OI IN NUMBERS

THE SHATTERING TRUTH

0.5 MILLION
people worldwide have OI
(Belgium: 700; Germany: 5,000; France and Italy: 4,000 each; Netherlands: 1,000; Switzerland: 500)

190,000 FRACTURES
are estimated to occur amongst people with OI each year, often followed by surgery and months of physical therapy.

50,000 BABIES
Worldwide are born each year with OI

Some children break one of their bones 10 TIMES A YEAR
People worst affected with OI break over 200 TIMES IN A LIFETIME

0 MEDICATION
has been developed specially for OI

WORKING TOGETHER FOR STRONGER BONES

550 VOLUNTEERS
active for Care4BrittleBones

900 RESEARCHERS
working with OI worldwide

25 FUNDRAISING EVENTS
organised in 2017 by Care4BrittleBones and its network

471,000 EUR
of funds raised in 2017

190,000 EUR
spent on our purpose (research and information/collaboration)

216,000 EUR
in addition allocated to specific research projects starting in 2018

90 RESEARCHERS
working with OI worldwide

21 VOLUNTEERS active for Care4BrittleBones

25 FUNDRAISING EVENTS organised in 2017 by Care4BrittleBones and its network

550 VOLUNTEERS active for Care4BrittleBones

900 RESEARCHERS working with OI worldwide

25 FUNDRAISING EVENTS organised in 2017 by Care4BrittleBones and its network

471,000 EUR of funds raised in 2017

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2017 - a year of big change and bigger impact

We started the year knowing it would bring important changes for the Care4BrittleBones foundation. Care4BrittleBones was set up in 2012. In the past 5 years we have established strong ways of working which enabled us to fund unique new research projects every year. But we also realised that this would not be sufficient to achieve our statutory objective: to improve the quality of life of people with OI. It would take a significant change in our ways of operating or else we would likely plateau at around €100.000 of funding each year driving some change but not creating a transformational impact.

We used 2017 to consider our learnings from the past 5 years and to look forward to what we really want to achieve: making a significant difference to the quality of life of people with OI. A difference people with OI can feel. Very quickly we realised that to make this happen we needed to change ourselves by working much more intensely with researchers, with the OI community, their network, our donors and sponsors in order to achieve this greater impact. Hence we had to find ways to raise significantly more funding for larger, more strategic and more international research projects.

Mid 2017 we decided to rise to the challenge and ensure that our foundation has a chance to achieve more impact. From that moment on we have evolved our approaches in all areas and documented them in a multiyear plan to guide our work with researchers, donors, funding institutions and the OI-community.

In addition, we decided to remodel the foundation to a 1 tier board including a professional director position. This change involved appointing a new Chairperson and Vice-chairperson. The previous board with five dedicated volunteer board members supported this change whole heartedly. New statutes and an enlarged and strengthened ‘core team’ as well as joining Goede Doelen Nederland and attaining CBF certification were other visible changes we have implemented on our journey towards becoming a truly professional foundation.

All of the above resulted in two main highlights of our work in 2017:

1.) We have spent €190.000 on research and have allocated a further €216.000 to specific research projects (ie €406.000 in total for research in 2019). The two largest projects are related to innovative gene–editing technology (CRISPR-CAS) and to psychosocial aspects of OI. This is more than four times as much as in 2016.

2.) Funds raised were €471.000 thanks to the generous support from donors, events such as the Unbreakable Spirit Gala (see page 25) and from trust funds. We are particularly grateful for a first public subsidy received by the Dutch ministry of Health (ZIN, Zorginstituut Nederland). The total amount raised is five times more than in 2016.

2017 has turned out to exceed all of our expectations and has given us much hope for the journey ahead. As long as it still may be, we will continue to make a difference for people we support and we are on the move; with bigger steps, more energy than ever and a faster pace towards a better future for people with OI.

We are very grateful for the support and trust in this year of big change! On behalf of the outgoing and new board of Care4BrittleBones: our sincere thanks for this important year for OI Research.

Graham Marshall
Chairman

Dagmar Mekking
CEO / Executive Board Member
Why we are supporting Osteogenesis Imperfecta (OI)

Brittle Bone Disease, also called OI, is a genetic bone condition that affects the connective tissue in 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. From ‘a few more fractures than normal’ to more than 200 fractures in a lifetime, a small impact can have big consequences for people with OI. Other symptoms include deformities, chronic pain, scoliosis, short stature, hearing and dental problems as well as severe breathing and heart issues.

OI is a purely physical disorder. 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 lighter 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 have a significantly reduced life expectancy.

Children are most heavily affected. Some children will have a fracture every few weeks, undergo 20 surgeries or more at a young age and spend half of 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 known for more than 100 years. However until today there is no treatment that fundamentally addresses the disease. The key approaches used today are ‘hand–me–down medications’ from other related diseases, e.g. Osteoporosis. These medications treat some of the symptoms, for example by making the bones harder (using Bisphosphonates). But whilst they clearly have benefits, they also come with potential adverse side effects. Moreover their long-term effects are unclear. Most strikingly 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). As for many other rare diseases, hardly any funding for research is available to change the status quo.
It is time to change what is holding back progress. We are keen to put the urgently needed support in place to address the challenges of OI in a strategic way. The key reasons for pushing forward now:

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 disease. Distributed around the world they previously worked mostly in isolation.

3. **Big data** for small diseases is coming within reach. Genetic testing has become accessible more widely and cheaply than ever before. Over time this will allow us to look at ‘scientific mysteries’ like the discrepancy between Genotype and Phenotype. The largest research ever done in OI addressed less than 3000 people. Significantly larger cohorts will be possible, enabling new insights on patterns and stronger research; just 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 still significant areas in the bone metabolism which are 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 been recognised by forming the European Reference Network for Rare Bone Diseases and the US-Canadian Brittle Bone Diseases Consortium. OI within both groups is clearly standing out as the top priority research area amongst the circa 450 rare bone diseases that exist.

These conditions create new opportunities for OI research. Care4Brittlebones has identified various short, mid and long term opportunities that have the potential to ameliorate quality of life for people with Osteogenesis Imperfecta and eventually to lead to a breakthrough therapy for OI.
Care4BrittleBones Organisation

Care4BrittleBones is an organisation dedicated to enabling a better quality of life for people with OI through research. It is an international charity with roots in the Netherlands. Founded in 2012 by family and friends of a child with OI (Dagmar and Peter Mekking and Jacqueline Hornman), the foundation has quickly grown to become the biggest fundraising organisation for OI research in Europe.

The Care4BrittleBones Organisation consists of five groups/teams which are crucial for input, advice, and carrying out Care4BrittleBones’ activities:
1. The Care4BrittleBones Board
2. The Care4BrittleBones Core Team
3. The 2 Advisory Boards
4. Our Ambassadors
5. Our Network Partners (country patients organisations)

1. The Care4BrittleBones Board

In 2016 and until 22 September 2017 our board consisted of five board members:
- Dagmar Mekking, Chairperson and Secretary
- Peter Mekking, Vice-Chairman
- Piet van Erk, Treasurer
- Jacqueline Hornman–Huberts
- Dieuwke Swain, PR and Communications

All of the board members worked as volunteers.

Throughout the first half of 2017 following internal reviews we have changed our board to a 1-tier board supported by completely updated statutes aligned with recommendations for the sector of charitable organisations in the Netherlands “Goede Doelen Nederland”. The Chairperson and Vice-chairperson were appointed by the previous board. The treasurer has continued his service in the new board. Dagmar Mekking has been selected as director / board member following an independent and open application process.

