

2022



**ANNUAL REPORT | 2022**  
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,

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

**100** VOLUNTEERS

**93.625** EUR

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

**17** %

Overhead

## REACHING OUT IN 2022

**115.063** EUR

Of funds raised in 2022 for much needed research for OI

**6.0** %

Fundraising Cost

**55** Speakers and Moderators

Involved in the Quality of Life 4 OI Conference 2022



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## 2022 | MOVING FORWARD AFTER THE PANDEMIC

The year 2022 was the year of our 10 Year Anniversary. The year was also marked by the fact that the Corona Pandemic finally got under control. The COVID-19 pandemic has been a difficult and challenging time for many people around the world and in particular people with rare diseases and with Osteogenesis Imperfecta (OI). The Pandemic brought extremely challenging delays of treatment and acute emotional stress for most people with OI. However, it has also brought about several positive lessons and changes that resonate deeply with how the Care4BrittleBones Foundation is looking at healthcare challenges in OI since we started in 2012. Here are some of them:

1. **Importance of public health:** The pandemic has highlighted the need for strong healthcare systems that are able to learn from each other and work together. Whilst healthcare systems are different, the underlying challenges of people and diseases don't have any boundaries.
2. **Community support:** The pandemic has shown that we are all interconnected, and that global solidarity is essential to tackle global challenges. The OI community has supported one another in virtual ways throughout the pandemic, helping people in isolation, keeping the spirit up in times of huge uncertainty, leveraging the creative capacity of many minds instead of fighting all on our own.
3. **Technological innovation:** The pandemic has accelerated technological innovation, such as the use of telemedicine, remote work, and online learning. We are benefitting a lot from that across all rare diseases. This is such a relief and improvement as long as Face2Face consultations remain possible when needed.
4. **Importance of science:** The pandemic has highlighted the importance of science and research in understanding and responding to health crises with objective data as opposed to emotional primal reactions.
5. **Prioritizing mental health:** The pandemic has brought attention to the importance of mental health and the need for more resources and support for individuals struggling with mental health challenges.

We have used 2022 wisely to build on all the lessons learned including the pandemic to make (even) more impact going forward. Find out in this Annual Report how things have moved forward! On behalf of the whole foundation Care4BrittleBones, we would like to thank you for our fruitful collaboration in 2022!



**Andreas Matsangos**, Chairman  
**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 of these 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. Our Ambassadors
5. 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 the year 2022 Care4BrittleBones was formally led by its Board of 6 team members (no changes compared to 2021). This was only possible due to the huge commitment of our board members. Many of them experienced significant personal health challenges or other big changes on their personal front (moving country, getting married). We would like to thank everyone whole heartedly for persisting and keeping the foundation going through it all. A true leadership team!



**Andreas Matsangos**  
Chairman/Secretary



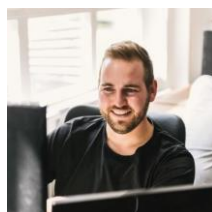
**Celine Disch**  
Vice-president



**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. We also meet 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 bi-weekly 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> , Iwona Juzwa-Parfus,
Fundraising	<b>Nicklas Teicke</b> , Dagmar Mekking, Lieke 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>Andreas Matsangos</b> , Dagmar Mekking
General Support	<b>Peter Mekking</b>

In the summer of 2022, the Core Team of the foundation met in person. Most of the board members had never met each other before. The weekend was used to discuss strategy and priorities and to build the team. The pictures below demonstrate the breadth of our activities undertaken during the weekend. The meeting was prepared by undertaking a review of the foundations strengths and weaknesses using a McKinsey Non-Profit Board assessment methodology ([LINK](#)). We found it very useful to reflect individually and collectively on the foundation's ways of working and agreed on various changes which have been included in our Multiyear plan as well as our operational plan.





Amsterdam June 2022, Care4BrittleBones Coreteam meeting



### 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

We are very proud of our Advisory Board which has been reconfirmed and refreshed in 2022 and 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



#### OI Community Advisory Board



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 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. Jasinthia D, OI Community, India



## Ways or working / Workload

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, their role is most prominent in the context of the **Proposal Rounds**, which are held every 1-2 years. In 2023 a proposal round takes place between 1 March and end of May.

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.

A more detailed description of the ways of working is available on request to [info@care4brittlebones.org](mailto:info@care4brittlebones.org)

## 4. | OUR AMBASSADORS

Our ambassadors are our eyes and ears and support us in words and actions where they can. Some of them are very active in the CARE4BONES Foundation too. Most of them either have OI themselves or have a relative with OI. We encourage anyone around the world who would like to support Care4BrittleBones by raising awareness and fundraising to get in touch (e-mail to [dagmar.mekking@care4brittlebones.org](mailto:dagmar.mekking@care4brittlebones.org)).

In addition, children with OI enthusiastically and effectively help us, too! They intuitively understand how difficult it is to be excluded from normal play and sports activities because their body is too fragile. They want to help and are very successful at involving their schools, sports clubs and friends to support Care4BrittleBones.

More information about the ambassadors and their stories can be found on the Care4BrittleBones website [www.care4brittlebones.org](http://www.care4brittlebones.org)



