

2020



**ANNUAL REPORT | 2020**  
Care4BrittleBones Foundation



## OI | IN NUMBERS

Some children break one of their bones

**500.000** PEOPLE

Worldwide have OI

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

**10** TIMES A YEAR

People most affected with OI break over

**200** TIMES IN A LIFETIME

## OI IN THE WORLD

**8.500** BABIES

Worldwide are born each year with OI

**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.

**150** VOLUNTEERS

**134.068** EUR

**9.4** %

Overhead

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

**112.882** EUR

## REACHING OUT IN 2020

Of funds raised in 2020 for much needed research for OI

**23** WORKSHOPS AND EVENTS

Organised in 2020 by Care4BrittleBones and its network

**11.3** %

Fundraising Cost



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## 2020 | DELIVERING ON AMBITIONS

We started the year with real momentum, having delivered on many key ambitions and major milestones for the Charity during the course of 2019, and having established a strong platform to continue to improve quality of life for people with OI. Yet even as we were putting the finishing touches to our last annual report, we began to foresee significant challenges and unique uncertainties unfolding in the world around us. Little did we understand, at that stage, just how profound the health and economic crises resulting

As you will read in the pages that follow, the macro context has impacted everything from our traditional sources of fundraising to the way we collaborate with our partners. And you will also see that, despite this, we can still take pride in having made substantive progress on a number of important fronts. We ran a significant Proposal Round which resulted in a great many applications for the funding of a diverse range of extremely impressive research projects. We continue to benefit from a number of valuable grants, subsidies and donations. We continue to play an important role in initiatives such as the flagship “Key for OI” project. And much more! Our sincere thanks go to all those who have both contributed to and enabled us to continue making a difference – including our valued sponsors, clinicians, researchers, allied health professionals, industry representatives and people with OI and other rare bone diseases.

So overall we look back on 2020 as a year which has brought many unique challenges, but also some special opportunities. We have worked tirelessly to sustain our momentum and ensure we move into 2021 as a thriving and viable Charity. We are encouraged by what we continue to achieve with our partners throughout the OI world, and feel real gratitude for the encouragement, support and trust placed in us. We will continue to work with all our dedication and focus to make a difference to the quality of life for people with OI.

On behalf of the whole foundation Care4BrittleBones, thank you!

**Graham Marshall**  
Chairman



**Dagmar Mekking**  
CEO/Directeur-Bestuurder





## 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.

*“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.”*

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.

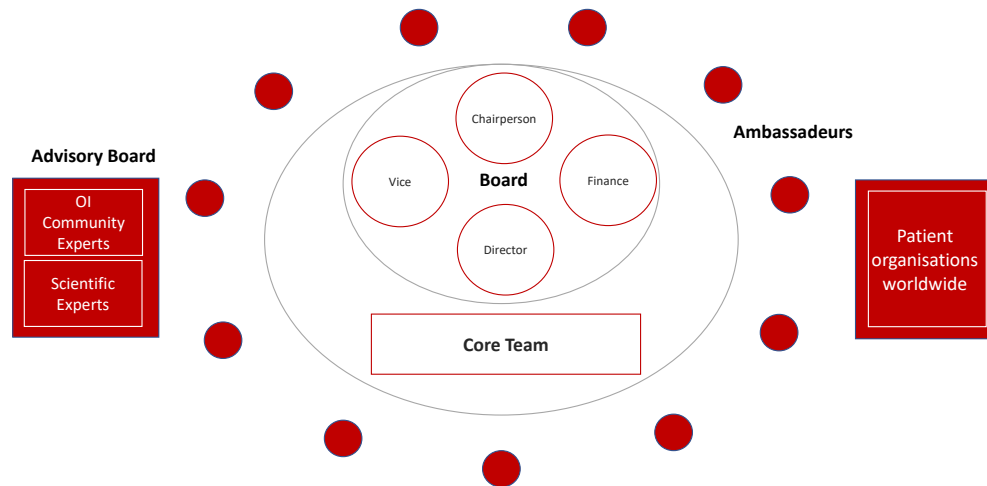
These circumstances create new opportunities for OI research. Care4BrittleBones has identified various short, mid and long-term opportunities that have the potential to improve the quality of life of people with Osteogenesis Imperfecta and eventually to lead to a breakthrough therapy for OI.



## 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



### 1. | THE BOARD

Care4BrittleBones is formally led by its Board of four team members:



**Graham Marshall**  
Chairman/Secretary



**Celine Disch**  
Communications



**Dirk-Jan Stegink**  
Treasurer



**Dagmar Mekking**  
Director

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 chairman and director meet weekly to consult on key topics. The Board will formally review 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>Dagmar Mekking</b> , Lieke Mekking, Graham Marshall
Communications	<b>Celine Disch</b> , Amy Hassett
IT / Data Privacy	<b>Henk Latour</b> , <b>Kees Mezouar</b>
Research	<b>Graham Marshall</b> , Dagmar Mekking, Lieke Mekking
Collaboration	<b>Dagmar Mekking</b> , Graham Marshall



As physical meetings were not possible in 2020 due to the COVID – Pandemic, we are reusing a picture for the core team from 2019.





### 3. | ADVISORY BOARD

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.

The Scientific Advisory Board Members have expertise in genetics, endocrinology, bone metabolism, paediatrics and rehabilitation, for example. 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 good knowledge of the disorder and a broad network in the OI community.

The Advisory Board advises on which research projects we should prioritise and steer on research strategy and communication. Marked with a (\*) are those who participated in the 2020 proposal round (see dedicated chapter in this Annual report).

#### THE SCIENTIFIC ADVISORY BOARD MEMBERS



**Fleur van Dijk**  
Genetics  
UK



**Oliver Semler**  
Pediatrics  
Germany



**Lena Lande Wekre**  
Rehabilitation  
Norway



**Lars Folkestad (\*)**  
Endocrinology  
Denmark



**Marianne Rohrbach**  
Endocrinology  
Switzerland



**Antonella Forlino (\*)**  
Research  
Italy



**Frank Zaucke**  
Research  
Germany  
(for this round only)

#### THE OI ADVISORY BOARD MEMBERS



**Margriet Crezee**  
Netherlands



**Ute Wallentin**  
Germany



**Eero Nevalainen (\*)**  
Finland



**Kevin Vanantwerpen**  
Belgium



**Therese Stutz-Steiger (\*)**  
Switzerland



**Leonardo Panzeri**  
Italy



**Benedicte Alliot**  
France

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



## 4. | OUR AMBASSADORS

Our ambassadors are dedicated to networking and fundraising for OI research. 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](mailto:dagmar.mekking@care4brittlebones)).



Andrea Kiel



Annemarie  
Visser & Kris  
Koenis



Danielle de  
Bakker



Diana Lips



Erik Meinen



Harry  
Vondenhoff



Leonie Rouweler



Irma van der  
Hoek



Jeanette  
Chedda



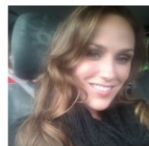
Jessy van de Pol



Karin Kragt-  
Vermolen



Laura Marx



Marijke van  
Liempt



Marina Gil



Melvin  
Elderhorst



Michaël Roele



Mira Thompson



Rebecca Meijer



Rene van der  
Rijst



Rick Brink



Roos Hoffmann



Rob & Rebecca  
van Berkel



Welmoed  
Santema



Zuhail Soyan

In addition, many children enthusiastically and effectively help us! 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

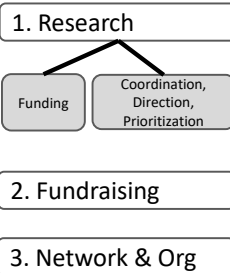
We work closely with various patient organisations in all of our activities. We believe that an active role for people with OI is an important aspect of a meaningful and impactful research agenda. Their willingness to advocate for research, articulate their needs and participate in research makes a major difference. We also maintain regular connections with OIFE (OI Federation Europe) and the OIF (OI Foundation based in the USA). In 2020 we have started to increase our work with patient organisations around the globe (see chapter Operational delivery / Network and reach)