Graham Marshall
Chairperson/Secretary

Aleksandra Wrobel
Vice-Chairman

Piet van Erk
Treasurer

Dagmar Mekking
Director
2. The Care4BrittleBones Core Team

The activities of the foundation are coordinated and carried out by the core team, which consists of 12 people, including the board. The Core Team acts as an extended Board. They define the strategy and operational plans, set and manage standards for fundraising and research (contracts and contract management), drive communications and PR within and beyond the OI community, 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 the following sectors: IT, Finance, Fundraising, Communications & PR and Learning/Capability Building. They all have significant experience working internationally and across different cultures. The core team comprises nationals of Germany, Latvia, Poland, The Netherlands, UK. They meet face-to-face on a monthly basis to discuss all matters concerning the foundation. The core team also has formed various subcommittees to put the plan into actions, measure effectiveness and capture learnings continuously.

| Finance: | Piet van Erk, Iwona Juzwa-Parfus |
| Fundraising | Graham Marshall, Dagmar Mekking, Lieke Mekking, Ambika Lucassen |
| Communications | Aleksandra Wrobel, Lieke Mekking, Ilse Balvert, Jennifer Leeuw, Peter Mekking |
| IT/Knowledge Mgt: | Peter Kemper |
| Research/OI-Community | Graham Marshall, Dagmar Mekking, Lieke Mekking, Sigita Zideluna |

Black = board member and core team member
White = core team member
3. The Advisory Boards

All 14 Advisory Board members have been chosen carefully 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 is composed of a variety of relevant disciplines with expertise in genetics, endocrinology, bone metabolism, paediatrics and rehabilitation. 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 members of the OI Advisory Board have OI themselves and have a good general knowledge of the disorder as well as a broad network.

The Advisory Boards advise us on which research projects we should prioritise. We also ask their steer on Research Strategy and communication about research.

- The Scientific Advisory Board

  Fleur van Dijk
  Genetics
  Expertise Center for Adults Isala, UMC Groningen, North West Health Care
  London
  NL/UK

  Oliver Semler
  Paediatric Endocrinology
  Children’s Hospital
  University of Cologne
  GERMANY

  Outi Mäkitie
  Paediatric Endocrinology
  Children’s Hospital
  University of Helsinki
  FINLAND

  Lena Lande Wekre
  Senior Consultant, Rehabilitation, TRS
  National Resource Centre for Rare Disorders
  NORWAY

  Lars Folkestad
  Endocrinology
  University of Southern Denmark (Odense)
  DENMARK

  Marianne Rohrbach
  Endocrinology
  Children’s Hospital, Department of Molecular Medicine, Biochemistry Unit
  University of Zurich
  SWITZERLAND

  Antonella Forlino
  Genetics
  Department of Molecular Medicine, Biochemistry Unit
  University of Pavia
  ITALY

- The OI Advisory Board

  Margriet Crezee
  VOI
  NL

  Ute Wallentin
  DOIG
  GERMANY

  Eero Nevalainen
  ERN-BOND
  EPAG

  Rebecca Tvedt
  SVOI/ASOI
  SWITZERLAND

  Karsten Jensen
  SVOI/ASOI
  SWITZERLAND

  Therese Stutz-Steiger
  ASITOI
  ITALY

  Leonardo Panzeri
  ASITOI
  ITALY

The Scientific and OI Advisory Board members and ways of working will be updated before the start of the next proposal round in 2019 to reflect the broader international spectrum covered by Care4BrittleBones and to demonstrate our partnership with national patient organisations.
4. Our Ambassadors

Our ambassadors are people who are completely convinced of, and committed to, the need to generate funding for OI research. Most of them either have OI themselves or have a relative with OI, and therefore know first-hand how impactful OI. We are open to anyone around the world who cares for this group of people and would like to support Care4BrittleBones by raising awareness and funding for research into OI (e-mail to dagmar.mekking@care4brittlebones).

Leonie Rouweler  Danielle de Bakker  Irma van der Hoek  Jessy van der Pol  Rene van der Rijst

Diana Lips  Annemarie Visser and Kris Koenis  Marijke van Liempt  Welmoed Santema  Rob en Rebecca van Berkel

Jeanette Chedda  Mira Thompson  Melvin Elderhorst  Karin Kragt-Vermolen  Chantal Stuiger

Rick Brink  Roos Louwen  Andrea Kiel  Laura Marx  Zuhal Soyan

In addition to the ambassadors above, many children enthusiastically and effectively help us! They intuitively understand how difficult it can be at times to not be able to participate in normal play and sports activities because their body is too fragile. They want to help and are brilliant at successfully involving their schools, sports clubs and friends to support Care4BrittleBones in raising funds for OI research.

Our heartfelt thanks to all of our amazing ambassadors!

More information about the ambassadors and their stories can be found on the Care4BrittleBones website www.care4brittlebones.org
5. Our Network partners
Care4BrittleBones works closely with various patient organisations to ensure we receive input from people with OI into research, we raise funds together and we advocate for research. Care4BrittleBones believes that an active role for people with OI is an important enabler of an impactful research agenda – their willingness to advocate for research, articulate their needs and participate in research is going to make a difference in improving quality of life of people with OI.

We are proud to be associated with the following Patient organisations who are our network partners:

- Belgium: ZOI
- France: AOI
- Germany: DOIG
- Italy: AS.It.OI
- Switzerland: SVOI/ASOI
- The Netherlands: VOI

Patient organisations who are interested to join forces and become a network partner can inquire for more information with dagmar.mekking@care4brittlebones.org
Strategy and ways of working

In 2017 we took the time to reflect on our achievements of the last five years and also to look for areas for improvement when considering our goal of improving the quality of life of people with OI through scientific research. We also looked to the future to identify the main threats and opportunities. As a result we have developed a multi-year plan (2018 – 2020) which transparently describes our assessment of the current status of our organisation and the environment we are operating in as well as the changes that are required to address the threats and opportunities of the future and to deliver on our goal. We have reconfirmed them in completely updated statutes, which were approved and formalised by notary and registered with the Chamber of Commerce in September 2017.

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:
   a. raising funds;
   b. funding research and activities enabling research;
   c. 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;
   d. informing stakeholders by issuing publications.

Whilst the activities have not profoundly changed, we have decided to emphasize our active role in research. As opposed to many other foundations we are not only a fundraising organisation but a coordinator, strategic partner and thought leader in research for OI. This has been documented now more explicitly in point c.

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

We believe that there is a special case for driving change when it comes to OI, based on three simple truths:
   1. The cause of OI is that the body does not produce the right quantity and/or quality of collagen, due to a genetic disorder.
   2. In all human beings – with or without OI – every bone is continuously degraded and regenerated throughout the lifetime.
   3. If we are able to ‘teach’ the body how to produce the right quantity and quality of collagen, this will over time improve bone quality and strength, no matter how old or young the person is.

Care4BritteBones has undertaken significant work in 2017 to develop the start of a research strategy, which is called “OIKOS” - a holistic approach to driving change in research and improving the quality of life of people with OI. In the next three years we will build on the three most important levers and drive strategic actions in the areas of Data, Strategy and Culture.
Care4BrittleBones has established itself as a ‘bridge builder’ to connect the three main groups active in the field of OI Research: the OI patient community, healthcare providers and (pharmaceutical and other) industry. We work actively 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. Increasingly we realise that we need to reach out beyond the OI networks to support related rare bone diseases where we can. This is important for all of us. The bone metabolism still has many ‘blind spots’ that are unknown territory to researchers worldwide.
As our first five year plan (2012 – 2016) had expired, we used 2017 to develop a new long term vision for Care4BrittleBones. This multiyear plan (2018 – 2020) is describing how we intend to work in 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 underpin the long term ambition and operationalise it.

3. Ways of working (compliance and transparency)

We are firmly committed to the highest standards of running a charitable organisation. This relates to every single process, but in particular to the aspect of 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).

We are recognised as charitable organisation in the Netherlands (ANBI status, Algemene Nut Beoogende Instelling).

To demonstrate our standards and ensure we stay up to date on the latest developments for charities we have joined:

- **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 is annually reviewing all key processes of a foundation and testing if they are robust with regard to governance standards and transparency. This provides extra assurance to our donors that we are operating according to strong internal standards.

We have started to work towards implementing the **EU-General Data Privacy Guideline** in 2017 and will ensure full compliance by the implementation date in May 2018.

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, to our fundraising activities and to the way we are interacting with each other and our stakeholders.

**Financial Compensation**

In 2017, none of the board members, core team or volunteers, ambassadors and Advisory Board members received a financial or other compensation except for the Director. The directors remuneration is explained in more detail in the financial report.