## 5. | 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



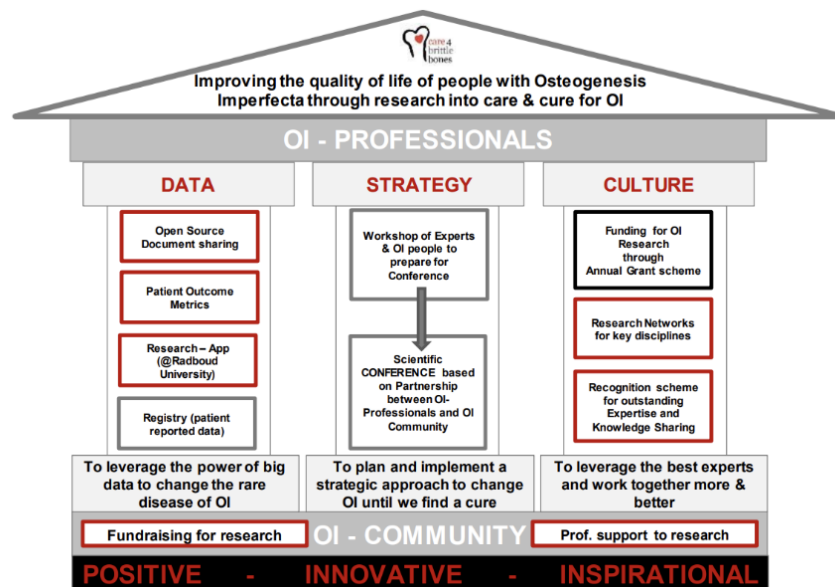
### 2. | STRATEGY

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



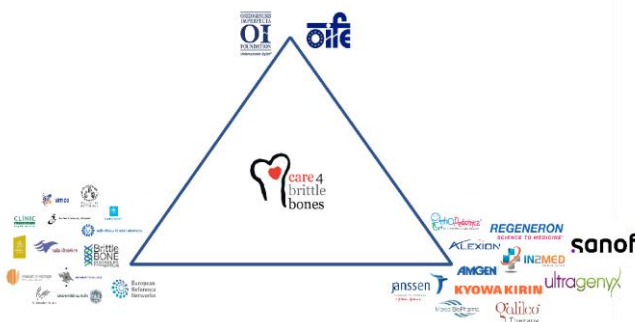
orthopaedic approach, physical rehabilitation, understanding scoliosis, etc.) and leveraging potential game-changing technologies, which may provide a cure for OI.

In 2021 Care4BrittleBones has 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 and in 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 has 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 centers 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 will celebrate its 10-year anniversary on 12 February 2022.

In 2021 we worked on the next Multi Year Plan which covers the period 2021 – 2026. The plan covers again all areas required to “move the needle” on quality of life 4 OI: Research, Fundraising, Networks & Reach, Communications and Fundamentals. Each of the areas is underpinned by a more detailed document, defining ways of working to further long-term ambitions and operations. All main stakeholders (eg Advisory Board, OIFE, OIF, ERN BOND) have been able to 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 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 2022 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 2022, 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 | 2022

The year 2022 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. Since 2021 our activities related to **education and communication** have changed considerably due to the existence of the CARE4BONES Foundation. The initiation of CARE4BONES and the associated platform has fundamentally transformed how we work together with researchers and with the OI community for improving quality of life for people with OI.

### Color coding:

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

## Review Operational Plan 2022



<b>1. RESEARCH</b> 	<ul style="list-style-type: none"> <li>• <b>Key4OI</b> <ul style="list-style-type: none"> <li>• Implemented in 5 hospitals and 5 “work in progress” (8 hospital work in progress, but if they will actually do it??)</li> <li>• Key4OI Learning environment operated by CARE4BONES</li> </ul> </li> <li>• Physical wellbeing Network -&gt; 3 webinars</li> <li>• Psychosocial network -&gt; 3 webinars 2 webinar</li> <li>• Orthopaedic Network established</li> <li>• Proposal Round – hold and wait for further developments/ funding Not enough funding</li> <li>• Basic Science Survey and follow up</li> <li>• Physical Wellbeing project ZonMW</li> <li>• Conference QualityofLife4OI delivered</li> </ul>
<b>2. COLLABORATION</b> 	<ul style="list-style-type: none"> <li>• Researchers: Mostly through Care4Bones.</li> <li>• OI Community: Mostly through CARE4BONES</li> <li>• OIFE and OIF maintain constructive relationship</li> </ul>
<b>3. FUNDRAISING</b> 	<ul style="list-style-type: none"> <li>• Explore professional support for fundraising</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> <div> <b>€ 100.000</b> </div>
<b>4. COMMUNICATION</b> 	<ul style="list-style-type: none"> <li>• <b>Sustainable resourcing</b> -&gt; Replacement Communications</li> <li>• Social Media impact</li> <li>• Engage OI Community and Professional community through Care4Bones</li> </ul>
<b>5. OPERATIONS</b> 	<ul style="list-style-type: none"> <li>• Multiyear plan refinement 2026</li> <li>• Continue operational excellence in Finance and IT</li> <li>• Team building</li> <li>• Advisory board 2022 engaged.</li> <li>• Monday.com</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.

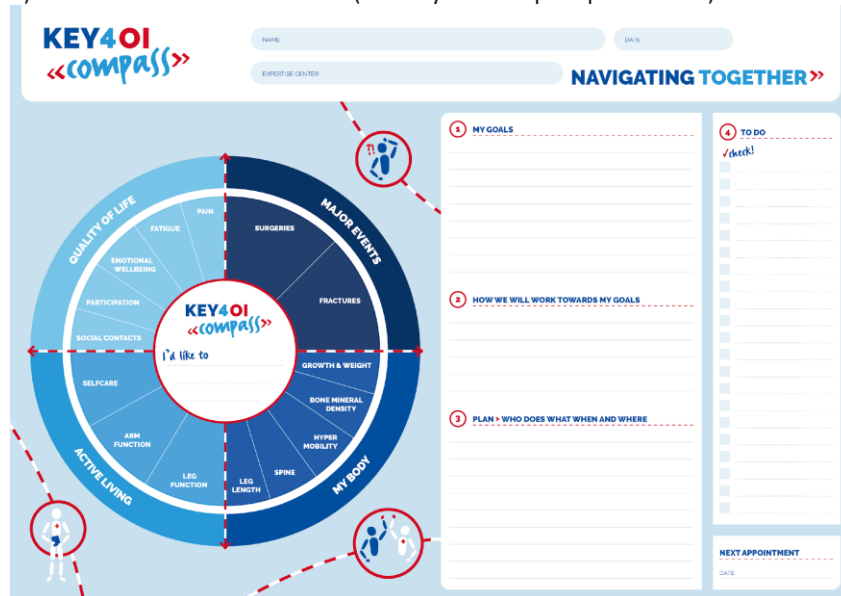
### Research projects status update

Foundation Care4BrittleBones has been involved in 8 research related activities in 2022. Our role varies per project:



## PROJECTS LED BY CARE4BRITTLEBONES

1. In 2022 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 on a monthly basis and is working together to develop a registry in 2023 to bring the data collected locally together for research. A special highlight was the Key4OI Presentation at the OI 2022 Conference in Sheffield (UK), which enabled the team to reunite. The presentation by Richard Kruse “Key4OI project update” was very well received.



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 the two



out of the three projects have already been accepted as scientific publications and the upcoming articles will be presented in the Annual Report 2023.

