve our ways of working all the time. This year a few insights became clearer than ever:

**Lesson Learned Nr. 1:** In this time of AI and Digitalisation, everyone is always busy. Many people find it hard to prioritise and find the space in their life for volunteer work. Delivering anything requires both a strong commitment and mastery of the process.

**Lesson Learned Nr. 2:** It is a great time for Research and Healthcare improvement. There are systems and processes in place today that allow us to discover patterns in new ways. This means having data in one place to analyse is what we have to strive for. Also: data privacy is a key concern and needs to be built in by design.

**Lesson Learned Nr. 3:** Virtual work enables substantial accomplishments, while periodic Face2Face gatherings are crucial for forging deep connections and ensuring alignment in our goals and actions.

The picture below combines two separate images, representing our only way to visually unite. It serves as a meaningful visual summary of the three key lessons learned in 2023.



**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 are able to 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.

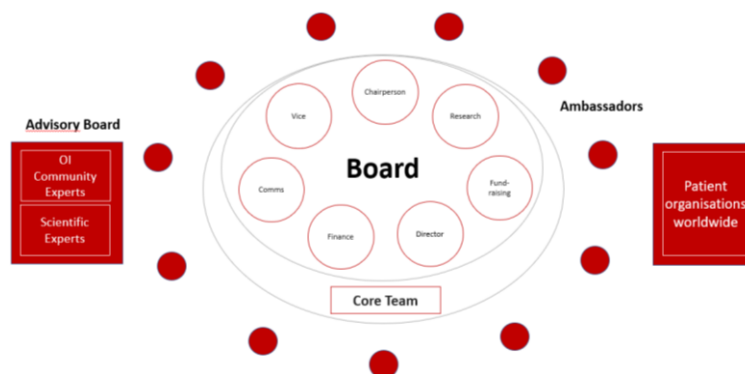
These circumstances create new opportunities for OI research. Care4BrittleBones has identified various short, mid, and long-term opportunities that have the potential to improve the quality of life of people with Osteogenesis Imperfecta and eventually to lead to a breakthrough therapy for OI.

## 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.



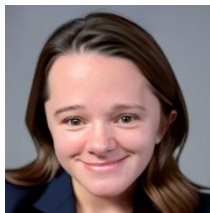
### 1. | THE BOARD

At the end of 2023, Care4BrittleBones was officially governed by a board of 6 members. The board continued in the same constellation as in 2022 except for the role of President of the Foundation. Andreas Matsangos has been the president since 2021. In 2022 he



indicated due to personal circumstances, that he needed to pass his responsibility on. The position was advertised transparently, and various candidates were considered. The successful candidate was Dr. Vanja Zivkovic. Vanja was born in Serbia and moved to Switzerland as a teenager. She studied medicine and was Swiss delegate for OIFE for about 8 years. After her studies she specialized in paediatrics and worked for many years in the University Hospital of Zurich in the field of intensive care for children. Since July 2022 she is working as head of the paediatric department at the Hospital of Winterthur in Switzerland. Her hobbies are travelling, bookbinding and reading. She has a deep interest and experience in science and healthcare and very much enjoys working with Care4BrittleBones to support the quality of life of people with OI around the world.

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



**Vanja Zivkovic**  
Chairman/Secretary



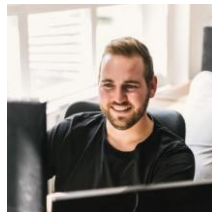
**Celine Disch**  
Vice-president



**Dagmar Mekking**  
Director



**Dirk-Jan Stegink**  
Treasurer



**Nicklas Teicke**  
Fundraising



**Lidiia Zhytnik**  
Research

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 meet on a monthly basis to discuss all matters concerning the foundation. The Core Team has various subcommittees:

Finance	<b>Dirk-Jan Stegink</b> , Robert Brabander,
Fundraising	<b>Nicklas Teicke</b> , Dagmar Mekking,
Communications	<b>vacancy</b> , Celine Disch
IT / Data Privacy	<b>Henk Latour</b> , <b>Kees Mezouar</b>
Research	<b>Lidiia Zhytnik</b> , Dagmar Mekking, Lieke Mekking,
Collaboration	<b>Vanja Zivkovic</b> , Andreas Matsangos, Dagmar Mekking
General Support	<b>Peter Mekking</b>

In the summer of 2023, we had the opportunity for various board members to see each other in person during a Conference organised by OIFE in Sweden. This was beneficial also because it allowed informal conversation about collaboration within the foundation and with our various stakeholders in the OI Community and the professional Community of Healthcare providers and researchers. It also supported the handover between the outgoing president, Andreas Matsangos, and the incoming president, Vanja Zivkovic.

#### **Stockholm June 2023 during OIFE Conference**







### 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 is multidisciplinary, representing the global reach of Care4BrittleBones and includes some of the brightest people in science, healthcare, and the OI Community.

#### **Advisory Board**

Scientific  
Advisory Board



Lars Follstedt  
Copenhagen University  
Hospital, Denmark

Antonella Forlino  
University of Pavia/Dept of  
Neuromuscular Medicine,  
Bocconi University, Italy

Richard Kruse  
Nemours Children's Health  
Wilmington/Delaware,  
USA

Kathleen Montpetit  
retired, former Shriners  
Hospitals for Children,  
Canada

Frank Rauch  
Shriners Hospitals for  
Children, Canada

Oliver Sander  
Children's University  
Hospital Cologne,  
Germany

Michael To  
University of Hong Kong,  
Shenzhen Hospital,  
China

Fleur Van Dijk  
North West Healthcare NHS  
University Trust England,  
UK

Frank Zeileke  
Goethe University  
Frankfurt/Main,  
Germany

Marionne Reibisch  
Children's Hospital  
Zürich,  
Switzerland

OI Community  
Advisory Board



Sander Culp  
The Netherlands

Leonardo Fozzari  
Italy

Uta Wallentin  
Germany

Amy Hassel  
Ireland

Benedicta Allot  
France

Eliot Aguirre  
United States

Sergio Rios  
Australia

Ighor Musil  
Poland

Enrique Grosser  
Australia

Justine D  
India



1. Lars Folkestad, Odense University Hospital, Denmark
2. Antonella Forlino, University of Pavia/Dept of Molecular Medicine, Biochemistry Unit, Italy
3. Richard Kruse, Nemours Wilmington/Delaware, USA
4. Kathleen Montpetit, retired, former Shiners Hospitals for Children, Canada
5. Frank Rauch, Shiners 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. Jasintha 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 2023 a proposal round took place between 1 March and the end of May. Find out more about the results in the chapter about "Research".