The exception is an occasional treat during fundraising activities! (See picture to the right)
As mentioned in the introduction, we started the year knowing it would be decisive for our future. Care4BrittleBones has been set up in 2012, we have worked hard and had established a solid basis and networks that allowed us to fund research projects that would otherwise not have been possible. But we also realised, that –without a significant change in our structures and ways of operating – we would likely plateau at around €100.000 of funds raised each year and a similar amount of small research projects enabled. This would not be enough to truly reach our goal to make a difference for people with OI. Our objective for 2017 therefore was: to deliver the 2017 goals and to re-invent ourselves to deliver significantly more in all 3 areas: Research impact, Fundraising and Network/Reach.

We are confident that we have delivered beyond expectations and plans in almost all areas.

1. RESEARCH:
   a. **Catalyst for Research strategy:** We used 3 important conferences/meetings in 2017 to act as a “catalyst” for a research strategy: ERN BOND meeting in Rome May 2017, ICCBH Würzburg June 2017, OI Oslo August 2017. During the conferences and in between we networked actively with the leading experts in the field bringing them to talk together on topics of shared interest, we gave presentations about research for OI and Care4BrittleBones, facilitated a workshop about the emerging OIKOS strategy, facilitated several meetings related to the physical rehabilitation project and developed a list of possible research priorities. We believe we have generated a very good basis for approaching OI Research strategically and sustainably. We created a “roadmap for change”, but not yet the change itself. More work is required with patient organisations, industry and health care practitioners worldwide to develop a shared vision with concrete priorities.
   b. We conducted our **annual proposal round** on time allowing us to select from a slate of very strong research proposals.
   c. Ahead of the proposal round the **Advisory Board was updated** based on new countries which had joined our network.
   d. We have taken time out to deep dive into our **contract management** processes for research. No major flaws were discovered, however there were learnings (e.g. about delays of projects) and we have seen best practice from other foundations which we wanted to adopt into our ways of working. We have proposed the changes to the Advisory Board and to the Board of Care4BrittleBones. They were adopted and implemented.
   e. Last but not least, we have **increased our Research spend** (including earmarked funding which will be spent in 2018) from €90.600 (2016) to €405.200 (2017). More information about specific projects, see chapter “Making a difference through Research”.

**Goals 2017**

- **OI - RESEARCH**
  1. Effective Catalyst for development of an OI Research Strategy
  2. Proposal round for OI Research Funding
  3. Review and update Advisory Board in line with Strategy
  4. Operational Excellence for Research Grant Process/Contracts

- **FUNDRAISING FOR OI - RESEARCH**
  1. Internationalisation of C4BB including better spread of fundraising across countries
  2. Sustainability: Establish 10% income through long term through partnerships with corporations, funds and “friends of care4brittlebones”
  3. Successful fundraisers, including 1 “signature event”
  4. Fundraising culture: EVERYONE working with Care4BrittleBones is actively supporting fundraising

- **NETWORK & REACH**
  1. Strong and professional organization (review of operating model) / context
  2. Ambassadors: Numbers are growing and ambassadors feel well supported and motivated to be active for OI Research
  3. Increasing awareness and active support for OI – Research from:
    a. the International OI Community
    b. our donors
    c. the scientific world
    d. public
Improvement opportunities, risks and uncertainties in this area:
We have to increase our communication with regard to research in 2018, which was a challenge for us in 2017 given limited resources. Also, as mentioned previously, more work is required to develop a research strategy for OI based on a shared view from the OI Community and embraced by the leading experts worldwide.

2. FUNDRAISING:
   a. **Internationalisation**: in 2017 we have established deeper connections with patient organisations in other countries. This is demonstrated in particular by the fact that several patient organisations have become a Network partner of Care4BrittleBones (see under Care4BrittleBones Organisation). Some of them have started to contribute with their own fundraising or by allowing us to fundraise in their country. This is vital to enable long term sustainability of our efforts. More is needed to ensure that we can continue to fund multicentre/international research projects which make the most impact to quality of life of people with OI and usually run for 2 years at least.
   b. **Sustainability**: we have raised the bar significantly on establishing relationships with donors, trustfunds and other funding institutions. This was enabled by methodically and diligently developing stakeholder relationships and segmenting potential funding organisation based on their goals. Secondly we also enhanced our case for support through the OIKOS strategy and by developing a Multiyear plan for 2018 – 2020. This has resulted in an increase of our long term support of >10%.
   c. **Signature event**: 5 major fundraisers were organised for or by us this year: A concert in Zwolle organised by the Lions Club, a Charity dinner in Hardenberg, a Lions night in Nooddorp-Pijnakker, a classical concert with Top Violinist Jeanine Jansen in Deventer and our first “Unbreakable Spirit Gala”, which took place in a castle in Wassenaar. Together they generated ca €120.000 of revenue for research. The “Unbreakable Spirit Gala” was such a success that we are likely going to repeat and evolve it into our annual signature event.
   d. Directly or indirectly **everyone** in Care4BrittleBones is **involved with fundraising** and is aware of the challenges and the satisfaction that it provides.
   e. **Income from fundraising** has grown significantly from €82.000 (2016) to €470.000 (2017).
Improvement opportunities, risks and uncertainties in this area
We need to continue the momentum of 2017 and (1) ensure we keep delivering on our commitments towards our sponsors/donors, (2) keep learning about new/additional donors / funding institutions, and (3) keep the focus on internationalising the fundraising income in good collaboration with the OI community in other countries to address the sustainability challenge.

3. NETWORK AND REACH
a. We have reviewed and updated our organisational model. The core team was extended and strengthened with important professional skills which we didn’t have before (e.g. IT, Data privacy, capability building, communications) and we have established a sub-team structure that allows the work to be progressed and increasing the focus of the monthly meetings on strategic topic relevant to everyone. “Ready for the next 5 years”.

b. We have again increased the number of our ambassador supporting Care4BrittleBones. We are particularly pleased with new ambassadors in countries outside the Netherlands who are joining us as people in the OI community worldwide are becoming more aware about our contribution to research.

c. We have made positive steps in the area of activating our networks in all communities we work with (researchers, patients, donors) to contribute actively to OI research. The most important success in this area was the establishment of a very motivated and professional group of physical rehabilitation experts / occupational therapists, who have worked together on a Consensus paper for Physical Rehabilitation in children with OI.

Improvement opportunities, risks and uncertainties in this area:
The main area for improvement is our regular communication through newsletters and research updates. Due to a resource discontinuity, this area has been too silent for too long in many ways, except for communication related to the change of our model, communication and engagement with our ambassadors and the engagements with researchers which were very well received. Also we did not develop a new poster campaign as the sponsoring advertising agency decided against continuing to provide free publicity. We are considering how to pick this up again in 2018.
4. Change Management / New model 2017

The most important change we made in 2017 was related to the transformation of our Foundation. The transformation process ran almost throughout the entire year.

- **Inquiry phase**: we started with asking feedback and input from our ambassadors, advisory boards, patient organisations on national and regional level (i.e. OIFE and OIF) as well as selected donors. We also reached out to some successful charities such as DON, Stichting Meta kids and ALS who kindly invested into us by sharing their experience with “growing up” as a foundation in NL. We engaged with charity sector organisations Nederland Filantropieland and Goede Doelen Nederland as well as with Centraal Beheer Fondsenwerving (CBF) and the ANBI-team of the Dutch Tax authority to understand the options available to us.

- **Selection phase**: the preparatory phase lasted about half a year and resulted in various options which were compared on the basis of agreed criteria. The new model was not fully crystalized yet but it became clear that a new leadership team would need to be formed with a part-time or full-time director taking care of the day-to-day operations of the foundation. This role was described on the basis of a job description for directors recommended by Goede Doelen Nederland, adapted with the specificities of the position in Care4BrittleBones. In May the community was informed that a director position would be created to enable more bandwidth and more impact for the activities of the foundation. An open selection process was conducted in May and June, inviting candidates to apply to the Director position. The position was advertised using e-mail and social media. This process resulted in the selection of Dagmar Mekking as Director. Given that she was the Chairperson of the board (working fulltime for the foundation since 1 January 2017), the change could not be implemented unless the full board and governance was reformed.