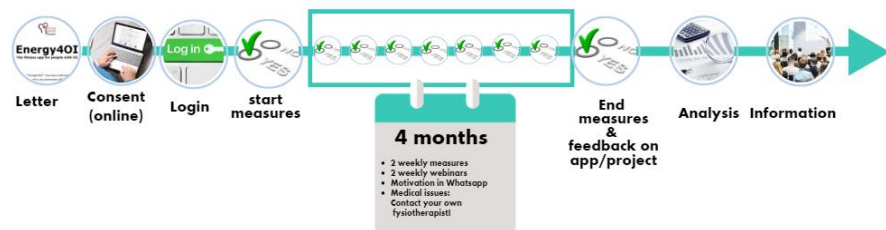
3. An important new project started 2022 was “**Energy4OI**”. From various surveys conducted by Care4BrittleBones Foundation, we know that physical wellbeing is a key priority for people with OI. Sufficient exercise plays an important role in this. For many reasons, regular exercise can be challenging for people with OI. The circumstances for them to engage in regular Fitness activity can rather discouraging and difficult. The Care4BrittleBones Foundation would like to offer everyone with OI the opportunity to exercise more often and safely. For this reason, it was decided to develop and test an app specifically by and for people with OI. The aim of the “Energy4OI” project is:

- To investigate whether a self-exercise app is suitable for making people with OI move more in a safe and responsible way.
  - To see if people with OI feel better by participating in the exercise program.
- The owner of this project is the Care4BrittleBones Foundation. The project is supported by a subsidy from the Dutch government (ZonMw). The Isala Hospital Zwolle advises 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 are conducted by the Care4BrittleBones Foundation for Phase 1 of the project, which is focussed on 50 individual people with OI in the Netherlands. If this leads to encouraging results the aim is to broaden the app to an international pilot in collaboration with Dr. Antonella Lo Mauro, Politecnico University of Milan, Italy.



The app used is called “[Physitrack](#)”. Physitrack is widely used by physiotherapists, among others. Worldwide, approximately 9 million users use the Physitrack app.

The trial will aim for behavioural change during a 4-month period.



#### PROJECTS SUPPORTED BY CARE4BRITTLEBONES

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 **Eat, Breathe, Sleep** by Dr. Antonella LoMauro (Politecnico, University of Milan, Italy) has been supported by the Care4BrittleBones Foundation as well as the Italian patient organisation As.It.O.I. The main goal



of this research was to verify, if the pathophysiology of OI in adult patients ensued a dangerous vicious circle, in which breathe, sleep and nutrition are tightly linked. Progress of the project has resulted in two open access peer reviewed scientific publications available at

<https://ojrd.biomedcentral.com/articles/10.1186/s13023-021-02058-y>

<https://ojrd.biomedcentral.com/articles/10.1186/s13023-022-02535-y>

6. 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 after COVID related delay. The project is a preclinical research project, looking into the root causes of OI bone brittleness, aiming to develop the fundamental thinking of how to address bone fragility in a completely new way. First results of the project and the report on the achievements are expected for May 2023.

#### b. Professional networks

The global professional networks are thriving:

- The **Psychosocial Network** held 2 online gatherings in 2022. Focussing on emotional wellbeing of people with OI according to the Expertise Finder Survey.
- The **Basic Science Network** was established in 2022 and is supported by a strong lead coalition of Lidiia Zhytnik, Antonella Forlino, Sergey Leikin, Roy Morello and Frank Zaucke. They held an important survey to uncover the needs of the Basic Scientist community and have built a strong curriculum from this information. The basic researchers conduct monthly webinars to strengthen networking, collaboration and knowledge exchange for preclinical and basic OI research.
- The **Orthopaedic Network** has held 6 Webinars in 2022 focussing on various aspects of orthopaedic treatment in OI.



- The **Physical Wellbeing Network** was led by Kathleen Montpetit, Lena Lande Wekre and Marjolein Verhoef in 2022. They conducted a major survey amongst the adolescents and adult OI community (16 years and older) in relation to physical wellbeing, movement and sleeping habits). This work has led to the new project called “Energy4OI” (see a.3).

Poster about the Survey about Physical Wellbeing with OI at the OI 2022 Sheffield Conference (from right: Marjolein Verhoef, Lena Lande Wekre and Dagmar Mekking.

#### c. Conference QUALITYOFLIFE4OI 2022 & 10 Year Anniversary of Care4BrittleBones Foundation.

In 2022 the Foundation Care4BrittleBones held its traditional QualityofLife4OI Conference for the first time in an Online format. This was necessary as the COVID uncertainties made it impossible to plan on time for an in-person-event. The Date was 12 February 2022, exactly 10 years after the Care4BrittleBones Foundation was founded which took place on 12 February 2012.



The event featured 55 speakers and moderators and 290 attendees.

## QUALITYOFLIFE Conference 2022: Key Metrics



290 live attendees  
• 69% professionals  
• 31% OI Community



Total time spent on  
conference platform:  
28 days, 16 hours,  
22 minutes, 1 second



57 Speed dates in the  
Networking Carousel



55 moderators and  
speakers



16 virtual Booths.  
177 unique visit to booths.  
2 days spent reviewing  
booth information



8 branded or topical  
Networking Tables



audience from 30  
different countries  
• 55% Europe  
• 25% Americas  
• 20% rest of the world



2 days of interaction with  
60 different sessions  
(presentations, panel discussions,  
live streaming, experience sessions,  
video's, workshops, networking  
carousel, Conference Café)



Sustainability:  
Kilometers saved by not  
travelling: 1.102.860 km.  
Saved kg/Co2 converted  
to trees: 4045

## QUALITYOFLIFE Conference 2022: Participant feedback

**99%**



of participants found the conference overall  
(very) good

**93%**



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

**94%**



of participants would (very) likely  
recommend the next Conference to others

**98%**



of participants said that speakers were (very)  
knowledgeable

**86%**



of participants said the event was  
useful for their daily practice

**88**



participants filled in the conference survey

**95%**



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

**8,4★ out of 10**

is the average rating participants gave to our Conference Platform

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.

### e. Research Spent

Excluding extraordinary income items, we spent EUR 93.625 EUR on our statutory goals: research, information sharing and collaboration for knowledge exchange (excluding exceptional items, see fin. report for details). This is similar and slightly above 2021 levels.