The key task involved in the proposal round are:

- Review of all proposals in Round 1 (proposals are ca 2 pages long each and written in scientific language).
- Feedback which proposals should proceed to Round 2
- Review of all proposals in Round 2 (proposals are ca. 5-10 pages long each and written in scientific language).
- Feedback which proposals should be considered for support from the Care4BrittleBones Foundation

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.



## 4. | PATIENT ORGANISATIONS

We work closely with various patient organisations in all our activities. 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 maintain regular connections with OIFE (OI Federation Europe) and the OIF (OI Foundation based in the USA).

## 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

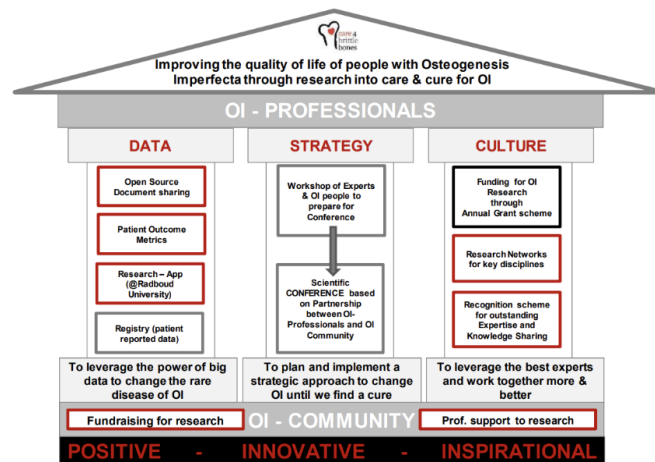




## 2. | STRATEGY

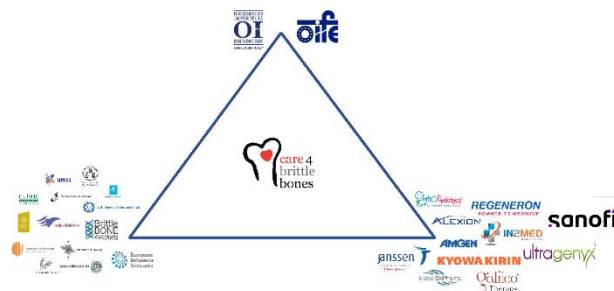
We believe that a two-pronged approach is needed to improve the quality of life of people with OI. Our approach focuses on improving quality of life through short- and medium-term research, related to clinical interventions close to the patient (e.g., improved orthopaedic approach, physical rehabilitation, 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 and 2023 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!*



### Multi Year 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, with the main “underperforming area”: the area of fundraising. Reflecting on our past performance, we see that our strength has been the

- the ability to orchestrate and support large scale research and healthcare improvement projects, working across many expertise centres in the world.
- the trusted 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.
- innovative edge and future oriented way of working.
- our strong reputation which has grown over almost 10 years. The foundation celebrated its 10-year anniversary on 12 February 2022.

All main stakeholders (e.g. Advisory Board, OIFE, OIF, ERN BOND) have been able to give feedback and contribute to the document. Once again, the discussions have proven very valuable to sharpen the priorities we need to focus on to make an impact. We are embarking on the next chapter towards improving quality of life with OI.

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

## 3. | 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 2023 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.







#### 4. | FINANCIAL COMPENSATION

In 2023, 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 | 2023





The year 2023 has been very productive. Whilst our **fundraising** was still low, most **research** activities were delivered as planned with the Quality of Life 4 OI – Conference and the Key4OI Outcome measurement Set as flagship projects.

### Colour coding:

<b>GREEN:</b>	Accomplished fully.
<b>AMBER:</b>	Mixed delivery
<b>RED:</b>	Below plans
<b>GREY:</b>	Hold

## Plan 2023



<b>1. RESEARCH</b> 	<ul style="list-style-type: none"><li>• <b>Key4OI</b><ul style="list-style-type: none"><li>• Implemented in 7 hospitals</li><li>• Key4OI Registry in place, working and robustly funded * and supported</li></ul></li><li>• Proposal Round 2023 for clinical research – to be issued as soon as possible. *</li><li>• Physical Wellbeing project (NL) ENERGY4OI ZonMW finalized 1 July 2023, on time and specs. / Sportdag in NL -&gt; Exceeded plans</li><li>• Physical Wellbeing (International) started (incl funding) *</li><li>• Adult healthcare guideline project started (incl funding) *</li><li>• Conference QualityofLife4OI delivered (400 participants, 20.000 income, Abstract book)</li></ul>
<b>2. FUNDRAISING</b> 	<ul style="list-style-type: none"><li>• Professional support for fundraising delivers return on investment</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</li><li>• Continue operational excellence in Finance</li><li>• IT review and update of tools / data privacy Q1. Migration Dropbox to Google Workspace</li><li>• Board successions and succession planning –Chairman + Care4Bones Talent pipeline solid.</li><li>• Team building (Sweden)</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.