- **Board appointment phase / Statutory update**: based on the information and advice in the first 2 phases, it had become clear that a 1 tier board with 4 individuals would be most appropriate way to govern the foundation, to remain closely aligned with the executive director role and to ensure the director position is sufficiently controlled. Based on the input from the Notary-desk of Goede Doelen Nederland and a review of our organization in terms of strengths, improvement areas today and threats and opportunities tomorrow (SWOT), we developed the final model in the months of July and August. This was followed by appointing the new board, members of which had emerged in conversations between former board members, new board members and the core team. During the entire process, old and new board members remained positive and constructively focused on what would enable the biggest impact for our goals whilst complying with all applicable standards, rules and procedures. We communicated the changes in our model and the newly appointed board members to our stakeholders in August. The new statutes were formally adopted and new board members on seat per 22 September 2017.

- **Implementation and Monitoring phase**: The remainder of the year was used to deliver on our 2017 goals and to take a fresh look at our processes and approaches, given the new team members we were onboarding. We closed this phase out by organizing a team away-day in December to look back on a very successful year 2017 and make plans for 2018. Mid 2018 we will undertake an evaluation of the new model.

From the right/back row: Graham Marshall (Chairman Care4BrittleBones), Lieke Mekking (core team, CT), Peter Mekking (CT), From the right/front row: Piet van Erk (Treasurer), Ambika Lucassen (CT), Aleksandra Wrobel (Vice-Chairperson), Dagmar Mekking (Director),
Making a difference through research

1. Approach: Annual Proposal Rounds

We believe that healthy competition in research leads to better outcomes for people with OI. We have therefore chosen to select which OI research projects receive funding based on “competitive” annual proposal rounds.

At the start of each proposal round Care4BrittleBones engages with its wide, international group of professionals that are involved with OI research by sending out a ‘Call4Proposals’, inviting research proposals to be submitted within a specified deadline. The Call is published on the relevant specialised websites and is sent directly to our network of 900 OI researchers worldwide. In 2017, as in previous years, the scope was very open, enabling virtually all subjects to be proposed (e.g. orthopaedic, genetic, paediatric, psychological, etc.).

After the submission deadline, we presented all proposals to our Scientific and OI Advisory Boards, which help us to make choices that are both the smartest from a scientific point of view as well as meeting the needs and priorities of people with OI. The members of both advisory boards study the submitted proposals and provide recommendations on which proposals Care4BrittleBones should fund. The final decision by the Care4BrittleBones board is heavily based on the advice of the advisory boards.

2. Outcome Proposal Round 2017

We were very pleased to receive 18 very interesting proposals from 12 different countries during the 2017 Grant scheme cycle. Based on the advice of the advisory boards, the following 4 projects were selected in 2017:

1. Dr. Fleur van Dijk / University of Groningen/Isala (The Netherlands): “Towards a therapy for OI – Next steps”: This project is working with very innovative gene-editing technology (CRISPR-CAS 9). A first phase of this project had been funded in 2015-2017. Given the successful completion of the first phase, Care4BrittleBones has decided to also fund the next step which involves testing of the idea in mouse models. Stage 1 already received a subsidy from the Zeldzame Ziekte Fonds for which we are very grateful. Stage 2 is requiring much more funding and was enabled by a combination of funding from the Zeldzame Ziekte Fund, and two other funds as well as our own funding generated by the Janine Jansen Concert and the Unbreakable Spirit Gala. The research is in preclinical stage and is trying to edit the genetic information which is leading to the incorrect production of collagen, the actual root cause of OI. Progress in this area could result in a breakthrough in treating OI in 4-5 years from now. The project will start in September 2018 and last about 2 years.

2. Dr. Antonella Lo Mauro / Politecnico di Milano (Italy): “Eat / Breath / Sleep”: Respiratory problems are the leading cause of death in people with a severe form of OI. This project is taking a scientific look into this subject and trying to measure and improve breathing, sleeping and eating habits of people with OI in the hope to break the vicious circle, ensued by the pathophysiology of OI.
3. Andy Willaert / University of Gent (Belgium): “Assessment of Bone Strength with Zebrafish”:
Testing new medication in animal models is an indispensable way to assure safety of clinical trials before testing new approaches on humans. Recently zebrafish have emerged as a very effective and much faster way to test medication for bones. Andy Willaert from the University of Gent in Belgium, which has a strong reputation in basic research in general, is one of the leading researchers pushing this development. We have supported part of his promising research.

4. Care4BrittleBones / Arjan Harsevoort (Isala) / Iris van Wijk (WKZ, Hoogstraat) / Bea Zoer (VOI) (The Netherlands): “Psychosocial consequences of Osteogenesis Imperfecta”:
OI is a purely physical disorder. Nevertheless there is significant evidence that psychosocial consequences can severely affect the quality of life of people with OI at any stage of life. Examples are depression, burn out, anxiety, feeling of loneliness, etc. This is true for people with OI as well as their close relatives. The project will inventorise what type of issues may be encountered by people with OI and how frequently these issues tend to occur. It will aim to develop suitable interventions to support dealing with psychosocial consequences more effectively. This project has been enabled by a generous grant from Zorginstituut Nederland (ZIN) and will take 2 years. In this project Care4BrittleBones has applied for a grant and is taking the lead of the project overall. The work as such is done very much with and through the 3 key stakeholders for OI, the 2 national expertise centers (For children: WKZ/Utrecht. For adults: Isala/Zwolle) and the Dutch OI Patient organization VOI. The project is coordinated by a project manager from curias.

3. Long term overview of Research supported by Care4BrittleBones (2012 – 2017)
Over the past 5 years Care4BrittleBones has enabled 18 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 changer 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 the complexity of the subject matter. Finalised / Reported out in 2017 or before: ✓
More information for each project can be found here.

Many research projects would be worthwhile highlighting. We have selected the Consensus Paper for physical rehabilitation in children with OI, as it demonstrates a process that we will try to replicate in many other areas: how to create consensus and continuous improvement for a specific aspect of OI.

Why more research for Physical rehabilitation is needed:
Many people with OI are seeing a physiotherapists and occupational therapists on a regular basis. When asking on social media how many hours people with OI are spending on Physiotherapy, the most frequently heard answer was “countless hours”. However there is hardly any research into what physiotherapy can and should accomplish in OI. There is also no information available about what does not work. Essentially most physiotherapists are working with just a few people with OI and are figuring out through “trial and error” what to do and what not. Whilst it is better than nothing, surely a more methodical approach to identify best practices and areas for attention or risk would enable significant improvements.

Approach
Based on this insight Dr Oliver Semler and Brigitte Müller from the University of Köln (Germany) submitted a request in the 2016 Grant proposal round for a large worldwide project to determine the “consensus” for physical rehabilitation in children with OI. Care4Brittlebones provided administrative support to the project to manage the workload where possible. To identify the leading experts worldwide, a survey was conducted amongst the ca. 150 physiotherapists and occupational therapists in the professional database of Care4BrittleBones. Based on a surprisingly strong response rate, it was possible to identify 14 individuals from 12 different countries who clearly stood out from the rest in terms of the long term of experience in working with many children with OI. They were asked to join a worldwide “expert group.” All of them accepted and worked together with Dr Semler and Brigitte Müller they generated the first worldwide OI Consensus Paper. The document is expected to be published in 2018 Q2.

Next steps
From the start our focus for the project was threefold:

a. to create the scientific insights working with the “best of the best” in this field.

b. to ensure these insights are translated into value in the OI community. For this various implementation projects were developed around year-end 2017 which will lead to practical tools and materials (videos / pdfs, etc.) for the OI community to use.

c. to keep our approach evergreen by monitoring the application and learning from these insights.

We have achieved our first goal in 2017 and were privileged to work with outstanding experts from so many different countries who were highly motivated to share their experience. Part of the work were also two very strong patient experts who provided input and kept the experts group focused on what matters to people with OI.

We have created a sound basis for (2) and (3) to follow in 2018 and 2019.
Fundraising by raising fun (and awareness)

1. Approach: Everything is allowed! Just stay true to our values...

When starting the charity, we were warned that raising funds is an extremely frustrating business, where a lot of resilience is required to keep going. We experienced it very differently!

We raise funds through events, products and donations in collaboration with our network of highly engaged volunteers. We operate from a concept of ‘everything is allowed’, as long as the activity is clearly in line with the values of our organisation: Positive, Inspiring and Innovative.

We encourage everyone who is fundraising for us to start by considering their own talents first. What do they love to do? What gives them great energy? This simple approach has led to a range of creative and deeply inspiring FUNdrasing moments, as well as a high satisfaction and even stronger participation from our wonderful volunteer community, many of them including people with OI and their friends and families.