**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 2022, 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 played a significant role in our fundraising efforts, with a total of €22,292 raised in 2022. We would like to highlight two notable fundraising projects:

a) "Road to Dakar for Brittle Bones" by Steven Kroesbergen and Kyra Haakman. Steven has a brother with OI. This initiative raised €5,335 through the support of 174 donors. The project aimed to raise awareness for OI and raise funds for Care4BrittleBones. Further details about this fundraising project can be found at [Road to Dakar for Brittle Bones](#).

b) "Initiative Einzigartig" (German Fundraiser): In 2022, this fundraiser contributed €2,595 to our cause.

Additionally, we have reactivated our email campaigns for a Christmas Fundraiser that has reached over 800 previous donors.

**Company Donations:** We are grateful for the support received from various companies. Through our collaborative activities, we raised €27,241 in corporate donations during 2022.

**Governmental Grants:** In 2022, the Care4BrittleBones Foundation secured €1,775 in grants from government sources. 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 €50,000 in donations from fellow non-profit organizations, reflecting our collective commitment to improving the lives of individuals with brittle bones.

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

To continually enhance our fundraising efforts, we are exploring improvement opportunities and addressing associated risks and uncertainties. In late 2022, we engaged a professional fundraiser to primarily focus on Dutch public funding. Throughout 2023, we plan to expand this approach internationally, leveraging their expertise and networks 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 behavior, 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 within the Care4BrittleBones Core team has benefited greatly from the fact that we have been able to come together once F2F in 2022. Whilst everyone individually wrestled with the impact of COVID-19 to their personal life and various members of the team had significant personal (health) challenges, we accomplished a lot together.

Collaboration with stakeholders outside of the foundation varied. We maintain 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 stronger 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 to building trust and collaboration also in 2023.

We have grown the number of people who receive our newsletter. Social Media activities have been relatively low. Most communication was centred around the QualityofLife4OI

The website [www.care4brittlebones.org](http://www.care4brittlebones.org) has been kept up to date. It provides comprehensive and user-friendly access to a wide range of resources which help professionals and people with OI to have a better quality of life.

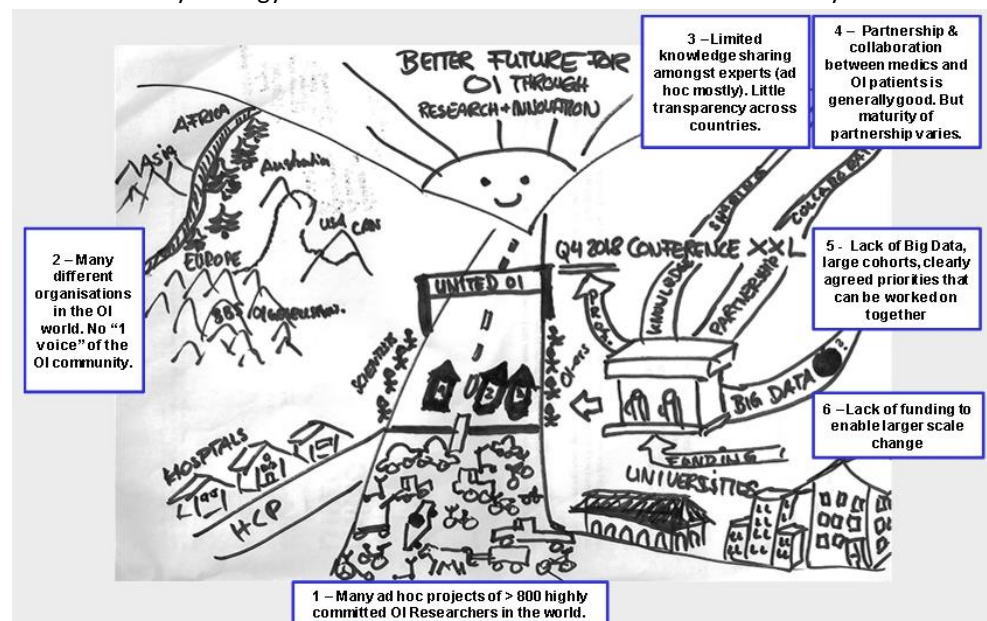
**Improvement opportunities, risks and uncertainties in this area:**

Our focus is on strengthening the relationships with the big OI umbrella organisations OIF and OIFE as everyone will benefit 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 2023 to work together in the OI Ecosystem in line with the goals set out in our Multi Year Plan.

**| 10 YEAR ANNIVERSARY:** 10 YEARS OF WORKING ON QUALITY OF LIFE FOR PEOPLE WITH OI (2012 – 2022)

This year marked the 10-year anniversary of the Care4BrittleBones Foundation. The foundation grew from a initiative of just 3 people (parents of a girl with OI and their neighbour) to a mature organization lead mostly by people with OI. The ideas and concepts developed in the early days of the Care4BrittleBones Foundation are still accurate today and our journey in the Multi Year Plan continues to take an ecosystemic approach to improving quality of life for OI.

One of the early strategy documents has all the elements of our vision today:





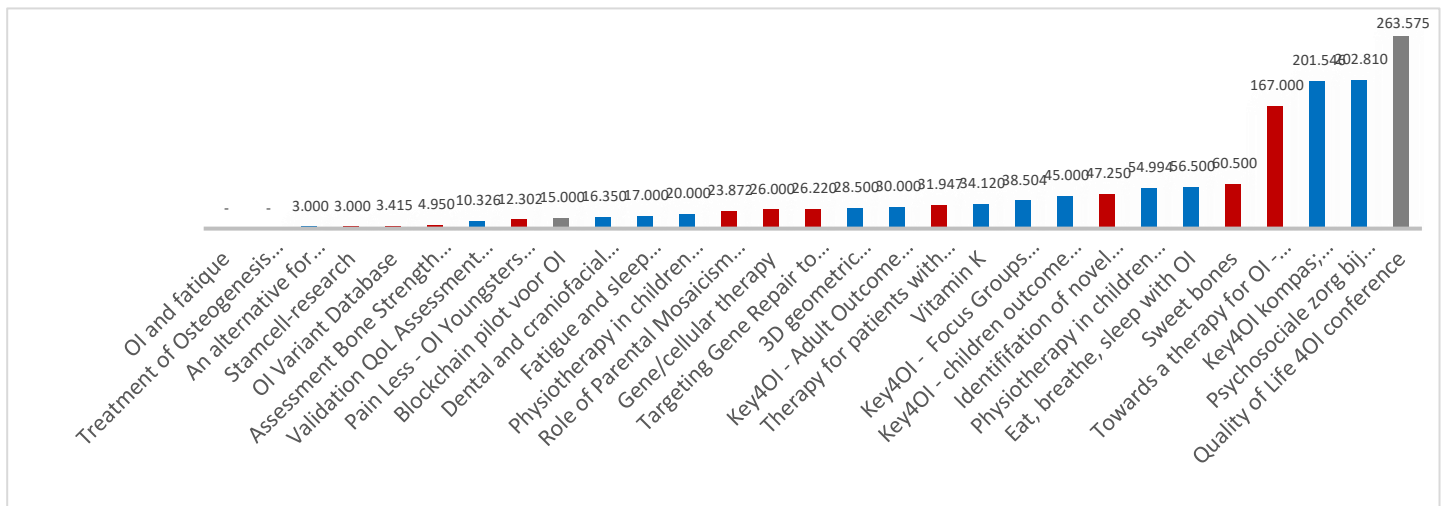


The start of Care4BrittleBones was explained by one of the Founders, Dagmar Mekking, in a TED-Talk: <https://youtu.be/jAOH-pUb2Zs>

Over the past 10 years Care4BrittleBones has collected 1,8 Mio Euros for Research and enabled 32 research projects, which are clearly linked to the quality of life of people with OI. These projects are a mix of basic research (focusing on the long term and potential game changing technologies) and clinical research (focusing on areas that bring potentially immediate benefit for people with OI in the short or mid-term). An overview of the research and research collaboration projects supported from 2012 – 2022 is displayed below.

A video summarizing the achievements in 10 years of Care4BrittleBones can be found [HERE](#). It was shown during the QualityofLife4OI Conference in February 2022.

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



## 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 2022.
- **e-bookkeeping tool**
- **Document management:** in 2022 we decided to move from Dropbox and prepared the transition to Google Workspace from December 2022 onwards
- **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 2023, 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 webbased 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 2022. The functionality has been reduced to enable a more cost effective yet user-friendly approach for fundraising.





## COMMUNICATIONS | NETWORKS

### | OI COMMUNITY NETWORKS

In 2022, more than 100 people have been involved as volunteers of Foundation Care4BrittleBones. They are active in raising awareness (e.g., our ambassadors), 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). We connect with our volunteers individually in webinars and video conferences. 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 quality of life for people with OI.

#### **VOI – Dutch OI Association**

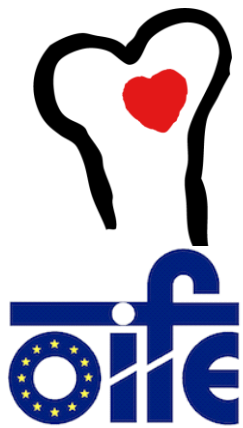


Foundation Care4BrittleBones originally started due to a call of the Dutch OI organisation VOI (Vereniging OI). In 2011, the VOI urged its members to consider what they could personally do to improve the lives of people with OI. The founders of Care4BrittleBones, parents of a daughter with OI and members 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 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. In June 2022 the director of the Care4BrittleBones Foundation was a speaker at the annual member meeting of the German OI Association.



## 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 frequently connects to 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 2021, 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 26 member states to support and address rare diseases. In 2021, they continued to develop their network and mature their working processes. 24 networks have been established, each of them focusing on a cluster of rare diseases. OI is part of the ERN-BOND, which covers more than 400 rare bone diseases. OI is one of the most important rare bone diseases, which is why it has been selected as one of the key focus areas of ERN-BOND. We are supporting the ERN-BOND EuRRBone database project which started in 2021 and are participating in a related working group. 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 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 2022 Care4BrittleBones Board members attended several virtual meetings and conferences (eg OIF meeting, OIFE Young Investigator meetings), the national meeting of the Germany OI association (DOIG) and all national meetings of the Dutch OI association (VOI) and the scientific Conference in Sheffield ([www.oi2022.org](http://www.oi2022.org)).
5. Over the course of the last 9 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. There is the facility to make a donation to support research and show various opportunities to help in other (non-monetary) ways. Our website is updated regularly with new events and is used as an archive.

### **Newsletter**

During 2022 we have sent out 14 newsletters, many of them in relation to the QUALITYOFLIFE4OI Conference. They reach 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.



#### **Instagram & Facebook**

Due to a lack of dedicated volunteers for this area, we were not very active on social media channels. The intent is to focus on this area more in 2023 and to adopt a more robust and proactive approach.

#### **LinkedIn**

The variety in channels gives us the opportunity to target different audiences. We use LinkedIn for professional messages in the widest sense.

#### **YouTube & Webinars**

We use YouTube as an archive for our webinars and other video material.

#### **Soundcloud**

We have ca. 10 podcasts available on soundcloud at the moment.

## **FINANCIAL REPORT**

### **SUMMARY OF FINANCIAL RESULTS INCLUDING EXPLANATION**

In 2022, like in 2021 our overall financial results were in line with our expectations for the year. We did manage to generate more income than planned, which ultimately led to a less negative balance, compared to plan, of income and expenses.

Combined with an increase in 'other reserves', our financial position was strong enough to launch a research proposal round at the end of the year with strong confidence we should be able to fund one or more projects from our own funds.

While the spend (expenses) on ongoing purpose related activities slightly increased compared to last year, our cash spend on projects we previously committed to remained much larger than our expenses. This in turn leads to lower total of reserves, funds and outstanding debts (to projects).

The EUR 10.000 adjustment in 'other spent' is an increase in the commitment for the Sweet Bones project. This is in fact a reversal of the adjustment to the project commitment that we made in 2021, when we reduced the commitment with EUR 10.500 based on contractual adjustments from the project lead. In our 2021 report we already indicated this adjustment was likely to be needed as the structure of the project was readjusted.

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

We managed to keep our absolute spend on Fundraising and Management costs in line with the low levels of 2021. The small increase in Management costs is due to the face-to-face team event and an increase in IT costs, offset by less time spent on this from our director. The small increase in fundraising costs is due to the part-time support from a freelance fundraiser, compensated again by less time spent on this activity by our director, a strategic choice from the board with the aim to free up our director's time for purpose related activities.

Our total 'overhead' ratio (combining the two categories mentioned above) continued to decrease: from 19% to 16%, excluding the extraordinary adjustment this would be 17% for





2022. This means that our overhead costs continue to be consistently and considerably lower than the recommended threshold of 25% for charities in the Netherlands.