### Research projects status update

Foundation Care4BrittleBones has been involved in 8 research related activities in 2023. Our role varies per project:

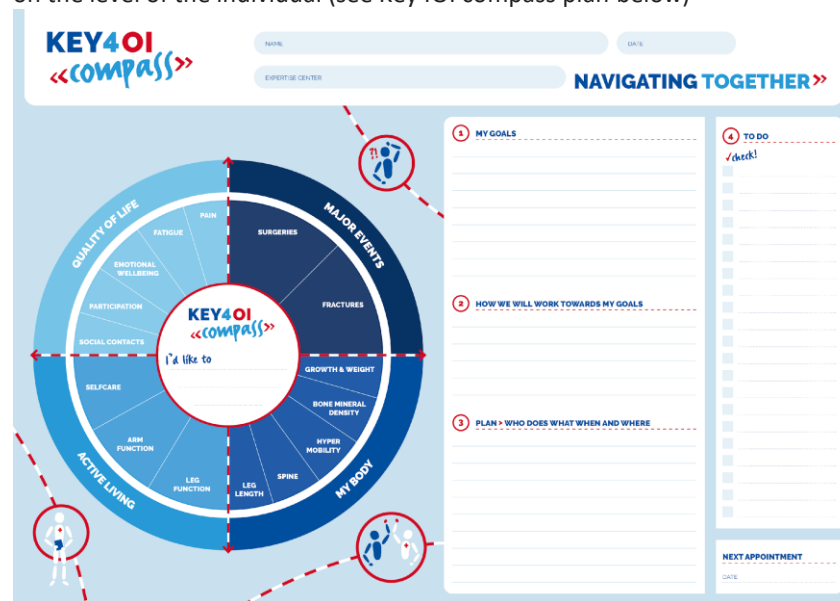
#### a) PROJECTS LED BY CARE4BRITTLEBONES in 2023

- 1) In 2023 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.

- 2) Three separate projects called “Key4OI PLUS...” for Lung, Hearing and Teeth/Jaw in OI were initiated in 2021 to inventorize and decide upon the outcome measures for people with OI in these areas. Each project was led a global team of experts including people with OI. In total 30 experts worked in bi-weekly or monthly meetings pro bono on this topic. Each project also held online focus groups to surface the view of people with OI. Results of two of the three projects (Lung and Hearing) have been published in 2023. The third one (Teeth/Jaw in OI) has been accepted for publication and will be published in 2024 in the Orphanet Journal of Rare Diseases.

- a) **Key4OI Plus Lung:** Publication in Chest: “Key4OI Recommendations for Lung Function Guidance in Osteogenesis Imperfecta” Chest. 2023 May;163(5):1201-1213. doi: 10.1016/j.chest.2022.12.047. Epub 2023 Jan 12. PMID: 36640996.  
b) **Key4OI Plus Hearing:** Publication in “The International Standard Set of Outcome Measures for the Assessment of Hearing in People with Osteogenesis Imperfecta”, Otology & Neurotology, Vol. 00, No. 00, 2023

- 3) An important new project was started in 2022 and continued and expanded in 2023: “**Energy4OI**”. From various surveys conducted by Care4BrittleBones Foundation, we know 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 tested and evaluated by 50 participants in a “Dutch pilot”. The project was supported by a subsidy from the Dutch government (ZonMw). The



Isala Hospital Zwolle advised us informally on this project. The exercises have been compiled with the help of the Isala Hospital / Rehabilitation Center Vogellanden. All data analysis, co-leadership were conducted by the Care4BrittleBones Foundation for Phase 1 of the project. The project was carefully evaluated and communicated back to all stakeholders (see [VIDEO RECORDING](#)).

Key findings:

- The use of the app was safe.
- The initiative of the app was seen as inspiring and value adding
- Next to the technical challenge of having exercises for people with OI, a key challenge is the behavioural change required to build in regular exercise.
- The app can be further improved and made more user friendly.

The pilot was an excellent way to prepare for a larger scale international pilot early 2024. Preparations for the international pilot started in 2023, with the ethical approval obtained and the Principal Investigator identified: Dr. Antonella Lo Mauro, Politecnico University of Milan, Italy.

In November 2023 we organised a fitness day, which was used to apply exercises and try out new techniques. It also was used to take ca. 50 different fitness videos with people with OI to ensure diversity in the video's used in the app.

#### **b) PROJECTS SUPPORTED BY CARE4BRITTLEBONES IN 2023**

- 4) The very innovative project "**Towards a therapy for OI**" of Dr. Fleur van Dijk (UMC Groningen/NHS Northwest London Hospital NHS Trust) is looking into the use of induced pluripotent stem cells for OI Gene Therapy using CRISPR-Cas gene editing technology. Due to COVID-19, the project had to be put on hold. The project has picked up again in Q4 2022 with hiring a postdoctoral researcher and will be completed in May 2024. The objective of this research is to develop a way to address the root cause of OI over time using gene editing technology, rather than treating the symptoms.
- 5) The project "Sweet Bones. Targeting collagen glycosylation to improve bone quality in osteogenesis imperfecta" of Dr. Ruud Bank (University Medical Center Groningen, the Netherlands) and Dr. Ralph Sakkers (UMC Utrecht, the Netherlands) funded by Care4BrittleBones in 2020, was launched in 2022 and completed in 2023. Most probably conditions have been identified (A) to obtain an enzymatically active preparation of lysyl hydroxylase, thus enabling the screening of > 100,000 compounds, and (B) it has been shown that the expression of lysyl hydroxylase 1 and 3 can be inhibited by means of epigenetic editing. Although much has to be done to translate the findings into a clinical setting, a good fundament is now available. If the new construct (CHO cells without StrepII with or without co-expression of FKBP65) is indeed enzymatically active (milestone 1), investors will likely be willing to pay for the next step, being the compound library screen (milestone 2). When all lentiviral vectors are ready (milestone 3) the next step can be executed, namely the testing of the constructs into osteoblasts of OI patients (milestone 4).  
The project report out was done with a written report as well as a webinar (see this [video recording](#)).
- 6) In the 2023 Proposal Round 2 research proposals were adopted for funding:
  - a) Study of Osteogenesis Imperfecta Tendon and ligament: retrospective and prospective assessment / Pierre Louis Docquier
  - b) Bone strength, Osteoarthritis and Soft Tissue Complication in Adult OI / Jannie Hald

#### **c) CONFERENCE QUALITYOFLIFE4OI 2023**

In 2023 we held the second online version of the QualityofLife4OI Conference. The event featured 100 speakers and moderators and 328 attendees.