2. Fundraising initiatives 2017

2017 has exceeded all our expectations with regard to fundraising. In total we raised 470,000 Euros. A large part of this amount originates from trustfunds and the subsidy from the Dutch Government related to one of our research projects (Psychosocial consequences of OI). About €150,000 originated from events and activities supported from the OI community. From concerts, to children’s runs, to dinner parties... there were many inventive ways in which enthusiastic fundraisers generated support.

Here we highlight just some of the many fantastic initiatives that took place throughout the year to raise the much-needed funds for research into OI.

Service Clubs in various countries and cities have been tremendously helpful. Rotary, Lions Clubs, Round tables, Ladies Circles... we owe them all!

One example out of many in 2017:

The Lions New Year Concert in Zwolle: The Event was organised in the magnificent theatre of Zwolle and featured various bands, singers and other performers. The best start of the year one could think of! During the event Dr. Guus Janus teamed up with Dagmar Mekking, Chairperson of the foundation, to explain what OI is and why there is a need to enable research. The response was very positive: €12,000. Also one of the people in the audience was so touched, he asked his own Lions Club to organise a concert for us in 2018!
Janine Jansen Concert for Care4BrittleBones (Lebuïnus church Deventer): Absolutely unforgettable was the Charity Concert which took place in September 2017. The evening was organised by a team led by Welmoed Santema, ambassador for Care4BrittleBones and mother of Benthe, who was undergoing challenging spinal surgery around that time. Janine had previously performed a concert for us in 2014 and the foundation was extremely thankful that she was willing to support our cause again this year. This time she invited Pianist Alexander Gavrylyuk and Cellist Thorleif Thedeen to join her for a magnificent evening filled with the emotional music of Shostakovich and Rachmaninov. Hosts of the evening were Wim Hilgeman and Pimm Grooten-Hilgeman, who are closely working with the foundation for years. They guided the audience through a diverse programme of Jazz featuring Jazz singer Mira Thompson accompanied by pianist Giovanni Agosti, a discussion with a scientist from UMC Groningen and a presentation from one of the leading geneticists Fleur van Dijk, an auction skilfully orchestrated by Samuel Schampers as well as an interview with Dagmar Mekking of Foundation Care4BrittleBones. The Lebuïnus – Church was filled with an enthusiastic audience and many supporters and sponsors for Care4BrittleBones. Thanks to the many sponsors, the evening yielded a net income of €30.000. (Photos copyright Adriaan Holsappel)

RUNNING FOR Care4BrittleBones: 2017 was a great year for fundraising through running challenges.
Dam tot Dam run: One of the biggest events each year for our foundation is the Dam to Dam run, where 50,000 participants enjoy the fun challenge of running the famous 16 km course from Amsterdam to Zaandam. Care4BrittleBones has participated with a team of 50 runners, which included 4 parents of children with OI, including our newly appointed Chairman Graham Marshall. The participating runners received a starting ticket and use of a specially designed T-shirt sponsored by www.attitudeholland.nl. The most magical moment was probably when our Care4BrittleBones ambassador Mira Thompson in the middle of the buzzing starting zone of the Dam tot Dam sang “I believe I can fly” to connect everyone to the cause. It worked: the Dam2Dam raised awareness as well as €15000 for much needed OI research.

Beats4BrittleBones: One of the most beautiful running initiatives that the foundation has ever seen was the event of Marieken. She decided to dedicate her very first marathon to people with OI and Care4BrittleBones. She invented a unique way of crowdfunding: http://beats4brittlebones.com/ “Your Track for my track”. She asked people to sponsor a song for her run. She got a huge response from the many people around her who care for her and felt inspired by her run. She raised €4200 for research and agreed to help share her way of raising funds. Through the music and the connection to the goal her run became even more meaningful and inspirational to her and we were inspired by her energy and the amazing response from the community around her.

All the runners who raise funds for Care4BrittleBones do so via geef.nl, one of the leading providers of fundraising websites. Care4BrittleBones has created an account free for anyone to use for fundraising for OI. It is easy! Go to www.geef.nl/en -> Select “start a campaign”-> “For Charity” -> type “care4brittlebones” and the rest will flow from here! On this very user-friendly site, runners can set up their personal action page within just a few minutes. Subsequently, they can share the link to their action page by email and social media with their networks, inviting them to support their personal and charity goal. The website is available in English or Dutch and is also used by Fundraisers for our foundation in other countries.

Want to run with Care4BrittleBones? Send an e-mail to run@care4brittlebones.org and let us know!
Charity Dinner Hardenberg: What a difference 1 person can make… Rick Brink has been connected to Care4BrittleBones for some time. In 2017 he decided to step up his involvement and become an ambassador for our foundation. His plan: to involve everyone in and around his hometown of Hardenberg for a charity dinner to raise awareness for OI and to generate funding for research! He partnered with the Alfa – College and Masterchef Bart van Berkel to create an evening full of culinary delights, networking and entertainment. Rick, who is a very well-respected and popular member of the local council, had invited the political leaders of the town and many other entrepreneurs, officials and friends to enjoy the evening with him. Two representatives of the Isala hospital, national expertise Center for adults with OI, Dr. Guus Janus and Arjan Harsevoort, provided insight into OI, an auction featured diverse items from the Hardenberg community and a video was created especially for the evening.

The evening was a true win-win: Care4BrittleBones was extremely grateful for the awareness and funding that was raised: €13000. And the city of Hardenberg has proven yet again what an incredibly caring and tightly connected community they are. Well done!!

Unbreakable Spirit Gala: the biggest event in 2017 was the Unbreakable Spirit Gala. We organised it for the very first time and involved all our networks and resources. Hosted in the romantic surroundings of Kasteel Oud Wassenaar, the evening featured a mix of entertainment, networking opportunities, and info-tainment in relation to OI.

The TV-presenter Sandra Schuurhof (a.o. Hart van Nederland) facilitated the evening and connected the various components: Guests were welcomed with drinks served in laboratory glasses, two live bands gave a swinging feel to the evening, the dinner was composed by star-cook Pierre Wind who surprised everyone with a creative 4 course meal composed of “ingredients that support strong bones”. One of the most loved parts of the evening was a magic show of Hans Kazan, who appeared together with his son and amazed everyone with his show about “how to make the impossible possible”... just like what our researchers are aiming to do for OI! The scientific context was excellently described by Dr Ralph Sakkers of the Wilhelmina Kinderziekenhuis in Utrecht, National Expertise Center for children with OI. More than 80 sponsors enabled the evening to be organized virtually “at zero cost”, which allowed the proceeds of the evening, a whopping €70.000, to go straight into research.
Communications and networks

OI has no borders. For OI, as for any rare disease, working together collaboratively amongst patients and amongst Health Care Professionals is absolutely essential. Key reasons why this is so important are:

1. To have a sufficient size of cohorts (group of patients) to conduct research
2. To compare results of treatment across different countries. There is not one country that applies the same treatment as another country.
3. To enable large, multinational projects effectively, efficiently and with maximum impact
4. To ensure the insights gained in one country are applied in other locations (in general, only 14% of research lead to change in another location after an average of 17 years!)
5. To cluster funding for maximum impact
6. To learn faster together and improve quality of life for people with OI more with the limited resources that we have. This is true for
   ▪ Working together across the OI Community
   ▪ Working together amongst OI Researchers
   ▪ Working together between OI Community and OI Researchers

These reasons really apply to any rare disease. For any rare disease working together is making “common sense”. Still it is not “common practice” and most rare diseases are mainly worked hard locally with limited resources. This is also still true for OI. Communications and strong networks are important to understand each other, trust each other and learn together.

1. OI Community Networks

In 2017, more than 550 people have been involved in raising awareness and funds for the foundation and the momentum continues to grow.

Care4BrittleBones was originally started due to a call of the Dutch OI organisation VOI (Vereniging OI) to consider what we could personally do to improve the lives of people with OI. Today the VOI and Foundation Care4BrittleBones serve complementary goals: whilst the VOI focuses on supporting each other as an OI community
to “make the best of today” by working with the national expertise centers (Isala/Zwolle and WKZ/Utrecht), Care4BrittleBones aims to bring change and create better opportunities for treatment “tomorrow”.