## Income

We improved our income generation for the year compared to 2020 and 2021, but still struggle to recover to pre-Covid levels. Thanks to a major subsidy and sponsoring for the Quality of Life 4 OI Conference 2022, we generated more income than planned from non-profit organisation as well as from companies. These have helped our income increase from EUR 90.410 in 2021 to EUR 115.063 in 2022.

Although the income from individuals was lower than previous years, we continue to appreciate all these contributions and are very happy to have the continued support from individual contributions to our foundation. We would like to remind the reader that we continue to receive strong support from our governmental and non-profit partners through previously committed funding (not recognised as income in 2022, but reflected on the balance sheet and in the cash flow statement)

## Spend on Purpose

The ratio of spend on purpose (including extraordinary items) vs total expenses increased to 84% from 81% in 2021. Including extraordinary items, spend was EUR 123.625.

Excluding extraordinary items, (underlying) spend on Research projects and other purpose-related activities (e.g. providing information about research and supporting knowledge sharing) was slightly below budget by EUR 6.200, but slightly above 2021 levels, increasing from EUR 92.390 to EUR 93.625.

As mentioned above, it is useful to note that the extraordinary item expenses booked in 2022 was related to changes in the contractual setup of the Sweet Bones project and did not impact the delivery of the project nor the delivery of other activities in 2022.

## Fundraising

The cost of fundraising of EUR 6.835 has slightly increase compared to 2021 when we spent EUR 4.634 on this. As mentioned earlier, most of these costs relate to the support in fundraising we received from a professional, freelance, fundraiser. The aim of hiring this support is to free up time for our director and to professionalise our approach to fundraising. We are happy to see early results of this approach paying off.

## Management & Admin

In 2022 we spent EUR 12.979 on management and admin related activities. This is well below our budget of 16.767 but above 2021 levels. As anticipated in the budget, the main driver for the increase in spent compared to last year was mainly due to our first face-to-face team event since the start of COVID-19.

We did on the other hand manage to keep the expenses in this category in check thanks to fewer hours spent on these activities from our director. This was quite exceptional and mainly thanks to the high efforts spent on research related activities and the conference. Hence, we expect to see some increases in absolute terms for management and admin costs in 2023.



## Financial Position

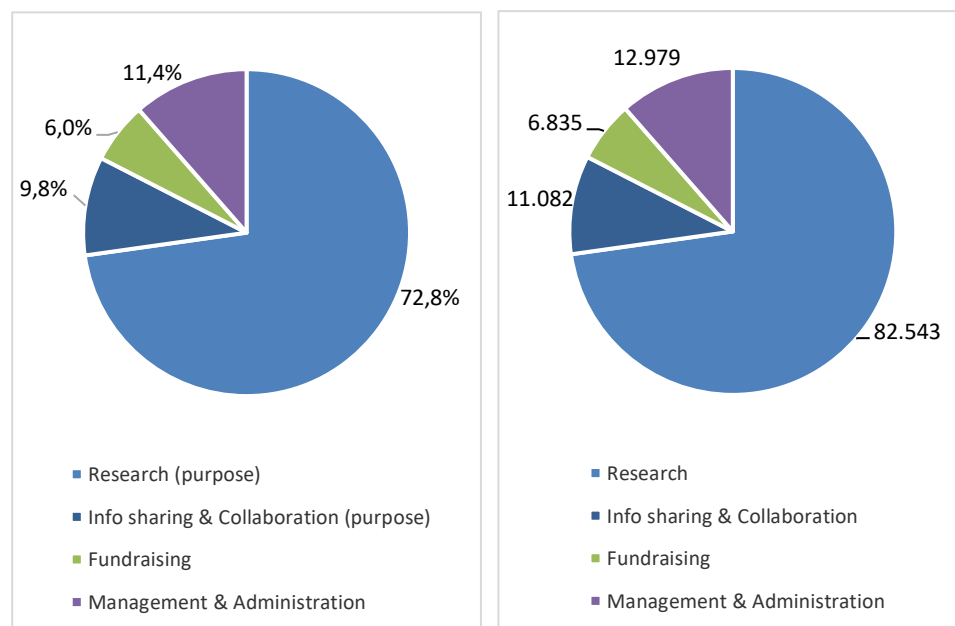
The financial position of the Foundation remains strong. Thanks to better than budgeted income, the net balance of income and expenses was less negative than expected. Thanks to contributions from the Earmarked Funds, a part of our expenses was covered. This means we were able to add to our Contingent Reserve, while Earmarked Reserved declined.

This means our Contingent Reserves increase from EUR 113.211 in 2021 to EUR 152.686 at the end of 2022. This also means that we exceeded the standard set by the Board for the reserve for Care4BrittleBones for a second year. This standard is set at a maximum of 1 time the annual costs of the organization. This standard stems from the Financial Management Guidelines for Charities of Goede Doelen Nederland. Using this standard, the maximum amount of contingent reserves at the end of 2022 was EUR 126.186. As mentioned earlier, we launched a research proposal round at the end of 2022. We intend to commit a sizeable part of our Contingent Reserves to one or more research projects in 2023 and are convinced this will bring our Contingent Reserves back in line with the standard.

## KEY NUMBERS

### How did we spend your contribution?

**Spent** in 2022: €123.439; graphs show spend excluding extraordinary expenses €113.439



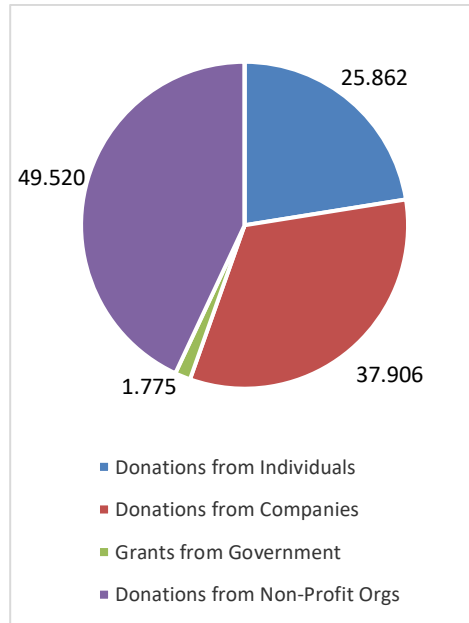
*Note: excludes extraordinary expenses as these are a correction to previous years. This makes %s deviate from %s in text above.*





## What are our sources of income?

Income in 2022: € 115,063





## BUDGET 2023

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 actually 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 2023 we have planned at a significantly higher ambition level than 2022. This mainly relates to further efforts in fundraising. The effects can be seen both on the expense and income side, respectively related to more effort by the fundraiser and better outcomes of these efforts. With fundraising through sizeable proposals and applications, our main focus, we expect to first incur fundraising costs and later generate additional income. The board considers this investment as required to boost our spend on purpose.