## Conference 2023: Key Metrics

QUALITY OF  
LIFE4OI



**328 live attendees**  
• 57% healthcare providers  
• 43% OI community  
**+ 12%**



**Time spent on  
conference platform:  
50 days, 1 hour  
**+ 78%****



**55 Speed dates in  
the Networking  
Carousel  
**- 3%****



**100 moderators and  
speakers  
**+82%****



**2-day conference,  
90 hours of programme**



**5 Themes**  
(children, adults, Key4OI,  
Basic Science, By OI and  
For OI)



**Audience from 45  
different countries**  
• 58% Europe  
• 19% Americas  
• 23% rest of the world  
**+50%**



**6 Virtual Booths.**  
117 visits to booths.  
2 days and 2 hours spent  
by audience reviewing  
booth information



**50 different sessions**  
(presentations, panel  
discussions, livestreaming,  
video's, workshops,  
networking carousel)

## Conference 2023: Participant feedback

QUALITY OF  
LIFE4OI

**93%**



of participants found the conference overall  
(very) good

**98%**



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

**99%**



Will keep the connection through CARE4BONES  
(existing member/new member)

**95%**



of participants said that speakers were (very)  
knowledgeable

**97%**



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

**78**



participants filled in the conference survey

**97%**



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

**8,7 ★ out of 10**

is the average rating participants gave to our Conference overall.

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.

### d) CONTRACT MANAGEMENT

We actively managed our research contracts. The status of all running contracts is part of a regular review process.

### d) RESEARCH SPENT

We spent €145.910 on our statutory goals: research, information sharing and collaboration for knowledge exchange (excluding exceptional items, see fin. report for details). This is significantly above 2022 levels, when we spent €103.625.

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

It remains more necessary than ever to connect experts to learn from each other and build on each other's work for impact. Bisphosphonates have -according to all leading experts- made a significant positive impact on people with OI since the treatments started in the early 1990's. Since that time, the speed of innovation has accelerated constantly, and the number of publications is increasing year on year. Several new medical treatment options are starting to come through the research funnel. Whilst this is all great news, these developments have not yet delivered improvement of quality life for people with OI. Going forward it is critical to ensure we have consistent measures to understand OI better and see which medical treatment options are indicated for which people with OI (personalised medicine). In this -exciting- environment, Key4OI is literally the key to unleash new improvements for quality of life for people with OI.

Project management and support remains important to enable researchers to work together, keeping their administrative workload as low as possible and making best use of their expertise. In the conditions of limited financial support for rare bone disorders research, including OI, Care4BrittleBones Foundation is dedicated to future support and raise funds for preclinical, translational and clinical OI research projects, aiming to improve quality of life of OI people.

## | FUNDRAISING

In 2023, the Care4BrittleBones Foundation successfully raised funds through various channels to support its mission of improving the lives of individuals with OI.

Fundraising was conducted in different ways during the year:

**Crowdfunding:** Individual donations amounted to a total of €6.833 raised in 2023. We would like to highlight two fundraisers which have been ongoing for several years. The steadiness of support is incredibly important for us:

1. "Initiative Einzigartig" was created in 2022 by parents of a child with OI. They have supported the Foundation each year with > €2000. In 2023, this fundraiser contributed €2.286 to our cause. Thank you, Nicklas & Lena!
2. We are also grateful for the support of a volunteer in Zaltbommel who is collecting trash from the streets of the municipality of Zaltbommel. In return the municipality donated to a good cause, chosen by the volunteer. He chose us and this helps us each year with €1.700. Thank you, Hessel!

**Company Donations:** We are grateful for the support received from various companies. Through our collaborative activities, we raised €26,191 in corporate donations during 2022. A good example for support from a company is Attitude Holland. The company is run by a family within the OI Community. They are focussing on inclusive fashion for absolutely everyone. They have a "Black Market" in which they sell items that have been returned or have a small fault of some kind and therefore can't be sold commercially. They have been donating the proceeds of the Black Market for years. In total over €18.000 have been donated. In 2023 they donated €2.000. Thank you, Rebecca & Rob!



**Governmental Grants:** In 2023, 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 €46,300 in donations from fellow non-profit organizations, reflecting our collective commitment to improving the lives of individuals with brittle bones.

**Professional fundraiser:** In 2023 for the very first time since the Care4BrittleBones started, we have worked with a professional fundraiser. The foundation has selected a fundraising professional to leverage the expertise, experience, and extensive network of a professional resource to approach trust funds more systematically. The partnership worked out well. It allowed us to plan our fundraising activities much better and has increased the revenue through skilled grant writing and targeted campaigns.

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

To continually enhance our fundraising efforts, we are exploring improvement opportunities and addressing associated risks and uncertainties. In 2023, we engaged a professional fundraiser to primarily focus on Dutch funds. Throughout 2024, we plan to expand this approach with a fundraising event in Germany to diversify our funding sources and broaden our reach.

However, it is important to acknowledge the presence of certain risks and uncertainties. Economic fluctuations, changes in donor behaviour, and evolving regulatory landscapes may impact our fundraising initiatives. To mitigate these risks, we maintain a proactive approach through careful planning, strategic initiatives, and ongoing evaluation of our fundraising activities.

The Care4BrittleBones Foundation is grateful for the support we have received from individuals, companies, governmental organizations, and fellow non-profit organizations. Their contributions have been instrumental in making a positive impact on the lives of those affected by brittle bones. Together, we are working towards a brighter future for individuals living with this condition.



## | COLLABORATION AND REACH

### **Summary:**

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 1,700 individuals, which is similar to 2020 and 2021 levels and about the number of professionals focussing on OI in the expertise centres around the world. 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 strengthening the relationships with the big OI umbrella organisations OIF and OIFE as everyone benefits from a friendly and mutually supportive relationship with maximum synergy and minimum overlap or other "noise". This requires continued attention and focus. The aim is to focus (even more) on relationships with key stakeholders in 2024 to work together in the OI Ecosystem in line with the goals set out in our Multi Year Plan.



## 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 complaints have been raised through this policy in 2023.
- **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 2023.