Care4BrittleBones is present at formal meetings of the VOI twice a year, engages with VOI members through the events and is regularly invited to address all participants during plenary meetings. Likewise, the president of the Dutch Patient organisation VOI, Cindy Wan, is attending the monthly meetings of the Care4BrittleBones core team. They regular share information about our foundation in their Newsletter and are an active participant in various large research projects sponsored by Care4Brittlebones. The connection is positive and strong and we are supporting each other in topics of shared interest.

During 2017, Care4BrittleBones had connections to about 30 national OI community organisations worldwide. Whilst most fundraising activities are organised in the Netherlands at the moment, we are seeing encouraging interest from our network outside of the Netherlands, in particular our network partners in Switzerland, Germany, Italy, Belgium and France. We are offering them help to build fundraising skills which can be beneficial as well for raising funds for their own patient organisation. Our network partners also are providing an OI Advisory Board member, ensuring that research we are funding is truly addressing the needs of people with OI.

We welcome activities from individuals around the world who would like to work together with us to enable more research for OI. Any person from any country can help to raise funds – one-off or long-term. The only requirement for Care4BrittleBones is that any fundraising activity for our foundation is aligned with our core values: Positive, Inspiring and Innovative.

In 2017, Care4BrittleBones continued its role as a supporting member of the OIFE (OI Federation of Europe). The OIFE is the overarching organisation of all European patients’ organisations of OI. Care4BrittleBones actively contributes to OIFE activities and networks and helps to promote collaboration amongst the medical world and people with OI in Europe. In 2017, Care4BrittleBones participated in the OIFE meeting in Warsaw (Poland).

Care4BrittleBones regularly connects with the president of the OIFE, Ingunn Westerheim.

Similarly, Care4BrittleBones is regularly engaging with Tracy Hart, CEO of the OIF (OI Foundation). The OIF is an organisation active in US and Canada since 1970 and very successful in connecting the OI community for peer support and raising funds. They have been investing considerable funding into research for OI over many years and have a tremendous track record in actively engaging the OI Community in the US and Canada and developing high quality, free educational material for various audiences.

To actively support exchange amongst the OI Communities worldwide, Care4BrittleBones hosted a monthly dialogue for OIFE, the OIF and the BBS (Brittle Bone Society, which supports people with Osteogenesis Imperfecta in the UK and Ireland). The meetings covered a wide range of topics, such as engaging our respective communities and working together for more research.
2. **Scientific Networks**

Collaboration in the medical world is paramount for achieving progress in OI research. In 2017, Care4BrittleBones engaged with the following scientific professional contacts:

1. **Annual Grant Scheme**: in 2017 our annual research grant scheme attracted research proposals with OI researchers from Australia, Belgium, Canada, Germany, Hong Kong, China, Italy, Netherlands, Portugal, Spain, United Kingdom and the United States.

2. **Advisory boards: our Advisory Board members come from 7 different countries** (Denmark, Finland, Germany, Italy, Norway, The Netherlands and Switzerland)

3. **ERN-BOND**: 2017 was an important year for rare diseases in Europe as it marked the formal start of the European Reference Networks, coordinated by the European Union, which drives for more collaboration across the 27 member states to support and address rare diseases in general. 24 Networks have been established, each of them focussing 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 top 3 largest of these and has therefore been selected as one of the focus areas of ERN BOND. Care4BrittleBones is having regular exchanges with the ERN-BOND coordinator Luca Sangiorgi and various leaders in the network.

4. **BBDC**: Care4BrittleBones has been invited to join BBDC’s meetings once or twice a year. The main role we are taking with them is to promote collaboration with researchers/Health Care providers outside US/Canada, which they are very open to. We are partnering in this area closely with OIF.

5. **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 Kinderziekenhuis Utrecht (specialising in OI in children), Isala Kliniek Zwolle (specialising in OI in adults) and Vrije Universiteit Amsterdam (specialising in genetic research) as well as the UMC Groningen (molecular biology / gene editing technology).

6. **Workshops and Conferences**: We actively participated in the following international meetings with researchers for OI:
   a. European Reference Network – BOND, Rome – May 2017
   b. ICCBH Würzburg – June 2017, international children’s bone health conference
   c. OI Oslo – August 2017 international OI conference

7. Over the course of the last 6 years, we have established a worldwide database of some 900 OI researchers and Health Care Providers across all disciplines required to support people with OI, 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. We are increasingly asked for help due to our unique knowledge of the extended global network of OI Researchers.

8. Our ‘Call4Proposals’ has again been published online via OrphaNews, one of the main online news channels for the medical world specialised in orphan diseases: [http://www.orpha.net](http://www.orpha.net).

3. **Newsletter**

Since 2013, Care4BrittleBones has sent updates every quarter to its ever-growing support community by means of a newsletter. The name of the newsletter is “Good news from Care4BrittleBones”. It covers all areas of interest; for example, fundraising, research or marketing. Given health challenges with our communications lead in 2017, we just published one newsletter in 2017 and we picked this up again in 2018 in January. We continued to keep the community update through e-mails and social media. Clearly this is an area that requires focused attention in 2018.
Two volunteers with professional communications experience have joined our team to ensure communications is improved in 2018.

4. Website / Social media

We actively engage with our networks through social media and have created an expanding community of people who are interested in our messaging about OI Community events, fundraisers and research activities through our website, Facebook, Linked-in and YouTube channels. Our plan is to provide more free resources (e.g. pdfs, researcher videos, educational material linked to our research projects) through our website to encourage knowledge sharing and learning across the OI community and for Health Care Professionals worldwide. To ensure the website can facilitate easy access to more material for a more diverse community it will be updated in 2018.
FINANCIAL REPORT
Summary of financial results including explanation

2017 has been a year of significant change, growth of income and growth of spend on the statutory purpose of the Foundation. A new governance model has been implemented and an Executive Director has been appointed. Since the start of the Foundation, it had generated around EURO 100,000 per annum (2012-2016). In 2017 the Foundation increased its income to EUR 470,000. Spend on the Foundation’s goals has more than doubled to EUR 190,000 and in addition EUR 215,000 have been set aside as earmarked funds for specific projects confirmed to start in 2018. Where income increased by EUR 388,000, Fundraising and Management expenditure only increased by less than EUR 56,000 compared to 2016, increasing the (potential) spend on the purpose of the Foundation spectacularly.

Income

Overall income of EUR 470,000 has exceeded 2017 budget of EUR 200,000 (+135%) significantly. Growth has been realized via all fundraising channels. Noticeable funding and grants has been received from Zorginstituut Nederland, a Health Insurer and Zeldzame Ziekte Fonds for Earmarked projects. Significant income has been generated via fundraising events: a Gala evening, a concert with Janine Jansen, a charity dinner, the Dam tot Dam run and many other events.

Spend on Purpose

The Spend on Research of EUR 159,000 is slightly below the 2017 budget of EUR 180,000. This amount is excluding EUR 215,000 that has been earmarked by donors and will be spent on specific research projects (together + 119%). Given some of the funding came available late in 2017, contracts still need to be established with research organizations to formalize the commitment towards them. Part of the EUR 215,000 are foundation costs in 2018/2019, as the Foundation is taking an active role to participate, support and lead research projects as well.

Fundraising

The cost of fundraising of EUR 44,000 has exceeded 2017 budget of EUR 27,000 (+63%) due to increase of the number of and size of internally managed fundraising events. Also, the hours spent by the director are higher than anticipated, resulting in a significant increase in income and international collaboration.

Management & Admin

The 2017 budget of EUR 20,000 has been slightly exceeded (+5%), mainly due to legal costs related to the establishment of new Articles of Association of the Foundation and the decision to apply to CBF and Goede Doelen Nederland, in order to confirm and demonstrate our standards around compliance, transparency and professionalism.

Financial Position

The Financial Position of the Foundation has developed positively during 2017. Donations are still largely on an ad-hoc basis, we therefore commit to the funding of new research projects and activities only after receiving cash from donations or firm commitments to receive cash in the near future. The Contingent Reserve (EUR 50,000) is sufficient to cover the committed cost of the organization in 2018.
Key numbers

How did we spend your contribution

- 61.6% Research (purpose)
- 17.3% Info sharing & Collaboration (purpose)
- 12.8% Fundraising
- 8.2% Management & Administration

Spent in 2017: €254,890

Income in 2017: €470,514

(A further €216,000 has been set aside as earmarked funds for specific research projects starting in 2018.)
Budget 2018

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. The most common is that the Foundation first receives the benefits and then only spends the funds and / or incurs the expenses.