# Overview Care4BrittleBones

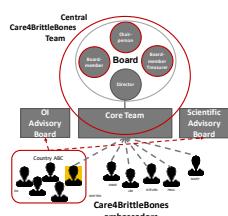
### PARTNERS IN RESEARCH

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

### WHAT WE DO



### WHO WE ARE



Improving Quality of Life for people with

**Osteogenesis Imperfecta**

through **RESEARCH**



### HOW WE WORK

#### Values

- Positive
- Inspirational
- Innovative

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

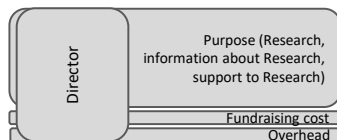
### PARTNERS IN OI COMMUNITY

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

### Communication channels

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

### COST



### LONG TERM APPROACH: Multi year plan

- Research
- Fundraising
- Networks
- Operations
- Fundamentals



## STRATEGY | AND 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:

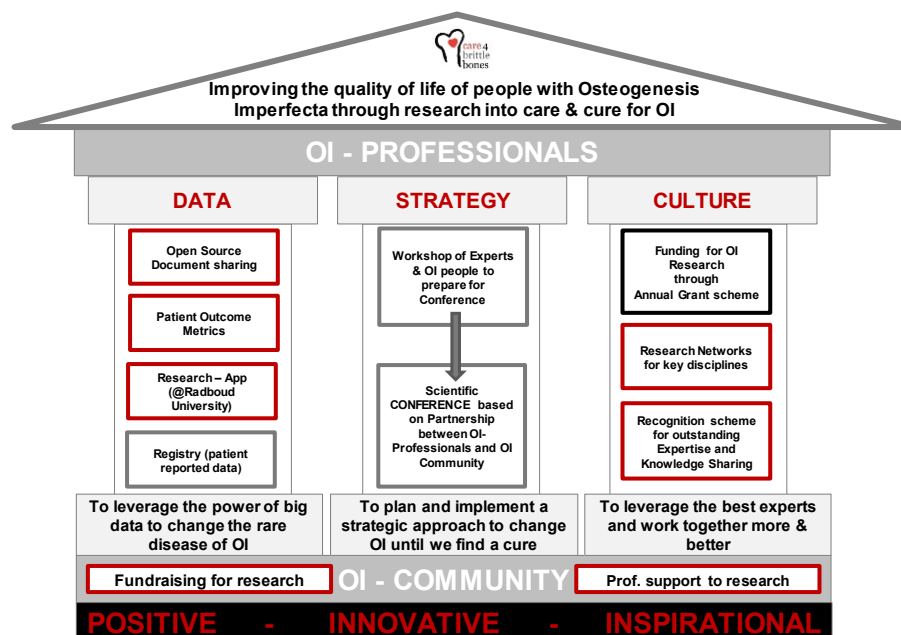
1. Raising funds;
2. Funding research and activities enabling research;
3. Contributing to impactful research by developing priorities and strategies for improving Osteogenesis Imperfecta, supporting collaboration and knowledge sharing regarding Osteogenesis Imperfecta and providing support to research 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.

### 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.

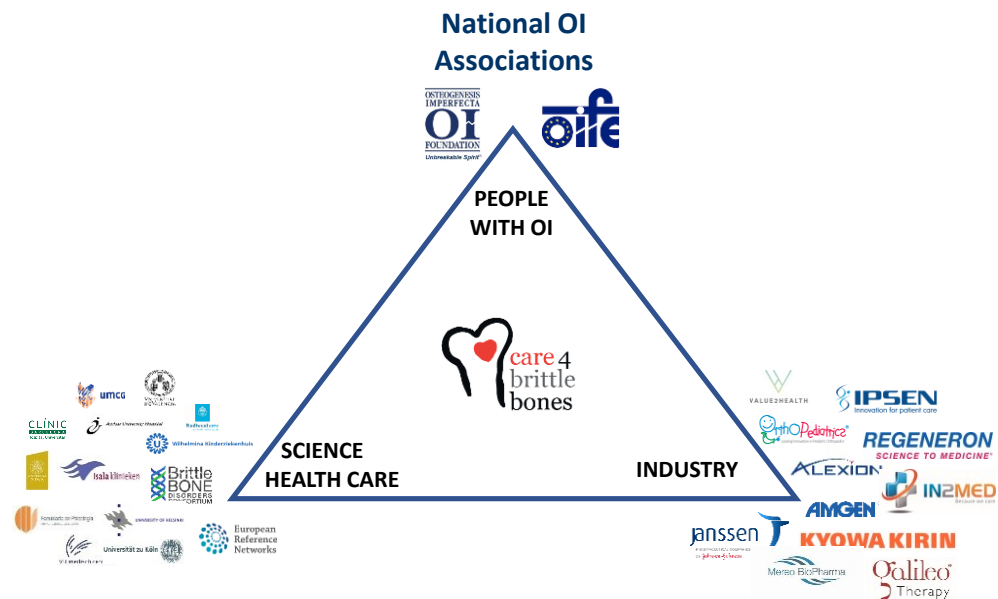
In 2020 Care4BrittleBones has continued to build on its research strategy, which is called "OIKOS". OIKOS is a holistic approach to driving change in research and improving the quality of life of people with OI. The three most important levers and associated strategic actions are: data, strategy and 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” Conference](#) held in 2019 exemplified this aspiration.

We actively work together with all of these 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 based on our current stakeholder relationships (2020).

Our current strategy is still described in the multiyear plan (2018 – 2020), which has been published online. A new multi-year plan is currently being developed. The plan covers the areas of Research (OIKOS), 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. A comparison between the multi-year plan, and the operational delivery of the plan is described in the next chapter.





### 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 2020 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 2020, 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 in Key4OI Compass project).

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







## OPERATIONAL DELIVERY | 2020

The year 2020 has been highly unusual for everyone, including Foundation Care4BrittleBones, due to the impact of the COVID-19 Pandemic. Whilst our **fundraising** was strongly negatively impacted, most **research** activities were delivered as planned including the research proposal round. In the area of **Collaboration and Communication**, 2020 has led to the creation of a second foundation, Foundation Care4Bones. The Foundation will only begin operation in 2021. The underlying thinking and relevant decisions, however, have taken place in 2020 and therefore are described in this annual report. The creation of Care4Bones as a foundation and the associated platform will fundamentally transform how we work together with researchers and with the OI community for improving quality of life for people with OI.

### Color coding:

- GREEN:** Accomplished fully
- AMBER:** Mixed delivery
- RED:** Below plans
- BLUE:** Different then planned due to COVID-19

### 1. RESEARCH



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

### 2. COLLABORATION



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

### 3. FUNDRAISING



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

### 4. COMMUNICATION



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

### 5. OPERATIONS



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

## | RESEARCH

### Summary

Given the extremely challenging circumstances healthcare providers and researchers found themselves in during the COVID-19 pandemic, the delivery on the research side was very strong.



a. **Research projects status update**

Foundation Care4BrittleBones has been involved in 10 research related activities in 2020. Our role varies per project:

1. The **Vitamin K** project of the UMC Utrecht continued in 2020. The project experienced a delay as routine healthcare in the hospital was suspended due to the pandemic. Due to financial constraints, Care4BrittleBones has indicated that previously available “buffer” funding could not be continued. We are looking forward to the delivery of the project report in 2021. The project examines whether children with OI have a Vitamin K deficiency.
2. The project **Eat, Breathe, Sleep** by Dr. Antonella LoMauro has progressed with some adaptation in scope. All work has been concluded in 2020 and the report is due in 2021. We are looking forward to sharing the findings with the OI community, researchers and clinicians.
3. We have developed a fundraising video in support of the **OI Variant database project** of Dr. R. Dalgleish, which was launched in March 2020. In the COVID-19 climate the response was disappointingly low, which was experienced by many other foundations in the crowdfunding area.
4. The **Blockchain project** was on hold for most of 2020 due to a lack of project funding. At the end of 2020 a prestigious Health Holland grant was awarded to the project and therefore it can now go ahead as originally planned in 2021. The project takes place in collaboration with Janssen Pharmaceuticals, Blockchain provider Embleema, Mijn gezondheid – Mijn data, Isala and NELL Living lab. The objective is to test Blockchain technology for the processing of healthcare data. The collaboration with Janssen Pharmaceuticals is purely based on our shared interest in this technology. They are not producing any medication for OI and therefore there is no conflict of interest.
5. The very innovative project “Towards a therapy for OI” of Fleur van Dijk (UMC Groningen/NHS North West London Hospital NHS Trust) is looking into the use of induced pluripotent stem cells for OI Therapy using CRISPR–Cas technology. Due to COVID-19, the project had to be put on hold. The plan is to continue with the next stage of the project (testing on OIM mice) as soon as the pandemic allows this.
6. In 2020 we made great progress in relation to Key4OI, our ambitious project to develop and implement consistent outcome measures for OI. (For more information, see the chapter: Highlights / Research). Many healthcare providers and scientists are following the project and are highly motivated to use Key4OI.



7. Three new research projects under the overarching name “Key4OI PLUS” were started, building on the Key4OI methodology focussing on Lung, Hearing and Teeth & Jaw in OI (See chapter: Highlights / Research for more information).