## COMMUNICATIONS | NETWORKS

### | OI COMMUNITY NETWORKS

In 2023, 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**



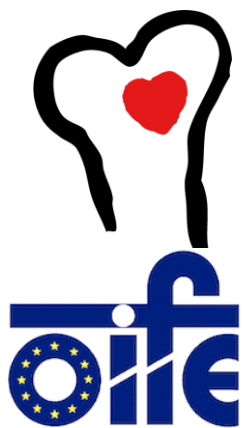
Foundation Care4BrittleBones originally started due to a call of the Dutch OI organisation VOI (Vereniging OI). In 2011, the VOI urged its members to consider what they could personally do to improve the lives of people with OI. The founders of Care4BrittleBones, parents of a daughter with OI and members 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 2023 and contributes to the positive climate for research into OI in the Netherlands. The director of the Care4BrittleBones Foundation was invited as keynote speaker at the 40<sup>th</sup> anniversary of the VOI.

#### **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 2023, 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 2023 Care4BrittleBones Board members attended several virtual meetings and conferences (eg OIF meeting, OIFE Young Investigator meetings), all national meetings of the Dutch OI association (VOI) and the OIFE Conference Sweden ("Balancing life with OI", see [website](#))



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

Starting 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 2023 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

In our annual report 2022 we looked ahead to 2023 with an ambitious financial plan. The main driver was an increase in fundraising activities. This was coupled with higher spend projected, but this had a good degree of flexibility. This was meant to keep the bottom-line result in line with our plan if revenues didn't materialise.

The increased efforts in fundraising partly paid off. We received several generous contributions (see Income). Overall, our income remained around the same as in 2022 and we had to adjust our spending. We continued with our research proposal funding round and other research related activities. We did however lower our spending across all other spend categories. The effect of these reductions was significantly less than the reduction in income. This ultimately led to a more negative balance, compared to plan, of income and expenses.

Along with this larger than planned negative result, a sizeable part of our income consisted of funding for specific activities and projects. Together with our commitments related to the research proposal round, we added €113.060 to our earmarked funds and reserves (gross additions). This attribution to earmarked funds and reserves means that the effect on our 'other reserves' is a net reduction of € -169.394. This leads to a negative position of € -16.709 in our other reserves. This is clearly an unwanted – and somewhat unexpected – position. We hope to be able to repurpose some of the dedicated funding we received in 2023 to more general, purpose related activities and the board has set a budget for 2024 that aims to return the other reserves position to positive. This budget also contains more flexibility to adjust spend when needed.

While we need to fully address our negative other reserves position in 2024, it does not lead to immediate concerns or issues, since our liquidity remains strong: Another key element of our financial position is the cashflow and the resulting cash position. In 2023 we managed to reduce the negative cashflow compared to 2022. 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 2023, 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. A further reason to be confident is that it fully covers our external commitments for 2024.

As in previous years, we continued to ensure that most of our (financial) resources were spent on research support and research projects.

In 2023 we did increase our fundraising activities and the higher spend on fundraising is mainly the fundraiser's time. This spend is however significantly lower than plan and the Board considers the use of a freelance fundraiser productive and effective in reducing our director's time spent on fundraising. We would like to note that the efforts in 2023 also led to several positive fundraising outcomes early in 2024. In this case the costs occurred in 2023, while the benefits materialised a few months later, in the next year.



Management & Administration costs decreased compared 2022. This was mainly thanks to a reduction in team activity costs: in 2022 our core team met face-to-face. We did not have a similar activity in 2023.

Our spend on purpose increased significantly compared to 2022. Combining this with a minor increase in our 'overhead' spend (the total of fundraising and management costs), our total 'overhead' ratio decreased. This means that we continued to remain well within the threshold for this ratio of 25% for charities in the Netherlands, namely 15% (compared to 16% in 2022).

## Income

Our income generated in 2023 was in line with that for 2022. At the same time the underlying sources of income saw a few major shifts. The once-off donations from individuals fell significantly compared to previous years. In 2024 we aim to organise one or more events to bring this income back to earlier levels.

This was balanced by a roughly equivalent increase in income from grants from government, most notably a grant to further develop the Energy4OI programme by launching an international pilot. While the income from other non-profit organisations remained roughly equal to 2022, we'd like to express our appreciation for several grants that help fund the Adult Health programme. Both Energy4OI and Adult Health are activities that will continue in 2024. It should be noted that the income for both activities is reserved as earmarked funds.

In total, our income was slightly down from €115.063 in 2022 to €106.059. The difference is mainly due to a correction in Income from Companies, where we reduced the income related to a cancelled project related to the use of blockchain for patient data.

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 increased to 85% from 84% in 2022. Total spend was €171.961, significantly more than the €123.439 we spent in 2022. Underlying spend of €145.910 on Research projects and other purpose-related activities (e.g. providing information about research and supporting knowledge sharing) was lower than budgeted, yet significantly above 2022 levels, when we spent €103.625.

Around €48.000 was spent (committed and reserved in earmarked funds) for two research projects that were awarded funding in the 2023 proposal round. In addition to this, we spent around €30.000 on the Energy4OI programme and around €20.000 for the annual Quality of Life 4 OI conference.

## Fundraising

The cost of fundraising of €16.165 increased significantly from 2022 when we spent €6.835 on these activities. As mentioned earlier, most of these costs relate to the support in fundraising we received from a professional, freelance, fundraiser. Thanks to her support, we managed to free up time for our director and started to professionalise our approach to fundraising. We clearly see that the costs come before the benefits for



fundraising: as stated above, we already saw further positive results from our 2023 efforts early in 2024.

## Management & Admin

In 2023 we spent € 9.886 on management and administration related activities. This is well below both our budget of €22.499 and our spent in 2022, which was €12.979. The decrease against 2022 was already discussed above and was mainly thanks to a reduction in team activity costs after our 2022 core team face-to-face meeting. Compared to the detailed budget for 2023, we mainly managed to keep costs low for communications, accounting costs, and travel and accommodation.