Furthermore, our financial position is very healthy and we exceeded the standard for contingent reserves by the end of 2022, so the board is convinced the Foundation can carry the risk of this investment and will be able to one or more research proposal in 2023. This does however lead to a planned sizable negative result of EUR -30.286.

## Income

For 2023 we have projected a sizeable increase from 2022. As mentioned in the previous section, this relates to the expected 'returns' on additional fundraising efforts. Our exceeded of the planned income in 2022 and the initial feedback on several applications provide us with confidence this is an achievable target. At the same time, the budgeted expenses contain a degree of flexibility that will allow us to keep the bottom-line result in line with our plan.

## Expenses

Given the availability of funds from our balance sheet and our additional efforts in fundraising, we have already announced new research proposal round at the end of 2022. The submissions and evaluation of the research proposal will run in the first half of 2023 and we intend to spend EUR 70.000 on funding new research.

We do intend to fund additional activities, such as further Key4OI related work and enhancing support to ongoing research that has no or limited funding. We also intend to ramp up information sharing activities. This relates mainly to our participation in key external research fora and conferences.

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 6% in 2021 actuals to 15% in 2023. While management and admin expenses also increase in absolute terms, they stay flat as a percentage of total expenses, at around 11%.

This means the percentage of spend on Foundation Goals is expected to be lower than previous years, at 74%. We expect this to be a once-off effect of our investment in fundraising efforts. When this hopefully, leads to more income, we fully intend to spend this income on our goals.



## Budget 2023 (continued)

Income & Expenses	Budget 2023		Actuals 2022		Budget 2022	
	EURO	EURO	EURO	EURO	EURO	EURO
<b>Income</b>						
Income from Individuals		40.000		25.862		40.000
Income from Companies		40.000		37.906		20.000
Income from Lottery Organizations						
Income from Grants from Government				1.775		
Income from Associated (international) Organizations				0		
Income from other Non-Profit Organizations		100.000		49.520		40.000
Total Acquired Income		180.000		115.063		100.000
Income as compensation for the delivery of:						
- Products and/or Services						
- Other income						
<b>Total Income</b>		<b>180.000</b>		<b>115.063</b>		<b>100.000</b>
<b>Expenses</b>						
<b>Spent on Goals</b>						
- Research	110.980		82.543		76.500	
- Information sharing & Collaboration	44.307		11.082		23.325	
- Other			10.000			
		155.287		103.625		99.825
<b>Fundraising costs</b>		<b>32.500</b>		<b>6.835</b>		<b>8.452</b>
<b>Management &amp; Administration costs</b>		<b>22.499</b>		<b>12.979</b>		<b>16.767</b>
<b>Total Expenses</b>		<b>210.286</b>		<b>123.439</b>		<b>125.044</b>
<b>Balance before Financial Income &amp; Expenses</b>		<b>(30.286)</b>		<b>(8.376)</b>		<b>(25.044)</b>
Balance Financial Income & Expenses				(91)		
<b>Balance Income &amp; Expenses</b>		<b>(30.286)</b>		<b>(8.468)</b>		<b>(25.044)</b>



## FINANCIAL STATEMENTS 2022

### Income Statement

Income & Expenses	Actual 2022		Budget 2022	
	EURO	EURO	EURO	EURO
<b>Income</b>				
Income from Individuals		25.862		40.000
Income from Companies		37.906		20.000
Income from Lottery Organizations				0
Income from Grants from Government		1.775		0
Income from Associated (international) Organizations				0
Income from other Non-Profit Organizations		49.520		40.000
Total Acquired Income		115.063		100.000
Income as compensation for the delivery of:				
- Products and/or Services				0
- Other income				
<b>Total Income</b>		115.063		100.000
<b>Expenses</b>				
<b>Spent on Goals</b>				
- Research		82.543		76.500
- Information sharing & Collaboration		11.082		23.325
- Other		10.000		
		103.625		99.825
<b>Fundraising costs</b>		6.835		8.452
<b>Management &amp; Administration costs</b>		12.979		16.767
<b>Total Expenses</b>		123.439		125.044
<b>Balance before Financial Income &amp; Expenses</b>		(8.376)		(25.044)
Balance Financial Income & Expenses		(91)		0
<b>Balance Income &amp; Expenses</b>		(8.468)		(25.044)
<b>Assignment Balance Income &amp; Expenses</b>				
<b>Addition to / Withdrawal from:</b>				
- Other Reserves		39.474		
- Earmarked Reserves		(25.000)		
- Earmarked Funds		(22.942)		
		(8.468)		

### Balance Sheet

	Notes	31-dec-22		31-dec-21	
		EURO	EURO	EURO	EURO
<b>Assets</b>					
Receivables & Accrued Assets	1	32.745		34.070	
Cash & Cash Equivalents	2	187.566		250.856	
			220.311		284.926
			220.311		284.926
<b>Liabilities</b>					
Reserves & Funds					
- Reserves					
- Earmarked Reserves	3	25.000		50.000	
- Other Reserves	4	152.686		113.211	
			177.686		163.211
- Funds					
- Earmarked Funds	5		8.700		31.642
			186.386		194.853
Long Term Debt	6		0		0
Short Term Debt	7		33.926		90.073
			220.311		284.926



## CASHFLOW STATEMENT

	2022	2021
<i>Cash collected from:</i>		
donations	59.628	78.635
Income from Grants from Government	1.775	84.646
Income from other Non-Profit Organizations	54.985	1.775
Products & Services	0	0
Interest received	16	0
<b>Total cash collected</b>	<b>116.404</b>	<b>165.057</b>
<i>Cash paid for:</i>		
Research projects	159.772	166.003
Sponsoring events		
Governance costs	12.979	11.125
Fundraising activities	6.835	4.634
Interest paid	108	56
<b>Total cash paid</b>	<b>179.694</b>	<b>181.819</b>
<b>Net cash from operations</b>	<b>(63.290)</b>	<b>(16.762)</b>
<i>Cash Balance:</i>	<b>2022</b>	<b>2021</b>
Opening balance ABN AMRO, SNS & Paypal	250.856	267.618
Closing balance ABN AMRO, SNS & Paypal	187.566	250.856
<b>Net cash from operations</b>	<b>(63.290)</b>	<b>(16.762)</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 2023 budget, a contingent reserve of a maximum of EUR 126.186 will follow as of 31 December 2022. The realized balance Other Reserves of EUR 152.686 is significantly above this threshold set by the Association Board. The plan for 2023 clearly aims to bring these reserves back 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