8. Based on our research proposal round conducted in Q3 2020, we have decided to newly fund the project of Ruud Bank / Ralph Sackers “Sweet Bones. Targeting collagen glycosylation to improve bone quality in osteogenesis imperfecta”. The work will only start in 2021. This preclinical project is looking into the root causes why bones are so brittle, developing the fundamental thinking how to address brittleness in a completely new way.

**b. Professional networks**

- The **Psychosocial Network** has conducted an expertise finder survey in 2020 which will be shared with the community in 2021. No webinars were held in 2020. This will be picked up again in 2021. This network is led by Kara Ayers, Ute Wallentin and Claire Hill.
- The **Physical Wellbeing Network** has started to undertake preliminary work in relation to Wellbeing of adolescents and adults with OI. The network is led by Kathleen Montpetit. The project that is under consideration also involves Lena Lande Wekre and Marjolein Verhoef.
- The **OI Conference in Sheffield** planned for September 2020 could not be held due to the COVID-19 Pandemic.
- We have regular exchanges with the **ERN-BOND initiated EuRR-BONE Database** project based out of Leiden University Medical Center in the Netherlands. We support their concepts and ideas in relation to a database that is open for everyone to use in order to boost research into OI.

**c. Conference 2021 exploration**

We have started to look into ways to hold a virtual Conference “Quality of Life 4 OI” in 2021, about years after the Amsterdam Conference. Watch that space!

**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**

We spent EUR 134.068 on our statutory goals: research, information sharing and collaboration for knowledge exchange. This is a decrease from 2019 and below the initial 2020 budget. The lower spend on these goals was due to the COVID-19 pandemic.

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

It remains necessary to connect experts to learn from each other and build on each other’s work. For many OI professionals, interacting with people with OI forms only a minor part of their professional responsibilities. However, with support from Care4BrittleBones, collaboration between people with OI and professionals can increase and accelerate collaboration and knowledge exchange and generate more impact. In 2020 we started to change our vision from bringing professionals and OI Community together on a project basis to developing networks that connect the two communities on an ongoing basis. This will help improve the quality of life for people with OI and is enabled by the [www.care4bones.org](http://www.care4bones.org) platform.





## | FUNDRAISING

### Summary

In 2020 fundraising was impacted strongly by the COVID-19 pandemic. Normally we hold various events for fundraising, such as running events or concerts. All of that was not possible. We really appreciate the continued support from our private donors who have loyally continued their support.

- a. **Trust funds:** We submitted ca. 600.000 Euros worth of proposals into various trust funds. Unfortunately the success rate was exceptionally disappointing this year. We believe that the reason was the general “uncertainty in relation to COVID-19” causing trust funds to also act more cautiously. Our track record and “impact story” is stronger than it has ever been. We will pursue our efforts in 2021 with at least the same level of dedication as we did in 2020.
- b. **Public funding:** We continue to have a very strong reputation in the Dutch public Health care system, namely Zorginstituut Nederland and the Dutch Ministry of Health. Given our very productive relationship with the Dutch Patient organisation (VOI) and the Dutch Expertise centers it is possible to implement tangible improvement in the Dutch Healthcare system which benefit everyone with OI in the country. We have two main projects ongoing funded with public subsidies:
  - The Key4OI approach is being implemented with a public subsidy from the Dutch government which was already awarded in 2019. The implementation takes 2 years and may be extended slightly due to COVID-19.
  - In 2020 we were awarded a significant grant to develop Care4Bones.org, an innovative platform for connecting the OI community internationally to work together and share knowledge (see chapter Highlights / Collaboration).
- c. **Fundraising event:** We only held one event to raise funds: A Christmas celebration! More information see the chapter: Highlights / Fundraising.
- d. **Crowdfunding:** In 2020 the level of crowdfunding was unprecedentedly low. We raised ca. 55.000 Euros in various ways from individuals, often involving our crowdfunding platforms research4oi.org, geef.nl or facebook.
- e. **Long term donors:** We have a small group of ca 10 long term donors. They all continued to support us in 2020 and we are extremely grateful for their loyalty.

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

Improving quality of life 4 OI requires long term thinking and long term delivery. The reduction of income to the foundation throughout this pandemic exposed the vulnerability of our foundation in relation to a continuous income stream. We have mainly worked from project to project. A key challenge for 2021, is ensuring that more robust, continuous income streams be made available to ensure the sustainability of the foundation.



## | COLLABORATION AND REACH

### Summary:

Collaboration within the Care4BrittleBones Core team and with our Ambassadors remained strong in 2020. Whilst everyone individually wrestled with the impact of COVID-19 to their personal life, the commitment to support the foundation and the trust amongst the team has been the key for the strength of Care4BrittleBones. Collaboration with stakeholders outside of the foundation varied. Our engagements in relation to the creation of [www.care4bones.org](http://www.care4bones.org) with national patient organisations as well as OIFE and OIF has started. Many reacted positively, others has had concerns or questions. The aim for 2021 is to build the trust in what Care4BrittleBones is doing and continue to look for synergies how we can all achieve more together.

- a. **Core team:** In 2020 we continued to deliver our work with support of the dedicated Care4BrittleBones Core team. It meets every month. Due to COVID-19 all meetings have been virtual. Each volunteer in the core team has strong professional acumen and expertise. The Core team discusses strategic topics relevant to everyone and important operational items. A robust infrastructure of collaboration tools are enabling us to work seamlessly together.
- b. **Ambassadors:** Ambassadors are people who believe with us in the importance of research for quality of life for people with OI. They are our eyes and ears to spot opportunities for fundraising and are often actively engaged in research projects or fundraising activities..



- c. **Engagement:** Given the breakdown of any physical meeting opportunities in 2020 due to COVID-19, it was particularly important to engage virtually on an individual level, through social media and with virtual engagements using zoom and teams.





- We have grown the number of people who receive our **newsletter**, the number of posts on social media has increased tremendously, underpinned by a very active communications team. Currently, our newsletter is sent out to 1,658 individuals.
- **Website:** The website 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. We organised two online **Concerts for the OI community**. One concert featured the artists Mira Thompson, Lea Gaelynn and Sparsh Shah. The other concert included a virtual OI choir singing “Count On Me”. No fundraising was involved. These were organised for the sole purpose of creating connection and support



within the global community.

- We also organised a first “**Living with OI**” workshop to provide peer support within the OI community. The “Living with OI” workshop concept was developed through a project in the Netherlands funded by Zorginstituut Nederland. The workshop demonstrated that the workshop design is also fit for international use. We are looking forward to several workshops in 2021.





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

Whilst we worked very hard to create connection and support virtually, it felt like we are just not connecting enough. Many people with OI felt alone and isolated throughout the pandemic period which brought unprecedented levels of health concerns and uncertainty for all of them. The goal of connecting the OI community, among other goals, has led to the creation of [www.care4bones.org](http://www.care4bones.org). It allows us to structurally increase connection and collaboration. It is our belief that over time this platform will benefit every single researcher and clinician, along with every person with OI including OIFE and OIF and national patient organisations. See more information in the Highlights / Care4Bones.

## HIGHLIGHTS | RESEARCH

### 1. | KEY4OI – OUTCOME MEASURES SET

2020 was an important year to develop and “road test” the Key4OI concept. Key4OI is the name of a set of Outcome measures for multidisciplinary care for children and adults with OI applicable to all different types of OI. The concept had been developed in 2018 and 2019 in a unique worldwide collaborative effort of many experts around the globe and many patient organisations. The results of this work have been published in the [OrphaNet Journal of Rare diseases](https://orphanetjournalofrare Diseases.com).

#### Professional participants:



#### OI Community Representation:



In 2020 we have started to pilot the concept in the following locations:


- (1) Shriners Hospitals for Children, Montreal / Canada,
- (2) Alfred I duPont Children's Hospital, Delaware / USA
- (3) Norway
- (4) HongKong SAR / China
- (5) NL (lead by Isala, Utrecht UMC)

Every quarter we updated for researchers, clinicians and the OI community around the world to keep them updated about the implementation of Key4OI with the so-called Key4OI Affiliate video conferences.