Income

Further growth of donations is anticipated in overall income, particularly from regular donors, Trust Funds and from outside of The Netherlands. The income from Grants from Government will depend on being successful in obtaining subsidy for a small number of research related projects. We further plan to organize a number of small and large fundraising events, comparable with 2017. Further growth of our income is anticipated in the next few years.

Expenses

Research

Funding of OI research projects takes place based on annual proposal rounds. The Call is published on the relevant specialized websites and is sent directly to our network of 900 OI researchers worldwide. Currently the scope is very open, enabling virtually all subjects to be proposed (orthopedic, genetic, pediatric, psychological etc.). Selection of sponsored projects takes place based on recommendations from our Scientific and OI Advisory Board. The percentage of spend on Foundation Goals is expected to increase from 75% in 2017 to 84% in 2018.

Fundraising

The costs of fundraising are expected to rise partly due to increase of in-house fundraising activities and partly due to some investments in technology that enable further growth of fundraising channels. The percentage of spend on Fundraising is however, based on budgeted activities, expected to reduce from 17% in 2017 to 11% in 2018.

Management & Admin

Also, the cost of Management & Admin is expected to grow with the growth of our activities, subscription fees and increase of FTE % of our Director from 85% in 2017 to 100% in 2018. The percentage of spent on Management & Admin is however, based on budgeted activities, expected to reduce from 8% in 2017 to 5% in 2018.
## Income & Expenses

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<tr>
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<th>Budget 2018</th>
<th>Actual 2017</th>
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<tr>
<td><strong>Income</strong></td>
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<td>- Products and/or Services</td>
<td>74.000</td>
<td>57.070</td>
</tr>
<tr>
<td>- Other income</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td>546.000</td>
<td>470.514</td>
</tr>
<tr>
<td><strong>Expenses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spent on Goals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Research</td>
<td>433.100</td>
<td>157.011</td>
</tr>
<tr>
<td>- Information sharing &amp; Collaboration</td>
<td>22.900</td>
<td>32.713</td>
</tr>
<tr>
<td>- Other</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td>456.000</td>
<td>189.724</td>
</tr>
<tr>
<td><strong>Fundraising costs</strong></td>
<td>62.600</td>
<td>44.188</td>
</tr>
<tr>
<td><strong>Management &amp; Administration costs</strong></td>
<td>27.400</td>
<td>20.978</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td>546.000</td>
<td>254.890</td>
</tr>
<tr>
<td><strong>Balance before Financial Income &amp; Expenses</strong></td>
<td>0</td>
<td>215.624</td>
</tr>
<tr>
<td><strong>Balance Financial Income &amp; Expenses</strong></td>
<td>-</td>
<td>213</td>
</tr>
<tr>
<td><strong>Balance Income &amp; Expenses</strong></td>
<td>0</td>
<td>215.837</td>
</tr>
</tbody>
</table>
# Income Statement

<table>
<thead>
<tr>
<th>Income &amp; Expenses</th>
<th>Actual 2017</th>
<th>Budget 2017</th>
<th>Actual 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>EURO</td>
<td>EURO</td>
<td>EURO</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income from Individuals</td>
<td>56.840</td>
<td>-</td>
<td>45.379</td>
</tr>
<tr>
<td>Income from Companies</td>
<td>33.989</td>
<td>-</td>
<td>17.415</td>
</tr>
<tr>
<td>Income from Lottery Organizations</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Income from Grants from Government</td>
<td>170.810</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Income from Associated (international) Organizations</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Income from other Non-Profit Organizations</td>
<td>151.805</td>
<td>-</td>
<td>19.304</td>
</tr>
<tr>
<td>Total Acquired Income</td>
<td>413.444</td>
<td>0</td>
<td>82.098</td>
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<tr>
<td>Income as compensation for the delivery of:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Products and/or Services</td>
<td>57.070</td>
<td>-</td>
<td>446</td>
</tr>
<tr>
<td>- Other income</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total Income</td>
<td>470.514</td>
<td>200.000</td>
<td>82.544</td>
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<tr>
<td>Expenses</td>
<td></td>
<td></td>
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<tr>
<td>Spent on Goals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Research</td>
<td>157.011</td>
<td>180.000</td>
<td>90.633</td>
</tr>
<tr>
<td>- Information sharing &amp; Collaboration</td>
<td>32.713</td>
<td>33.000</td>
<td>235</td>
</tr>
<tr>
<td>- Other</td>
<td>-</td>
<td>-</td>
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</tr>
<tr>
<td></td>
<td>189.724</td>
<td>213.000</td>
<td>90.868</td>
</tr>
<tr>
<td>Fundraising costs</td>
<td>44.188</td>
<td>27.000</td>
<td>7.247</td>
</tr>
<tr>
<td>Management &amp; Administration costs</td>
<td>20.978</td>
<td>20.000</td>
<td>1.385</td>
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<tr>
<td>Total Expenses</td>
<td>254.890</td>
<td>260.000</td>
<td>99.500</td>
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<tr>
<td>Balance before Financial Income &amp; Expenses</td>
<td>215.624</td>
<td>-60.000</td>
<td>-16.956</td>
</tr>
<tr>
<td>Balance Financial Income &amp; Expenses</td>
<td>213</td>
<td>-</td>
<td>744</td>
</tr>
<tr>
<td>Balance Income &amp; Expenses</td>
<td>215.837</td>
<td>-60.000</td>
<td>-16.212</td>
</tr>
<tr>
<td>Assignment Balance Income &amp; Expenses</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Addition to / Withdrawal from:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Other Reserves</td>
<td>367</td>
<td>-60.000</td>
<td>-16.212</td>
</tr>
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<td>- Earmarked Reserves</td>
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<tr>
<td>- Earmarked Funds</td>
<td>215.470</td>
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</tr>
<tr>
<td>Total</td>
<td>215.837</td>
<td>-60.000</td>
<td>-16.212</td>
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Balance Sheet

<table>
<thead>
<tr>
<th>Notes</th>
<th>31-dec-17</th>
<th>31-dec-16</th>
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</thead>
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<td></td>
<td>EURO</td>
<td>EURO</td>
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<tr>
<td>Assets</td>
<td></td>
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<tr>
<td>Immaterial Fixed Assets</td>
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<td>-</td>
</tr>
<tr>
<td>Material Fixed Assets</td>
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<td>-</td>
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<tr>
<td>Financial Fixed Assets</td>
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<td>-</td>
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<tr>
<td>Stocks</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Receivables &amp; Accrued Assets</td>
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<td>182.557</td>
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<tr>
<td>Securities</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Cash &amp; Cash Equivalents</td>
<td>2</td>
<td>436.502</td>
</tr>
<tr>
<td>Liabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reserves &amp; Funds</td>
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<td></td>
</tr>
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<td>- Earmarked Reserves</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>- Other Reserves</td>
<td>3</td>
<td>100.458</td>
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<tr>
<td>- Funds</td>
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<td></td>
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<tr>
<td>- Earmarked Funds</td>
<td>4</td>
<td>215.470</td>
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<tr>
<td>Long Term Debt</td>
<td>5</td>
<td>92.000</td>
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<tr>
<td>Short Term Debt</td>
<td>6</td>
<td>211.131</td>
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</table>

Cash Flow Statement:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash collected from:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donations</td>
<td>104.545</td>
<td>110.884</td>
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<tr>
<td>Income from Grants from Government</td>
<td>51.243</td>
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</tr>
<tr>
<td>Income from other Non-Profit Organizations</td>
<td>99.337</td>
<td></td>
</tr>
<tr>
<td>Products &amp; Services</td>
<td>56.020</td>
<td>446</td>
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<tr>
<td>Other Fundraising</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Interest received</td>
<td>-</td>
<td>744</td>
</tr>
<tr>
<td>Total cash collected</td>
<td>311.145</td>
<td>112.074</td>
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<tr>
<td>Cash paid for:</td>
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<tr>
<td>Research projects</td>
<td>75.248</td>
<td>85.230</td>
</tr>
<tr>
<td>Sponsoring events</td>
<td>6.862</td>
<td>235</td>
</tr>
<tr>
<td>Governance costs</td>
<td>4.028</td>
<td>1.385</td>
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<td>Fundraising activities</td>
<td>16.616</td>
<td>7.247</td>
</tr>
<tr>
<td>Total cash paid</td>
<td>102.754</td>
<td>94.097</td>
</tr>
<tr>
<td>Net cash from operations</td>
<td>208.391</td>
<td>17.977</td>
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</tbody>
</table>

Cash Balance:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Opening balance ABN AMRO &amp; SNS Bank</td>
<td>228.111</td>
<td>210.134</td>
</tr>
<tr>
<td>Closing balance ABN AMRO &amp; SNS Bank</td>
<td>436.502</td>
<td>228.111</td>
</tr>
<tr>
<td>Net cash from operations</td>
<td>208.391</td>
<td>17.977</td>
</tr>
</tbody>
</table>
Notes to the Accounts

General

The consolidated financial statements for 2017 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.