	2022	2021
	EURO	EURO
<b>Receivables &amp; Accrued Assets</b>		
Receivables from Individuals	-	-
Receivables from Companies	22.840	18.700
Grants from Government	-	-
Interest		
Receivables from Non-Profit Organizations	9.905	15.370
<b>Total</b>	<b>32.745</b>	<b>34.070</b>

### Note 2

	2022	2021
	EURO	EURO
<b>Cash &amp; Cash Equivalents</b>		
ABN AMRO Current Account	7.593	39.005
ABN AMRO Savings Account	65.967	98.952
SNS Bank Savings Account	99.940	99.950
PayPal	14.066	12.949
<b>Total</b>	<b>187.566</b>	<b>250.856</b>

### Note 3

	2022	2021
	EURO	EURO
<b>Earmarked Reserves</b>		
balance 1/1	50.000	60.500
Additions	10.000	
Withdrawals	(35.000)	(10.500)
<b>Balance 31/12</b>	<b>25.000</b>	<b>50.000</b>

### Note 4

	2022	2021
	EURO	EURO
<b>Other Reserves</b>		
balance 1/1	113.211	46.717
Additions	57.942	66.495
Withdrawals	(47.208)	0
<b>Balance 31/12</b>	<b>123.946</b>	<b>113.211</b>

*The Additions relate to the closing of obligations for closed and cancelled projects.*

### Note 5

	2022	2021
	EURO	EURO
<b>Earmarked Funds</b>		
balance 1/1	31.642	79.931
Additions	0	0
Withdrawals	(22.942)	(48.289)
<b>Balance 31/12</b>	<b>8.700</b>	<b>31.642</b>

*The withdrawals are related to movements in commitments for the Key4OI Kompas.*





#### Note 6

	2022 EURO	2021 EURO
<b>Long Term Debt</b>		
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

	2022 EURO	2021 EURO
<b>Short Term Debt</b>		
Project Commitments	26.481	70.278
Creditors	7.444	19.795
Total	33.926	90.073

*The 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 & Collaboration			Fundraising costs		Management & Admin		Total Actual 2022	Budget 2022	Total Actual 2021
	Research											
Project contributions	21.390		389							21.779	21.957	15.754
Outsourced work	12.842		0			5.028				17.870	20.000	16.068
Remuneration of director	48.311		10.693			1.807		3.077		63.888	66.320	71.051
Office and general costs								9.902		9.902	16.767	5.276
Other	10.000									10.000		-25.500
<b>Total</b>	<b>92.543</b>		<b>11.082</b>			<b>6.835</b>		<b>12.979</b>		<b>123.439</b>	<b>125.044</b>	<b>108.149</b>



## PROJECT OVERVIEW – SPENT ON GOALS

Year	Project Title	Category	Lead Country	Institution	Lead researcher	Status	Project Committed 1/1/2022	movement in commitment 2022	Total Commitment 31/12/2022	py Paid/reserved	Outstanding 1/1/2022	CY Paid/reserved	Directors' remuneration 2022	Total actual to date	Outstanding to be paid/received 31/12/2022
2017	Towards a therapy for OI - Next Steps	Basic science	Netherlands	Ibala / UMC Groningen	Fleur van Dijk	Committed	156.600	-16.600	140.000	140.000	0	0	0	140.000	0
2019	Key4OI Kompas;		NL	Care4BB		Committed	201.546	0	201.546	168.980	26.620	26.620	5.946	201.546	0
2019	Blockchain pilot voor OI		Netherlands	UMCG	Ruud Bank	Committed	15.000	-6.300	8.700	0	6.491	0	1.282	1.282	-8.700
2020	Sweet bones					Committed	50.000	10.000	60.000	0	60.000	35.000	0	35.000	25.000
2022	Energy 4OI			ZonMw		Committed	49.520	0	49.520	0	49.520	8.185	19.095	27.280	-9.905
	Other research projects		Netherlands			Ongoing	0	0	0	0	0	0	37.565	37.565	0
Total Projects	Total Projects						472.666	-12.900	459.766	308.980	142.631	69.805	63.888	442.673	6.395
Overall Total	Overall Total						472.666	-12.900	459.766	308.980	142.631	69.805	63.888	442.673	6.395



## NOTES ON THE ROLE AND REMUNERATION OF THE DIRECTOR

### Notes on the role and remuneration of Management

Name	Dagmar Mekking
Position	Director
Line of work	Contract
Hours	29.3/week
Parttime percentage	73%
Period	1/1/2022-31/12/2022

Annual remuneration (gross)	63,888 *
Vacation payment	-
Year-end payment	-
Compensation holidays not utilised	-
<b>Total</b>	<b>63,888</b>
Taxable reimbursement	-
Pension payments (Foundation)	-
Pension compensation	-
Other long term remuneration	-
End of Service payment	-
<b>Total</b>	<b>63,888</b>

*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 2022 led to a so-called BSD-score of 310 points with a maximum annual income of EUR 82.520,- 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 EUR 99.975 (1 FTE/12 months). The total remuneration of the Director (self employed) on a full-time basis of EUR 87.120 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).*



## ACCOUNTING CONTROL STATEMENT

2022 control statement:

### Accounting Control Statement

The Auditing Committee in the person of Ms E.L. Koster and Mr. R. Le Grand have on Friday 9 June 2023, in the presence of Treasurer Mr. D.J. Stegink, Mrs. I Juzwa-Parus and Mr. R. Brabander, checked the books of the Care4BrittleBones foundation for the financial year 2022.

The Committee states that:

- The Annuals Accounts give a correct representation of the income and expenses for the year 2022
- The balance sheet as at 31 December 2022 give a true and fair view of the Reserves.

Den Haag, 7 July 2023

The Auditing Committee

E.L. Koster

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>