## A standard set of outcome measures for the comprehensive assessment of osteogenesis imperfecta

Wouter Nijhuis , Anton Franken, Kara Ayers, Chantal Damas, Lars Folkestad, Antonella Forlino, Paolo Fraschini, Claire Hill, Guus Janus, Richard Kruse, Lena Lande Wekre, Lieve Michiels, Kathleen Montpetit, Leonardo Panzeri, Valerie Porquet-Bordes, Frank Rauch, Ralph Sakkars, Jean-Pierre Salles, Oliver Semler, Jony Sun, Michael To, Laura Tosi, Yangyang Yao, Eric Hiu Kwong Yeung, Lidia Zhytnik, Maria Carola Zillikens & Marjolein Verhoef [-Show fewer authors](#)

*Orphanet Journal of Rare Diseases* 16, Article number: 140 (2021) | [Cite this article](#)

611 Accesses | 3 Altmetric | [Metrics](#)

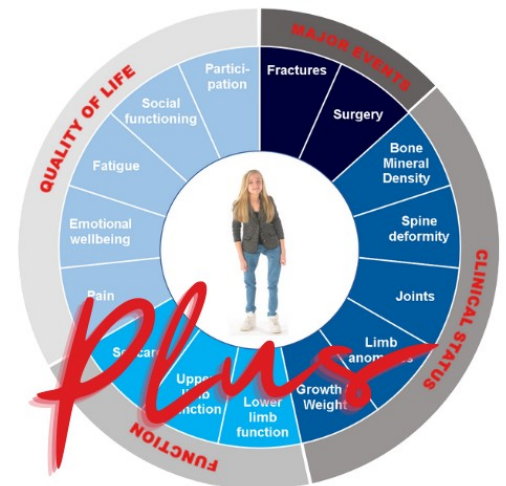
## 2. | KEY4OI PLUS

Given our experience with Key4OI and the importance of specific topics for the OI community many stakeholders suggested that we should continue to develop recommended outcome measures for clinical care. The priority was given to the following 3 topics due to their impact on quality of life:

- Teeth & Jaw
- Hearing
- Lung

Again we used our networks to seek out the best expertise that is available for the three topics. We are most grateful for the collaboration from so many clinicians and researchers as well as highly qualified “OI patient experts”.

All of them are contributing on a pro-bono basis. The project team group began work in 2020. In 2021 we will gather input from focus groups and we will recommend outcome measures using the same proven Delphi based methodology as in Key4OI.





Clinicians and OI patient experts involved in Key4OI Plus:

## Key4OI Plus

### Teeth:

[i.blokland@vogellanden.nl](mailto:i.blokland@vogellanden.nl)

### Pulmonary Function

[hchaney@childrensnational.org](mailto:hchaney@childrensnational.org)

### Hearing

[t.goderie@amsterdamumc.nl](mailto:t.goderie@amsterdamumc.nl)

34 people from 14 different countries involved.

Last Name	First Name	Country	KEY4OI PLUS <sub>17</sub>
Loundon	Natalie	France	hearing
Maroger	Diane	France	hearing
Musacchio	Angela	Italy	hearing
Goderie	Thadé	Netherlands	hearing
Smits	Cas	Netherlands	hearing
Hendicks	Sebastian	United Kingdom	hearing
Vernick	David	United States	hearing
Folkestad	Lars	Denmark	pulmo
Beeri	Eliezer	Israel	pulmo
Eekhoff	Elisabeth (Mar)	Netherlands	pulmo
Franken	Anton	Netherlands	pulmo
Kamp	Otto	Netherlands	pulmo
van den Aardeweg	Joost	Netherlands	pulmo
de Bakker	Danielle	Netherlands	pulmo
Micha	Dimitra	Netherlands	pulmo
Radunovic	Zoran	Norway	pulmo
Barreiros	Ceu	Portugal	pulmo
Rebello	Monica	Portugal	pulmo
Chaney	Hollis	United States	pulmo
Rush	Eric	United States	pulmo
Li	Mengquan	China	teeth & jaw
Zhou	Liwei	China	teeth & jaw
Gjørup	Hans	Denmark	teeth & jaw
Arponen	Heidi	Finland	teeth & jaw
Blokland	Lieke	Netherlands	teeth & jaw
Giljijamse	Marjolijn	Netherlands	teeth & jaw
Colijn	Sander	Netherlands	teeth & jaw
Andersson	Kristofer	Sweden	teeth & jaw
Stutz-Steiger	Therese	Switzerland	teeth & jaw
Ahmad	Armaana	United Kingdom	teeth & jaw
John	Rebecca	United Kingdom	teeth & jaw
Parekh	Susan	United Kingdom	teeth & jaw
Retrouvey	Jean-Marc	United States	teeth & jaw



### 3. | RESEARCH PROPOSAL ROUND 2020 FOR BASIC SCIENCE

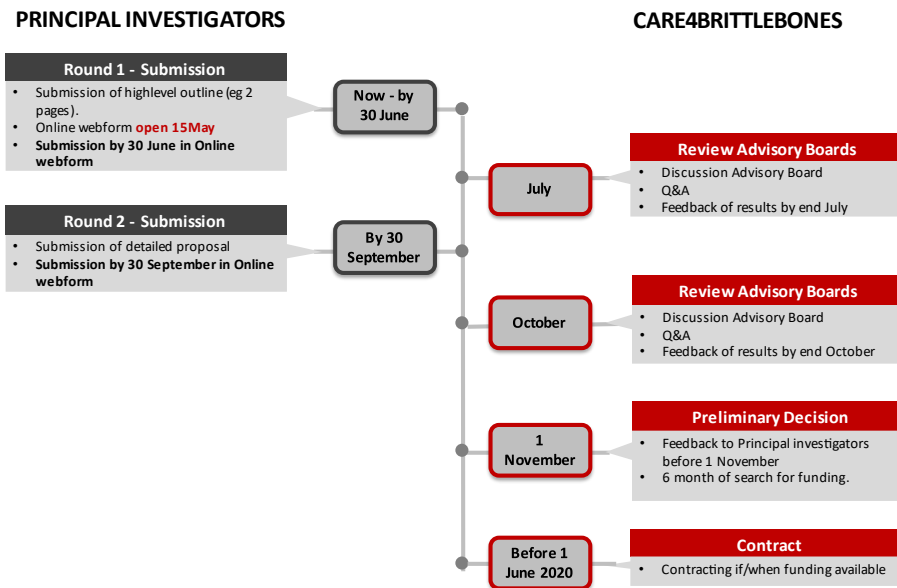
In 2020 we held a proposal round focussing on Basic science based approaches that may lead to fundamentally new ways for treating OI in the long term. In round 1 we received 25 proposals from many different healthcare and academic institutions from around the world. 3 proposals proceeded to the last round. The principal investigators presented their proposals during a zoom call to the Care4BrittleBones Advisory Board and Care4Bones Coreteam members.

One project was directly funded: Ruud Bank / Ralph Sackers: “Sweet Bones. Targeting collagen glycosylation to improve bone quality in osteogenesis imperfecta”.

In case more funding becomes available an additional project may be funded at a later stage. We would like to congratulate Ruud Bank and Ralph Sackers on this achievement!



## Care4BrittleBones Proposal Round 2020

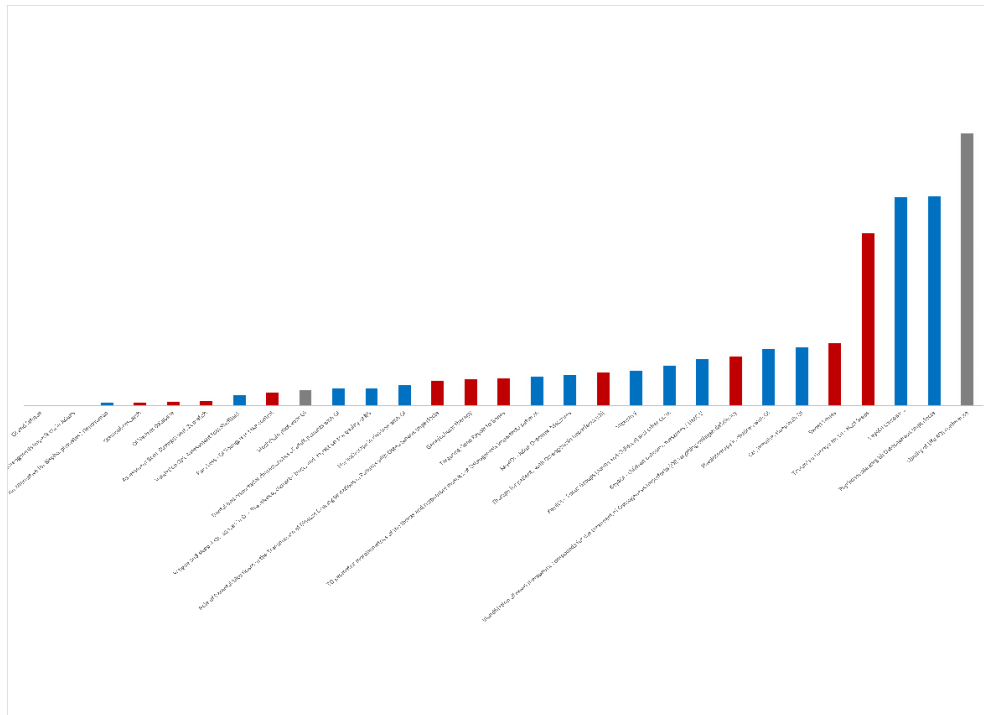


### 4. | LONG TERM OVERVIEW OF RESEARCH SUPPORTED BY CARE4BRITTLEBONES (2012 – 2020)

Over the past 9 years Care4BrittleBones has 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). Many of them are still ongoing, as they often take longer than 2 years to complete due to their complexity and comprehensiveness. An overview of the research and research collaboration projects supported from 2012 – 2020 is displayed on the next page.