## Financial Position

As mentioned above, the financial position of the Foundation has changed significantly due to the higher-than-expected loss and sizeable movements on our balance sheet. As mentioned above, we did book a large part of our income in 2023 to our Earmarked Funds. Furthermore, we booked our commitments from the research proposal rounds to Earmarked Reserves. Taken together, this means that, our Other Reserves declined significantly, while our Earmarked Funds and Reserves increased.

More specifically, our Contingent Reserves decreased from €152.686 at the end of 2022 to € -16.709 at the end of 2023.

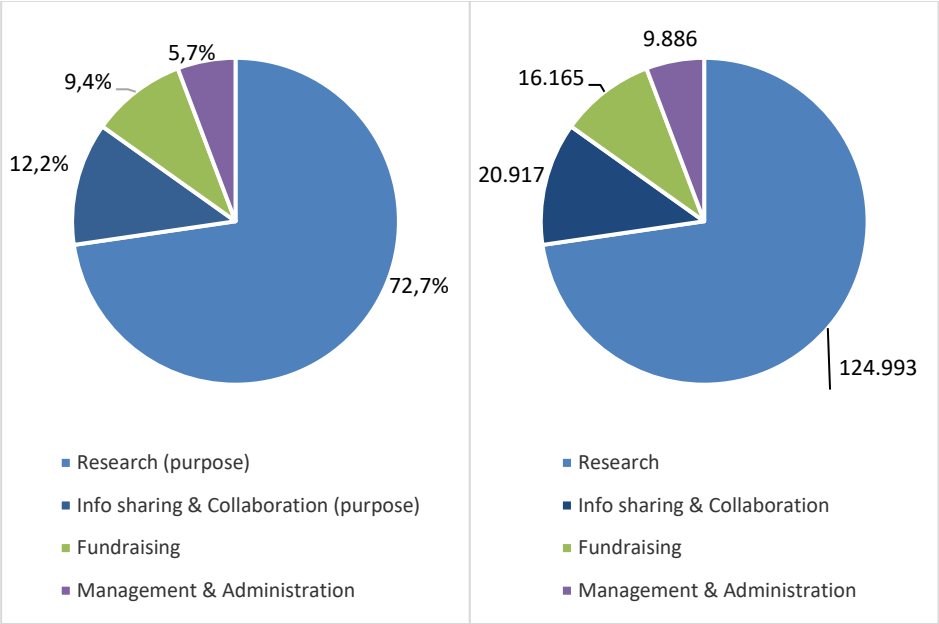
The current level of Other Reserve is too low to be sustainable in the mid-term: the Board set a prudent aim to have sufficient Contingent Reserve to cover 6 months of costs for our Foundation. In this light it should be noted that the budget for 2024 contains a significant amount of spend tied to fundraising events and activities. We will adjust this spend in line with expected income it generates, but find most of it key to improving our Other Reserves position. We will monitor our reserves position and spend on overhead activities very carefully in 2024.



## KEY NUMBERS

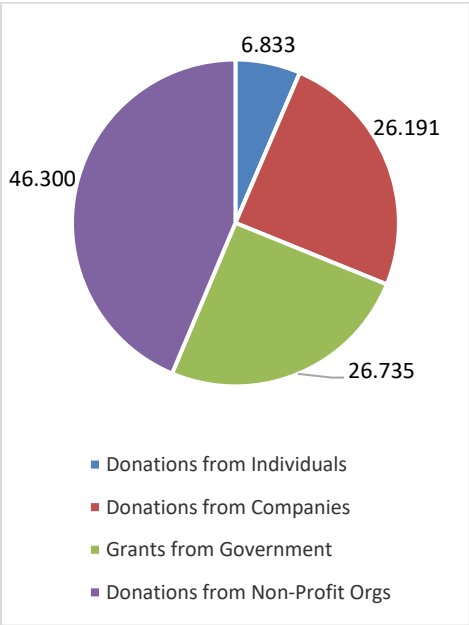
### How did we spend your contribution?

Spend in 2023: € 171.961



### What are our sources of income?

Income in 2023: €106.059 (including a €8.700 for previous years)





## BUDGET 2024

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.

For 2024 we have planned at a significantly higher ambition level than 2023. This mainly relates to further efforts in fundraising. The effects can be seen both on the expense and income side, most notably a further increase in fundraising costs associated with a charity event in Germany on the cost side. On the income side, we expect a jump in income from individuals tied to this charity event and from a very generous donation of paintings that the Foundation can use to raise funds, e.g. through an auction and/or another charity event.

Given our financial position at the end of 2023, 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.

## Income

For 2024 we have projected a sizeable increase from 2023. As mentioned in the previous section, this relates to the expected 'returns' on additional fundraising efforts. As mentioned above, by the end of 2023 we had already received further positive feedback on several applications. Commitments to grant our Foundation funding were made early 2024.

We also expect a charity event in Germany to take place towards the end of 2024. Although there are of course no guarantees this will generate a positive 'return', we agreed to only go ahead when we have a firm outlook on attendance and likely income generation.

Like in 2022 and 2023, we ensured that the budgeted expenses contain a degree of flexibility that will allow us to keep the bottom-line result in line with our plan, i.e. we are ready adjust our level of expenses as needed to live within our means.

## Expenses

In 2024 we plan to have a proposal round for research grants for early career scientists. The intention for this round is to provide funding for several post-PhD research projects for a period up to one year. Given our Other Reserves position, we will only launch this proposal round if our Other Reserves allow for it.

Other key activities for 2024 are the continuation and expansion of the work on Key4OI, Adult Health and Energy4OI. We also plan to host the 2024 QualityofLife conference. With the additional effort spend on fundraising, also including a fundraising event, we expect a sizeable increase in both absolute and relative terms in this category.



The increase as a percentage of total spend is expected to be from 9% in 2023 to 22% in 2024. Management and admin expenses also increase in both absolute and relative terms. This is mainly due to an increase in IT costs and staff related spend. As a result, this category of spend is expected to increase from 6% to 14%. Combined, this means the percentage of spend on Foundation Goals is expected to be lower than previous years, at 64%. We expect this to be a once-off effect of our investment in fundraising efforts and in IT efforts. Of course, we intend to spend the additional income from fundraising activities on our goals and expect to be back in line with the CBF guidance in 2025.