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



## HIGHLIGHTS | CHRISTMAS FUNDRAISER

In 2020 given the COVID-19 constraints we were only able to organise a single fundraiser. It was a Seasonal fundraiser and took place 2 weeks before Christmas.





It felt like a global family reunion of people who care for OI. 125 people from more than 20 different countries participated.

We enjoyed wonderful Christmas songs by [Marieke Zevenbergen](#), enjoyed an inspiring new video from [Sparsh](#), adored the beautiful story of the 12 year old boy Zak and simply loved how our lovely host and ambassador, [Danielle de Bakker](#), who led us through this event! We would like to thank them once again!

All together we have raised **12.000 Euros** for research into OI! All sponsors were provided with the unique cookie-book and the wonderful story of ZAK's Chat with Corona.

**Zak's  
Chat  
with  
Corona**



## HIGHLIGHTS | COLLABORATION & REACH

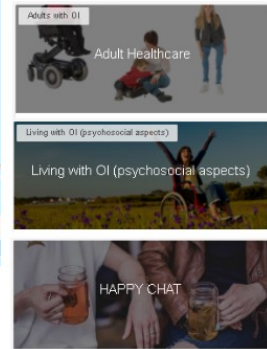
Unprecedented crisis can sometimes lead to unprecedented opportunity. In 2020 we felt more than ever that it was very hard to keep communication up across different projects. As the amount of e-mails, social media groups and online meetings increased for everyone due to COVID-19, the quality of the engagement did not necessarily increase. This year we discovered that new technology can help us to, not only over these issues, but also to strengthen the sense of connection within our communities. Thanks to a grant from the Dutch Ministry of Health, we were able to develop a new way of networking, sharing knowledge and working together towards positive change. We developed the platform [www.care4bones.org](http://www.care4bones.org)



# CARE4BONES

**1. Let's connect,**

**3. and work together!**



**2. understand OI**



Care4Bones is an open research and healthcare engagement platform in the widest sense of the word, with the objective supporting connection and collaboration, all in support of Quality of Life for OI! Care4Bones is by everyone who cares for OI, for everyone who cares for OI.

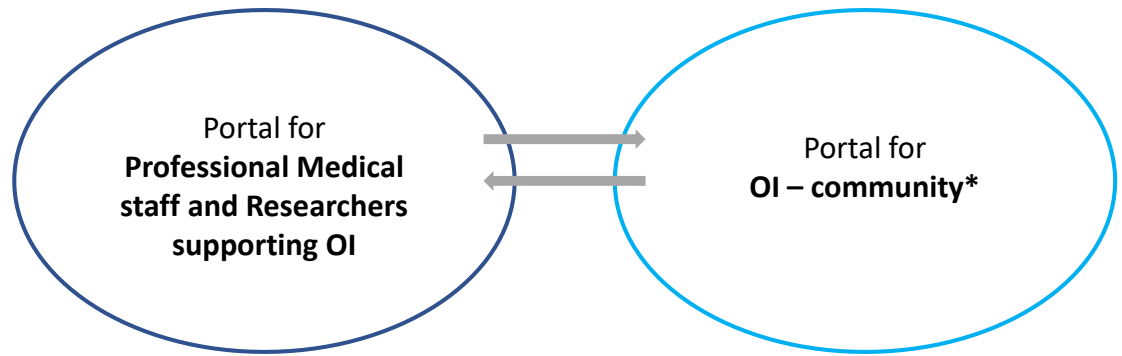
We established Care4Bones in order to

- learn and innovate how we can engage our communities better and make more impact
- strengthen relationships with all players in the system
- develop capability within the OI ecosystem by fostering knowledge exchange and education
- be open for everyone and sustainable.

The desire of Care4BrittleBones from the start had been to share the platform with OIF and OIFE. We invited them for the first time in July 2020 and had several meetings with the representatives of both organisations in the second half of 2020. They hold off on participating with the platform so far, which we regret. We have agreed on regular update meetings to keep each other posted on progress. We believe that the platform should transfer to a global community organisation at some stage in the future. We therefore set the platform up under a separate legal entity called Foundation Care4Bones.

The portal serves one single purpose: Improving quality of Life 4 OI. To achieve that two separate platforms are operating under the unified landing platform:





### Why would a professional user join Care4Bones?

#### CARE4BONES WILL ENABLE YOU TO

- ✓ Connect with colleagues supporting OI from around the world based in your own area of interest - corona-proof, low budget, open for everyone
- ✓ Access a library of free resources for OI
- ✓ Attend free webinars of experts
- ✓ Share knowledge with others
- ✓ Contribute to discussion groups on key themes
- ✓ Stay on top of the latest news in your sector
- ✓ Engage in international collaborative research
- ✓ Lead or join a research network or best practice sharing platform

#### CARE4BONES WILL BE USED BY

- ✓ Healthcare providers and allied healthcare providers from all disciplines involved in care for OI
- ✓ Multidisciplinary teams
- ✓ Researchers
- ✓ Patient experts
- ✓ Experts for paediatric care for OI and experts for health care for adults with OI
- ✓ Healthcare providers from around the globe

### Why would a person in the OI Community join Care4Bones?

#### CARE4BONES WILL ENABLE YOU TO

- ✓ Connect with people with OI around the world based in the area of healthcare and research in the widest sense - corona-proof, low budget, open for everyone
- ✓ Access a library of free resources for OI
- ✓ Attend free webinars of experts (scientific experts and patient experts)
- ✓ Share knowledge with others
- ✓ Contribute to discussion groups on key themes
- ✓ Stay on top of the latest news developments in research and healthcare
- ✓ Engage in international collaborative research
- ✓ Lead or join a research network or best practice sharing platform

#### CARE4BONES WILL BE USED BY

- ✓ During the pilotphase (until 1 July): selected national patient organisations and other OI networks.
- ✓ People with OI from around the globe and (separately) Healthcare providers, allied healthcare providers and researchers from all disciplines involved in care for OI.
- ✓ Family members of people with OI

#### How does Care4Bones differ from Facebook?

- Data privacy with focus only on the benefits for OI QoL
- No need for a new group every time. One place for all groups.
- Facebook is great for quick help and feedback on individual issues. Care4Bones is great for moving important topics forward for all of us.

2021 will be dedicated to getting both communities up and running. In the long term, the ambition the platform is expected to serve the OI Research ecosystem on many fronts:





FROM



TO

**THEMES (actions)**

- Focus on treatment process
- Lack of treatment goal
- No consistent data / impossible to compare and know what is "beter"
- Unclear about patient priorities for research
- Complete lack of continuous improvement agenda
- No treatment standard. Lack of transparency of data
- Expertise not transparent ("incrowd" only)
- Limited collaboration and knowledge exchange. Sometimes duplication. Lack of infrastructure, experience and resources)
- Sensitivities to allow other experts. "I am the king"
- Local data "ownership", small scattered data
- Intransparent / trust issues
- Little dialogue to what patients need. They drive and OI reacts
- National "islands" with limited onnections internationally
- Many countries under supplied with even the most basis information and support.
- Lack of trust and collaboration
- Little education, lack of role models



**Patient Outcomes**  
Better QoL



**HCPs**



**Industry Partners**



**OI Community**

- Focus on patient priorities
- Patients empowered to set goals jointly with HCPs
- Personalised treatment based on know what is best for whom, based on benchmark data
- Strategic priorities for research based on OI Community, supported by a continuous improvement agenda
- Clear standards of excellence based on benchmarkable data
- Expertise easily and transparently available for all (HCP and OI)
- Frontrunner in Systemic culture of For all rare diseases – Embracing the need to work together and build on each other,
- Culture of using each others expertise. Replicate best practices. Impact to QoL is king, wherever that may be.
- Open data, abundance of data
- Strategic partnership to solve some of the most urgent challenges. OI set's the objectives and measures for success
- Smart partnerships for affordable medicines and products
- Supplementing national networks with an international community, starting with research.
- Supporting the exchange of knowledge and best practices
- Trust in strong collaboration around key priorities
- Strong approach to develop people with OI to take charge



## 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:

- **e-bookkeeping tool**
- **Dropbox**
- **Website Care4BrittleBones.** All key information about Care4BrittleBones is available on our website which is updated on a regular basis
- **Website Conference QualityofLife4OI** We are keeping the 2019 conference website live as we consider to use it again for conferences
- **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 2020.
- **Formdesk for surveys:** We conducted several anonymous Delphi surveys, facilitated by ourselves, supported by a user friendly web based tool, which fully protects the privacy of people participating in our surveys.
- **Mailchimp:** Our newsletter provider is Mailchimp. We continue to watch the data privacy compliance.
- We are working with various **social media channels and other platforms such as YouTube and SoundCloud, where we have dedicated channels** (see also the chapter on communications)
- **Crowdfunding platform [www.research4OI.org](http://www.research4OI.org)** continued to run in 2020. Whilst it works technically well, we are currently reviewing our approach to crowdfunding and have decided to not continue with a paid account in 2021..





## COMMUNICATIONS | NETWORKS

### | OI COMMUNITY NETWORKS

In 2020, more than 150 people have been involved as volunteers of Foundation Care4BrittleBones. They are active in raising awareness, in supporting research, in raising funds and last - but not least – running the activities of our foundation. 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 2020 Foundation Care4BrittleBones and VOI worked together successfully on several projects, especially on the Key4OI Compass project, the Key4OI Plus project and the "Living with OI" project.

#### **National Patient organisations internationally**

Through the introduction of Care4Bones.org, we have engaged with many national Patient organisations. This has helped to strengthen the connections, and the large majority are looking forward to working together. The organisations who don't have an established infrastructure around OI are particularly expected to benefit from the collaboration.



## 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 30 member organisations. 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 2020, 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 2020, they continued to develop their network and mature their working processes. Twenty-four 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 2020 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:** We are connected to the Dutch OI Group, a group of 15 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), the University Medical Center of Amsterdam 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 2020 all gatherings were cancelled due to the COVID-19 Pandemic.



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 VIA MULTIPLE MEANS

We are using a multi-channel approach for engaging our communities. The main goals are to create and continue solid foundations and create impact, engagement & awareness. We strive for integration of all platforms and support research, fundraising and collaboration where possible. Below is an overview of our various channels.

**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.

Care4BrittleBones aims to improve the quality of life of people with Brittle Bones Disease



Osteogenesis Imperfecta (OI) ▾

Research ▾

Care4BrittleBones ▾

Information Platform

Donate

Contact



I am Chedda  
and I have **OI**

### Newsletter

During 2020 we have sent out 11 newsletters about a variety of topics. They reach 1.544 healthcare providers, researchers and people in the OI community.

### Instagram & Facebook

We started an Instagram account in 2019, and it has proven to be successful already. We experience engagement and positive feedback with our community. By sharing our Instagram posts directly to Facebook, we reach an even bigger audience. Facebook



remains a separate channel for less visual messages and communication within (closed) groups such as “Ouders met OI” or “Parents with OI”.

#### **Twitter**

Care4BrittleBones also has a twitter account, from which information that is posted from Instagram/Facebook is also shared.

#### **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.

#### **Care4Bones.org (through Foundation Care4Bones.org)**

As mentioned previously a new separate but related communications channel has been opened by Foundation Care4Bones, enabling direct communication and engagement across researchers, healthcare providers and people with OI.





# FINANCIAL REPORT

## SUMMARY OF FINANCIAL RESULTS INCLUDING EXPLANATION

Our financial results for 2020 were heavily impacted by the Covid-19 situation. While we were unaware of the major consequences this would have on our finances, we did go through a scenario planning exercise at the start of 2020 to make sure our financial situation would be robust in positive and (severely) negative scenarios. In our budget for 2020 we allocated an ambitious amount for the 2020 Research Proposal round. Due to lower income, we were only able to fund one research proposal. We hope to provide financial support for an additional project from the basic research round at a later stage. However, the lower spent on this research round has helped us to limit the negative amount of our balance of income and expenses to a responsible level. Still, most of our (financial) resources continued to be geared to research support or research projects.

With our income severely impacted by the Covid-19 situation and lower than planned spend on research, the ratios of Fundraising and Management costs versus our total expenditure have gone up vs. previous years. In absolute terms, these costs remain roughly flat against 2019 though. Still, Fundraising and Management expenditures are now 9% and 11% respectively of total spend in 2020, compared to 4% and 2% in 2019. Even with these increases, our overhead costs remain consistently and considerably lower than the recommended threshold of 25% for charities in the Netherlands.

### Income

As mentioned, we struggled to deliver on planned income: our total income was EUR 112,882 against a 2020 budget of EUR 400,000. This was largely due to the Covid-19 impact, in particular when it comes to income from trust funds and from charity events.

We were happy to have the continued support from individual contributions to our foundation. We'd also like to mention that a significant part of the donations from non-profit organisations came from a sponsor that was initially focused on a project that got cancelled in 2019 (leading to a -/- EUR 80.000 reversal in 2019). Despite the project being cancelled, the sponsor committed a part of the original amount to us in 2020 (EUR 32.000), recognizing the progress that had been achieved towards the goals.

### Spend on Purpose

The Spend on Research projects and other purpose-related activities (eg providing information about research and supporting knowledge sharing) of EUR 134,068 (79% of the total spend) is significantly below the 2020 budget of EUR 389,515. As mentioned in the introduction of this chapter, this mainly relates to lower spend on the basic research proposal round. The underlying reason for this was solely the availability of funding (income). We would have loved to sponsor additional research projects, since many submissions were of very high quality. Sadly, we were not able to do this at this moment in time.



## Fundraising

The cost of fundraising of EUR 19,166 has been significantly lower than the 2020 budget of EUR 32,500 mainly due to a decrease in the number of and size of fundraising events. This was again very much a Covid-19 effect.

## Management & Admin

The 2020 budget of EUR 19,570 has been underspent mainly thanks to many small savings, like lower travel and communications costs.

## Financial Position

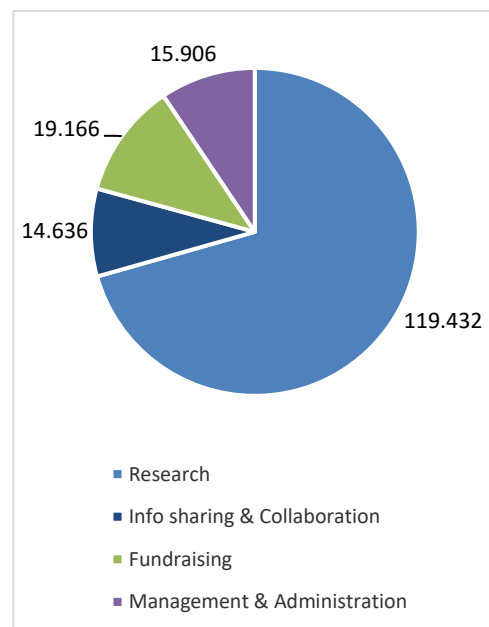
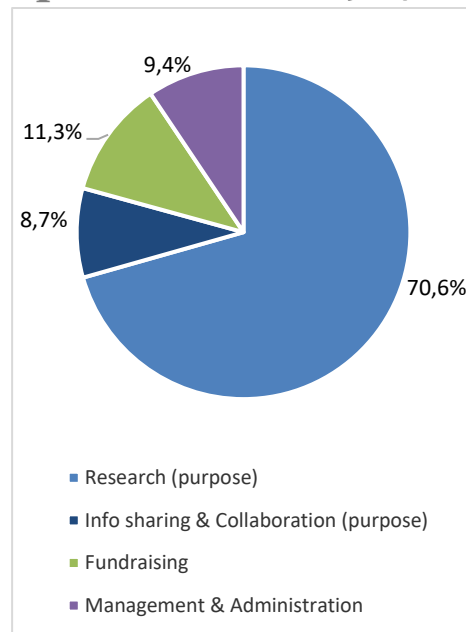
The financial position of the Foundation is still solid, despite strong headwinds, during 2020. Since we aim to spend as much of our funds on our purpose as we can, while keeping the foundation financially sound, we budgeted for a negative result in 2020. For the reasons explained above, the actual result was slightly more negative.

Our Contingent Reserve has reduced significantly, as expected. It is now back in line with the board's ambition to keep an uncommitted reserve of ca EUR 50.000 to ensure continuity of operations and financial stability. The Contingent Reserve is more than sufficient to cover known, but not earmarked, commitments in 2021.