## Budget 2024

Income & Expenses	Budget 2024		Actuals 2023		Budget 2023	
	EURO	EURO	EURO	EURO	EURO	EURO
<b>Income</b>						
Income from Individuals		135.000		6.833		40.000
Income from Companies		25.000		26.191		40.000
Income from Lottery Organizations				26.735		
Income from Grants from Government						
Income from Associated (international) Organizations						
Income from other Non-Profit Organizations		70.000		46.300		100.000
Total Acquired Income		230.000		106.059		180.000
Income as compensation for the delivery of:						
- Products and/or Services						
- Other income						
<b>Total Income</b>		<b>230.000</b>		<b>106.059</b>		<b>180.000</b>
<b>Expenses</b>						
<b>Spent on Goals</b>						
- Research	111.038		124.993		110.980	
- Information sharing & Collaboration	20.000		20.917		44.307	
- Other			0			
		131.038		145.910		155.287
<b>Fundraising costs</b>		<b>45.500</b>		<b>16.165</b>		<b>29.500</b>
<b>Management &amp; Administration costs</b>		<b>29.820</b>		<b>9.886</b>		<b>22.499</b>
<b>Total Expenses</b>		<b>206.358</b>		<b>171.961</b>		<b>207.286</b>
<b>Balance before Financial Income &amp; Expenses</b>		23.642		-65.902		-27.286
Balance Financial Income & Expenses						
<b>Balance Income &amp; Expenses</b>		<b>23.642</b>		<b>-65.902</b>		<b>-27.286</b>





## FINANCIAL STATEMENTS 2023

### Income Statement

Income & Expenses	Actual 2023		Budget 2023	
	EURO	EURO	EURO	EURO
<b>Income</b>				
Income from Individuals		6.833		40.000
Income from Companies		26.191		40.000
Income from Lottery Organizations				0
Income from Grants from Government		26.735		0
Income from Associated (international) Organizations				0
Income from other Non-Profit Organizations		46.300		100.000
<b>Total Acquired Income</b>		<b>106.059</b>		<b>180.000</b>
Income as compensation for the delivery of:				
- Products and/or Services				0
- Other income				
<b>Total Income</b>		<b>106.059</b>		<b>180.000</b>
<b>Expenses</b>				
<b>Spent on Goals</b>				
- Research	124.993		110.980	
- Information sharing & Collaboration	20.917		44.307	
- Other	0			
		<b>145.910</b>		<b>155.287</b>
<b>Fundraising costs</b>		<b>16.165</b>		<b>29.500</b>
<b>Management &amp; Administration costs</b>		<b>9.886</b>		<b>22.499</b>
<b>Total Expenses</b>		<b>171.961</b>		<b>207.286</b>
<b>Balance before Financial Income &amp; Expenses</b>		<b>-65.902</b>		<b>-27.286</b>
Balance Financial Income & Expenses		868		0
<b>Balance Income &amp; Expenses</b>		<b>-65.034</b>		<b>-27.286</b>
<b>Assignment Balance Income &amp; Expenses</b>				
<b>Addition to / Withdrawal from:</b>				
- Other Reserves		-169.394		
- Earmarked Reserves		48.100		
- Earmarked Funds		56.260		
		<b>-65.034</b>		

### Balance Sheet

	Notes	31/Dec/23		31/Dec/22	
		EURO	EURO	EURO	EURO
<b>Assets</b>					
Receivables & Accrued Assets	1	40.358		32.745	
Cash & Cash Equivalents	2	171.634		187.566	
			211.992		220.311
			<b>211.992</b>		<b>220.311</b>
<b>Liabilities</b>					
<b>Reserves &amp; Funds</b>					
- Reserves					
- Earmarked Reserves	3	73.100		25.000	
- Other Reserves	4	-16.709		152.686	
			56.391		177.686
- Funds					
- Earmarked Funds	5		64.960		8.700
			121.351		186.386
Long Term Debt	6		0		0
Short Term Debt	7		90.641		33.926
			<b>228.701</b>		<b>220.311</b>



## CASHFLOW STATEMENT

	2023	2022
<i>Cash collected from:</i>		
donations	55.496	59.628
Income from Grants from Government	21.745	1.775
Income from other Non-Profit Organizations	21.205	54.985
Products & Services	0	0
Interest received	868	16
<b>Total cash collected</b>	<b>99.314</b>	<b>116.404</b>
<i>Cash paid for:</i>		
Research projects	89.195	159.772
Sponsoring events		
Governance costs	9.886	12.979
Fundraising activities	16.165	6.835
Interest paid	0	108
<b>Total cash paid</b>	<b>115.246</b>	<b>179.694</b>
<b>Net cash from operations</b>	<b>-15.932</b>	<b>-63.290</b>
<i>Cash Balance:</i>		
	<b>2023</b>	<b>2022</b>
Opening balance ABN AMRO, SNS & Paypa	187.566	250.856
Closing balance ABN AMRO, SNS & Paypal	171.634	187.566
<b>Net cash from operations</b>	<b>-15.932</b>	<b>-63.290</b>



## NOTES TO THE ACCOUNTS

### General

The consolidated financial statements for 2022 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 maximum of 1 time the annual costs of the organization. Based on the 2024 budget, a contingent reserve of a maximum of €113.858 will follow as of 31 December 2023. The realized balance Other Reserves of €-16.709 is significantly below this threshold set by the Association Board and below levels deemed healthy. The plan for 2024 clearly aims to bring these reserves back to a healthy level, 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

	2023 EURO	2022 EURO
<b>Receivables &amp; Accrued Assets</b>		
Receivables from Individuals	-	-
Receivables from Companies	368	22.840
Grants from Government	4.990	-
Interest		
Receivables from Non-Profit Organizations	35.000	9.905
<b>Total</b>	<b>40.358</b>	<b>32.745</b>