## KEY NUMBERS

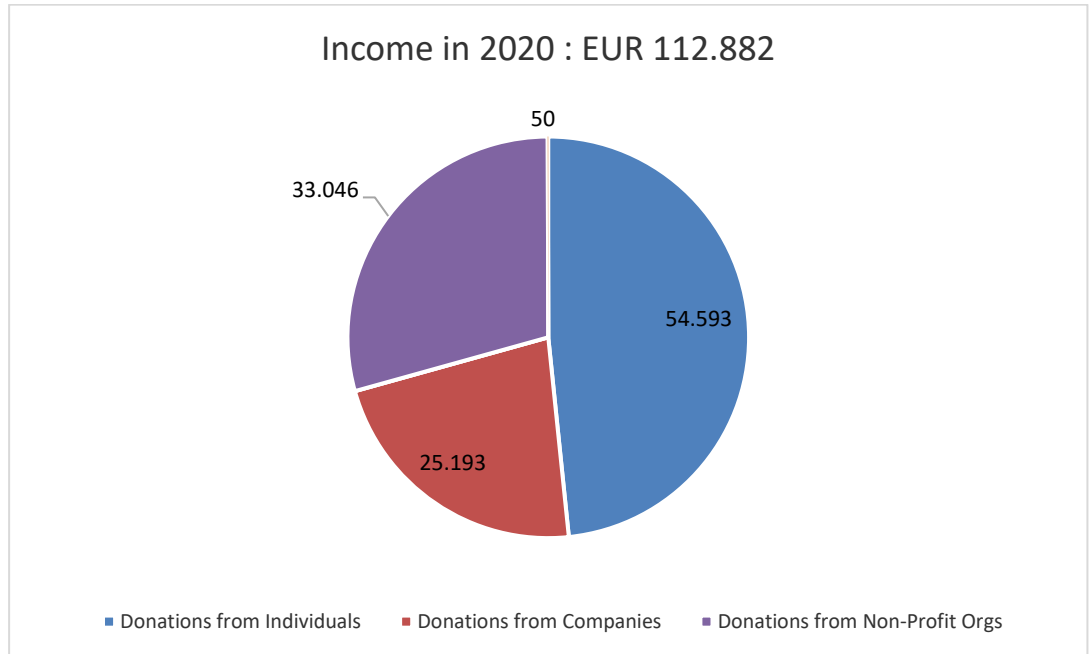
### How did we spend your contribution?

**Spent in 2020: €169.140**





## What are the sources of income to fund research for OI?





## BUDGET 2021

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. Given the limited financial room in our Other Reserves on our balance sheet, the Foundation has prudently budgeted to spend slightly less than the income it generates. This means that the 2021 budget approved by the Board aims for a positive result of EUR 1.730.

### Income

For 2021 we have not projected a return to pre-COVID-19 days. Given the uncertain outlook, we projected the same level of income as that of 2020. We continue our focus on generating income from non-profit organisations and individuals. Should we be able to generate more income, we have nominated a second proposal from the 2020 Basic research proposal round that we might fund.

### Expenses

#### Foundation Goals

Given the limited availability of funds, we do not aim to fund new research in 2021, but intend to only fund ongoing activities, such as further Key4OI work and supporting ongoing research. Compared to 2020 we intend to spend a larger part of our funding on goals on information sharing. This relates to the setup of the new C4B platform. This means the percentage of spend on Foundation Goals is expected to be 80%. Though this is a slight decrease from 2020, it requires significant reductions in the fundraising and management & admin activities.

#### Fundraising

The absolute level of fundraising costs is expected to come down by more than half against 2020 actuals. This mainly translates to less time spend by our director on these activities. This allows us to keep the share of fundraising costs as part of our total costs at 7%, flat against 2020 budget and significantly below 2020 actuals (11%). This is a painful measure to balance the budget and would be a category to increase if income permits since we believe more time spend on fundraising will generate positive outcomes.

#### Management & Admin

The cost of Management & Admin is expected to reduce against 2020 actuals in absolute terms. However, due to fixed costs for memberships, IT, communications, insurance, etc. we cannot reduce these costs proportionately to the rest of the budget and hence the share of Management & Admin costs is expected to increase from 9% in 2020 actuals to 12% in 2021.



## Budget 2021 (continued)

<b>Income &amp; Expenses</b>	<b>Budget 2021</b>	<b>Actuals 2020</b>	<b>Budget 2020</b>
Income from Associated (international) Organizations			
Income from other Non-Profit Organizations	70.000	33.046	200.000
<b>Total Acquired Income</b>	<b>110.000</b>	<b>112.832</b>	<b>400.000</b>
Income as compensation for the delivery of:			
- Products and/or Services			
- Other income		50	
<b>Total Income</b>	<b>110.000</b>	<b>112.882</b>	<b>400.000</b>
<b>Expenses</b>			
<b>Spent on Goals</b>			
- Research	55.805	119.432	377.015
- Information sharing & Collaboration	31.274	14.636	12.500
- Other	-	-	-
	87.079	134.068	389.515
<b>Fundraising costs</b>	<b>7.856</b>	<b>19.166</b>	<b>32.500</b>
<b>Management &amp; Administration costs</b>	<b>13.335</b>	<b>15.906</b>	<b>19.570</b>
<b>Total Expenses</b>	<b>108.270</b>	<b>169.140</b>	<b>441.585</b>
<b>Balance before Financial Income &amp; Expenses</b>	<b>1.730</b>	<b>-56.259</b>	<b>-41.585</b>
Balance Financial Income & Expenses			
<b>Balance Income &amp; Expenses</b>	<b>1.730</b>	<b>-56.259</b>	<b>-41.585</b>





## FINANCIAL STATEMENTS 2020

### Income Statement

Income & Expenses	Actual 2020		Budget 2020	
	EURO	EURO	EURO	EURO
<b>Income</b>				
Income from Individuals		54,593		70,000
Income from Companies		25,193		120,000
Income from Lottery Organizations				
Income from Grants from Government				10,000
Income from Associated (international) Organizations				
Income from other Non-Profit Organizations		33,046		200,000
<b>Total Acquired Income</b>		<u>112,832</u>		<u>400,000</u>
Income as compensation for the delivery of:				
- Products and/or Services				-
- Other income		50		
<b>Total Income</b>		<u>112,882</u>		<u>400,000</u>
<b>Expenses</b>				
<b>Spent on Goals</b>				
- Research		119,432		377,015
- Information sharing & Collaboration		14,636		12,500
- Other		0		-
		<u>134,068</u>		<u>389,515</u>
<b>Fundraising costs</b>		<b>19,166</b>		<b>32,500</b>
<b>Management &amp; Administration costs</b>		<b>15,906</b>		<b>19,570</b>
<b>Total Expenses</b>		<u>169,140</u>		<u>441,585</u>
<b>Balance before Financial Income &amp; Expenses</b>		-56,259		-41,585
Balance Financial Income & Expenses		0		0
<b>Balance Income &amp; Expenses</b>		<u>-56,259</u>		<u>-41,585</u>
<b>Assignment Balance Income &amp; Expenses</b>				
<b>Addition to / Withdrawal from:</b>				
- Other Reserves		-74,816		
- Earmarked Reserves		40,085		
- Earmarked Funds		-21,528		
		<u>-56,259</u>		

### Balance Sheet

	Notes	31-Dec-20		31-Dec-19		31-Dec-18	
		EURO	EURO	EURO	EURO	EURO	EURO
<b>Assets</b>							
Receivables & Accrued Assets	1	108,716		253,574		200,996	
Cash & Cash Equivalents	2	<u>267,571</u>		<u>259,930</u>		<u>394,254</u>	
			376,287		513,504		595,250
			<u>376,287</u>		<u>513,504</u>		<u>595,250</u>
<b>Liabilities</b>							
Reserves & Funds							
- Reserves							
- Earmarked Reserves	3	60,500		20,415		118,200	
- Other Reserves	3	<u>46,670</u>		<u>121,533</u>		<u>48,166</u>	
			107,170		141,948		166,366
- Funds							
- Earmarked Funds	4		<u>79,931</u>		<u>101,459</u>		<u>191,048</u>
			187,101		243,406		357,414
Long Term Debt	5		22,100		100,358		75,000
Short Term Debt	6		<u>167,086</u>		<u>169,740</u>		<u>162,836</u>
			<u>376,287</u>		<u>513,504</u>		<u>595,250</u>



## Cashflow statement

	2020	2019
<i>Cash collected from:</i>		
donations	102,668	196,162
Income from Grants from Government	100,776	96,707
Income from other Non-Profit Organizations	54,246	2,544
Products & Services	-	93,345
Interest received	50	103
<b>Total cash collected</b>	<b>257,740</b>	<b>388,861</b>
<i>Cash paid for:</i>		
Research projects	207,720	497,713
Sponsoring events		
Governance costs	23,166	4,771
Fundraising activities	19,166	20,702
<b>Total cash paid</b>	<b>250,052</b>	<b>523,185</b>
<b>Net cash from operations</b>	<b>7,688</b>	<b>(134,324)</b>
<b>Cash Balance:</b>		
	<b>2020</b>	<b>2019</b>
Opening balance ABN AMRO, SNS & Paypal	259,930	394,254
Opening balance ABN AMRO, SNS & Paypal	267,618	259,930
<b>Net cash from operations</b>	<b>7,688</b>	<b>(134,324)</b>



## | NOTES TO THE ACCOUNTS

### General

The consolidated financial statements for 2020 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***

### General

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 times the annual costs of the organization. Based on the 2021 budget, a contingent reserve of a maximum of EUR 102,270 will follow as of 31 December 2020. The realized balance Other Reserves of ca EUR 46,670 is well within the threshold set by the Association Board and around the minimum threshold of EUR 50,000 the Board set.