### Note 2

	2023 EURO	2022 EURO
<b>Cash &amp; Cash Equivalents</b>		
ABN AMRO Current Account	25.328	7.593
ABN AMRO Savings Account	44.322	65.967
SNS Bank Savings Account	100.409	99.940
PayPal	1.837	14.066
<b>Total</b>	<b>171.895</b>	<b>187.566</b>

### Note 3

	2023 EURO	2022 EURO
<b>Earmarked Reserves</b>		
balance 1/1	25.000	50.000
Additions	48.100	10.000
Withdrawals	0	-35.000
<b>Balance 31/12</b>	<b>73.100</b>	<b>25.000</b>

### Note 4

	2023 EURO	2022 EURO
<b>Other Reserves</b>		
balance 1/1	152.686	113.211
Additions	8.700	57.942
Withdrawals	-178.094	-18.468
<b>Balance 31/12</b>	<b>-16.709</b>	<b>152.686</b>

*The addition relates to the (old) Blockchain for OI project.*

*The withdrawals relate to the balance for 2023, commitments from the research proposal round moving to Earmarked Reserves and specifically dedicated funding from external parties in 2023 moving to Earmarked Funds.*

### Note 5

	2023 EURO	2022 EURO
<b>Earmarked Funds</b>		
balance 1/1	8.700	31.642
Additions	64.960	0
Withdrawals	-8.700	-22.942
<b>Balance 31/12</b>	<b>64.960</b>	<b>8.700</b>

*The withdrawal is related to the cancellation of the (old) Blockchain for OI project.*



#### Note 6

	2023 EURO	2022 EURO
<b>Long Term Debt</b>		
Project Commitments	<u>0</u>	<u>0</u>

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

#### Note 7

	2023 EURO	2022 EURO
<b>Short Term Debt</b>		
Project Commitments	73.508	26.481
Creditors	<u>17.133</u>	<u>7.444</u>
Total	<u>90.641</u>	<u>33.926</u>

*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 2023	Budget 2023	Total Actual 2022
Project contributions	76.434	0			76.434	97.436	21.779 0
Outsourced work	0	0	12.391	0	12.391	20.000	17.870
Remuneration of director	48.559	20.917	3.775	3.095	76.346	67.351	63.888
Office and general costs				6.790	6.790	22.499	9.902
Buitengewone lasten	0				0		10.000
Total	124.993	20.917	16.165	9.886	171.961	207.286	113.439



## PROJECT OVERVIEW– SPENT ON GOALS

OF

## NOTES ON THE ROLE AND REMUNERATION THE DIRECTOR

	Year	Project Title	Lead Country	Institution	Lead researcher	Status	Originally Committed pre 2023	movement in commitment 2023	Total ITD Commitment 31/12/2023	PV Paid	Outstanding payment on 1/1/2023	CY Paid	Directors' remuneration 2023 (included in Paid)	Outstanding to be paid (to be received) 31/12/2023
2019	2019-022	Blockchain pilot voor OI	Netherlands			committed	15,000	-8,700	0	6,300	8,700	0	0	0
2020	2020-023	Sweet bones		UMCG	Ruud Bank	committed	60,000	0	60,000	35,000	25,000	0	0	25,000
2022	2022-029	Energy 401		ZonMw		committed	49,520	0	49,520	27,280	22,240	22,240	8,942	0
2023	2023-027	Adult health		Stichting Aanmoedigingsfonds van de Koninklijke Faculteit & W.M. De Hoop Stichting & Versteeg Kitty		committed	0	40,000	40,000	0	0	5,000	405	-35,000
2023	2023-024	2023-024 Study UCLouvain				committed	0	19,100	19,100	0	0	0	0	19,100
2023	2023-026	2023-026 ENERGV401-INT2023		Carre4BB		committed	0	24,960	24,960	0	0	19,970	1,648	-4,990
2023	2023-029	Purpose>Projects>2023-029 OI – Bone strength, osteoarthritis Jannie		Jannie Held		committed		29,000	29,000	0	0	0		29,000
		Other research BIOJECTS	Netherlands			Ongoing	0	0	0	0	0	0	40,382	0
Total Projects		Total Projects					124,520	104,360	222,580	68,580	55,940	47,210	50,678	33,110
		conference												0
Overall Total		Overall Total		Conference 2023-2024			124,520	104,360	222,580	68,580	55,940	47,210	69,476	33,110





2023

Notes on the role and remuneration of Management

Name	Dagmar Mekking
Position	Director
Line of work	Contract (2 years)
Hours	25.4/week
Parttime percentage	63%
Period	1/1/2023-31/12/2023
Annual remuneration (gross)	76.346 *
Vacation payment	-
Year-end payment	-
Compensation holidays not utilised	-
Total	76.346
Taxable reimbursement	-
Pension payments (Foundation)	-
Pension compensation	-
Other long term remuneration	-
End of Service payment	-
Total	76.346

*In setting the remuneration policy and the actual director's remuneration Care4BrittleBones follows the "Regeling beloning 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 2023 led to a so-called BSD-score of 310 points with a maximum annual income of € 85.419,- 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 € 106.061 (1 FTE/12 months). The total remuneration of the Director (self employed) on a full-time basis of € 99.424,- excl VAT (or € 120.303,- 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).*



## 2023 ACCOUNTING CONTROL STATEMENT

### Accounting Control Statement

The Auditing Committee in the person of Mrs. I Juzwa-Parus and Mr. R. Le Grand have on Wednesday 19 June 2024, in the presence of Treasurer Mr. D.J. Stegink and Mr. R. Brabander, checked the books of the Care4BrittleBones foundation for the financial year 2023.

The Committee states that:

- The Annuals Accounts give a correct representation of the income and expenses for the year 2023
- The balance sheet as at 31 December 2023 give a true and fair view of the Reserves.

Den Haag, 24 June 2024

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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 Twitter	@Care4BB
 YouTube	<a href="https://www.youtube.com/c/care4brittlebonesOrg070">www.youtube.com/c/care4brittlebonesOrg070</a>
 LinkedIn	<a href="https://www.linkedin.com/company/10639515">www.linkedin.com/company/10639515</a>