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

	<b>2020</b>	<b>2019</b>
	<i>EURO</i>	<i>EURO</i>
<b>Receivables &amp; Accrued Assets</b>		
Receivables from Individuals	-	1,280
Receivables from Companies	8,700	30,302
Grants from Government	84,646	185,422
Interest		
Receivables from Non-Profit Organizations	15,370	36,570
<b>Total</b>	<b>108,716</b>	<b>253,574</b>

### Note 2

	<b>2020</b>	<b>2019</b>
	<i>EURO</i>	<i>EURO</i>
<b>Cash &amp; Cash Equivalents</b>		
ABN AMRO Current Account	22,922	16,079
ABN AMRO Savings Account	143,951	143,949
SNS Bank Savings Account	99,903	99,903
PayPal	795	
<b>Total</b>	<b>267,571</b>	<b>259,930</b>

### Note 3

	<b>2020</b>	<b>2019</b>
	<i>EURO</i>	<i>EURO</i>
<b>Earmarked Reserves</b>		
balance 1/1	20,415	118,200
Additions	60,500	3,415
Withdrawals	-	-101,200
<b>Balance 31/12</b>	<b>60,500</b>	<b>20,415</b>

### Note 4

	<b>2020</b>	<b>2019</b>
	<i>EURO</i>	<i>EURO</i>
<b>Other Reserves</b>		
balance 1/1	121,533	48,166
Additions	41,943	292,249
Withdrawals	-	-218,882
<b>Balance 31/12</b>	<b>46,717</b>	<b>121,533</b>

*The Additions relate to the closing of obligations for closed and cancelled projects. Withdrawals concern the balance of Income & Expenses for 2020 after movement in the Earmarked Funds.*





Note 5

<b>Earmarked Funds</b>	<b>2020</b> EURO	<b>2019</b> EURO
balance 1/1	101,459	191,048
Additions	-	101,459
Withdrawals	- 21,528	-191,048
<b>Balance 31/12</b>	<b>79,931</b>	<b>101,459</b>

*The withdrawals are related to movements in commitments for the Key4OI Kompas and the pilot Blockchain projects..*

Note 6

<b>Long Term Debt</b>	<b>2020</b> EURO	<b>2019</b> EURO
Project Commitments	22,100	100,358

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

Note 7

<b>Short Term Debt</b>	<b>2020</b> EURO	<b>2019</b> EURO
Project Commitments	167,086	142,416
Creditors	-	27,324
<b>Total</b>	<b>167,086</b>	<b>169,740</b>

*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		Fundraising costs	Management & Admin	Total Actual 2020	Budget 2020	Total Actual 2019
	Research	Information sharing & Collaboration					
Project contributions	2,850	160			3,010	277,804	83,776
Outsourced work	67,915	0	6,119		74,034	57,091	376,574
Remuneration of director	48,667	14,476	13,047	10,930	87,120	87,120	87,120
Office and general costs				4,976	4,976	19,570	7,977
<b>Total</b>	<b>119,432</b>	<b>14,636</b>	<b>19,166</b>	<b>15,906</b>	<b>169,140</b>	<b>441,585</b>	<b>555,447</b>



## PROJECT OVERVIEW– SPENT ON GOALS

Year	Project title	Category	Lead Country	Institution	Lead researcher	Status	Project Committed 1/1/2020	movement in commitment 2020	Total Commitment 31/12/2020	PY Paid/reserved	Outstanding 1/1/2020	CY Paid/reserved	Directors' remuneration 2020	Total paid to date	Outstanding to be paid 31/12/2020
No contract	Vitamin K	Clinical research	Netherlands	Wilhelmina Kinderziekenhuis	Bee Zver and Alie van Dijk	Ongoing	10,000	0	10,000	0	10,000	0	0	0	10,000
2017-0111	Towards a therapy for OI - Next Steps	Basic science	Netherlands	Isala UMC Groningen	Fleur van Dijk	committed	156,600	0	156,600	50,000	106,600	50,000	0	100,000	56,600
2017-0012	Eat, breathe, sleep with OI	Clinical research	Italy	Politecnico di Milano Dipartimento di Elettronica	Antonella Lo Mauro	completed	35,000	-5,000	30,000	15,000	15,000	15,000	0	30,000	0
2018-0116	Quality of life for children with OI and Research Priorities		UK	Sheffield Children's NHS foundation	Claire Hill and Nick Bishop	completed	10,326	0	10,326	5,000	5,326	5,326	0	10,326	0
2018-0117	Key4O - Outcome measures for adult OI	basic science	Netherlands	Isala	Anton Franken, Gius Janus, Ralph Sakkers	completed	30,000		30,000	13,000	17,000	17,000	0	30,000	0
2019-020	OI Variant Database		UK	University of Leicester	Raymond Dargleish	completed	3,415	0	3,415	0	3,415	3,415	0	3,415	0
2019-021	Key4O Kompas		NL	Care4BB		committed	201,546	0	201,546	10,067	191,479	43,778	19,383	73,228	128,318
2019-022	Biochain pilot voor Other research projects		Netherlands			committed	15,000	0	15,000	927	14,073	8,700	2,353	11,980	3,020
2020-023	Sweetbones		Netherlands	UMCG	Roud Bank	committed	0	60,500	60,500	0	0	0	41,407	41,407	0
	<b>Total Projects</b>						<b>461,887</b>	<b>55,500</b>	<b>456,887</b>	<b>99,994</b>	<b>362,893</b>	<b>143,219</b>	<b>63,143</b>	<b>300,356</b>	<b>197,938</b>
	<b>Overall Total</b>						<b>461,887</b>	<b>55,500</b>	<b>456,887</b>	<b>99,994</b>	<b>362,893</b>	<b>143,219</b>	<b>63,143</b>	<b>300,356</b>	<b>197,938</b>



## 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 (2 years)
Hours	40/week
Parttime percentage	100
Period	1/1/2020-31/12/2020

Annual remuneration (gross)	87,120 *
Vacation payment	-
Year-end payment	-
Compensation holidays not utilised	-
<b>Total</b>	<b>87,120</b>
Taxable reimbursement	-
Pension payments (Foundation)	-
Pension compensation	-
Other long term remuneration	-
End of Service payment	-
<b>Total</b>	<b>87,120</b>

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

*The assessment of the circumstances of C4BB is done annually by the Board. The assessment over 2020 led to a so-called BSD-score of 310 points with a maximum annual income of EUR 88.928,- 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 108.492 (1 FTE/12 months). The total remuneration of the Director (self employed) of EUR 87.120 remains within this maximum. It should be noted that it also falls within the job grade D which was the outcome of previous assessments.*

*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

### 2020 control statement:

The Auditing Committee in the person of Ms. E.L. Koster and Mr. R. Le Grand have on Saturday 15<sup>th</sup> May 2020, in the presence of Treasurer Mr. D.J. Stegink and Mrs. I Juzwa-Parus checked the books of the Care4BrittleBones foundation for the financial year 2020.

The Committee states that:

- The Annuals Accounts give a correct representation of the income and expenses for the year 2020.
- The balance sheet as at 31 December 2020 give a true and fair view of the Reserves.

Den Haag, June 25<sup>th</sup> 2020

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 research, working in hospitals, universities and other health related institutions around the world. We explicitly include in this also our partners in the 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 take away pain and fractures. Your work gives us hope for a better future.

And of course – a big thank you everyone who support 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>