System change

In October 2016, the Council for Annual Reporting 2016-2016 issued 2016-13 with the result that the Guideline 650 for Fundraising Organizations has been amended. This Guideline must be applied for accounting years beginning on or after 1 January 2017. By introducing this Directive, the presentation of the benefits has mainly been adjusted and the comparative figures have been reclassified to allow comparison.

Accounting policies for valuation and determination of results

General

Unless stated otherwise, the assets and liabilities are valued at the acquisition price or 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 account and saving account bank balances. 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 recognized in the year in which they were received and at the latest when 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 as “Other Reserves”, is intended as a buffer for disappointing income or unexpected expenses. With this reserve, Care4BrittleBones can continue its activities in poorer times.

As a CBF quality mark holder, 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 2018 budget, a contingent reserve of a maximum of € 126,800 will follow as of 31 December 2017. The realized balance of € 100,458 is substantially lower and thus more than meets both the CBF guideline and the own directive.

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

Note 1

<table>
<thead>
<tr>
<th>Receivables &amp; Accrued Assets</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receivables from Individuals</td>
<td>2,334</td>
<td>2,999</td>
</tr>
<tr>
<td>Receivables from Companies</td>
<td></td>
<td>10,000</td>
</tr>
<tr>
<td>Grants from Government</td>
<td>119,567</td>
<td></td>
</tr>
<tr>
<td>Interest</td>
<td>212</td>
<td></td>
</tr>
<tr>
<td>Receivables from Non-Profit Organizations</td>
<td>60,444</td>
<td>9,977</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>182,557</strong></td>
<td><strong>22,976</strong></td>
</tr>
</tbody>
</table>

Note 2

<table>
<thead>
<tr>
<th>Cash &amp; Cash Equivalents</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABN AMRO Current Account</td>
<td>10,965</td>
<td>15,075</td>
</tr>
<tr>
<td>ABN AMRO Savings Account</td>
<td>325,946</td>
<td>113,445</td>
</tr>
<tr>
<td>SNS Bank Savings Account</td>
<td>99,591</td>
<td>99,591</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>436,502</strong></td>
<td><strong>228,111</strong></td>
</tr>
</tbody>
</table>

Note 3

<table>
<thead>
<tr>
<th>Other Reserves</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance 1/1/2017</td>
<td>100,091</td>
</tr>
<tr>
<td>Additions</td>
<td>367</td>
</tr>
<tr>
<td>Withdrawals</td>
<td>0</td>
</tr>
<tr>
<td><strong>Balance 31/12/2017</strong></td>
<td><strong>100,458</strong></td>
</tr>
</tbody>
</table>

The additions concern the balance of Income & Expenses for 2017 after movement in the Earmarked Funds and consist of the Contingent Reserves.

Note 4

<table>
<thead>
<tr>
<th>Earmarked Funds</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance 1/1/2017</td>
<td>0</td>
</tr>
<tr>
<td>Additions</td>
<td>215,470</td>
</tr>
<tr>
<td>Withdrawals</td>
<td>0</td>
</tr>
<tr>
<td><strong>Balance 31/12/2017</strong></td>
<td><strong>215,470</strong></td>
</tr>
</tbody>
</table>

The additions concern funds that have been given a specific destination by donors for the projects “psycho-social care at OI” and “Physiotherapy for children with OI”

Note 5

<table>
<thead>
<tr>
<th>Long Term Debt</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project Commitments</td>
<td>92,000</td>
<td>-</td>
</tr>
</tbody>
</table>

The project commitments concern commitments to research organizations for the funding of projects with a remaining duration of more than 1 year.
Note 6

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

<table>
<thead>
<tr>
<th>Spent on objectives</th>
<th>Research</th>
<th>Information sharing &amp; Collaboration</th>
<th>Fundraising costs</th>
<th>Management &amp; Admin</th>
<th>Total actual 2017</th>
<th>Budget</th>
<th>Total Actual 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project contributions</td>
<td>153.331</td>
<td>6.863</td>
<td>160.194</td>
<td>198.000</td>
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<td></td>
<td>90.868</td>
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<tr>
<td>Outsourced work</td>
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<td>16.616</td>
<td>16.616</td>
<td>12.000</td>
<td></td>
<td></td>
<td>7.247</td>
</tr>
<tr>
<td>Remuneration of director</td>
<td>3.680</td>
<td>25.850</td>
<td>16.950</td>
<td>74.052</td>
<td>45.000</td>
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<td>0</td>
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<tr>
<td>Office and general costs</td>
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<td></td>
<td>4.028</td>
<td>4.028</td>
<td>5.000</td>
<td></td>
<td>1.385</td>
</tr>
<tr>
<td>Total</td>
<td>157.011</td>
<td>32.713</td>
<td>44.188</td>
<td>20.978</td>
<td>254.890</td>
<td>260.000</td>
<td>99.500</td>
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</tbody>
</table>
## Project Overview – Spent on Goals

<table>
<thead>
<tr>
<th>Project Title</th>
<th>Category</th>
<th>Lead Country</th>
<th>Institution</th>
<th>Lead researcher</th>
<th>Status</th>
<th>Total Committed 3/1/2017</th>
<th>Movement in Commitment 2017</th>
<th>Total Committed 31/12/2017</th>
<th>Actualcy</th>
<th>Director’s remuneration</th>
<th>Total actual to date</th>
<th>To be paid / reserved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapy for patients with Osteogenesis Imperfecta (OI)</td>
<td>Basic science</td>
<td>Netherlands</td>
<td>VU Medical Center</td>
<td>Fleur van Dijk</td>
<td>ongoing</td>
<td>30.447</td>
<td>1.500</td>
<td>31.947</td>
<td>22.469</td>
<td>9.478</td>
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<td></td>
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<tr>
<td>Treatment of Osteogenesis Imperfecta in Adults</td>
<td>Basic science</td>
<td>Denmark</td>
<td>Aarhus University Hospital</td>
<td>Bente Langbath</td>
<td>Cancelled</td>
<td>30.000</td>
<td>-10.000</td>
<td>20.000</td>
<td>0</td>
<td>0</td>
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<td></td>
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<tr>
<td>Role of Parental Mosaicism in the Transmission of Disease Causing Mutations in Patients with Osteogenesis Imperfecta</td>
<td>Basic science</td>
<td>Spain</td>
<td>Fundació Clinic per a la Recerca Biomèdica, Barcelona</td>
<td>Eva Gonzalez-Roca</td>
<td>ongoing</td>
<td>23.872</td>
<td>9.549</td>
<td>23.872</td>
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<tr>
<td>3D geometric morphometrics of the thorax and respiratory muscles of Osteogenesis Imperfecta patients</td>
<td>Basic science / clinical</td>
<td>Spain</td>
<td>Department d'Anatomia i Embriologia Humana</td>
<td>Juan Alberto Sanzis and Markus Bastir</td>
<td>completed</td>
<td>28.500</td>
<td>9.500</td>
<td>28.500</td>
<td>28.500</td>
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<tr>
<td>Identification of novel therapeutic compounds for the treatment of Osteogenesis Imperfecta (OI) targeting collagen deficiency</td>
<td>Basic science</td>
<td>Netherlands</td>
<td>Vumc, Clinic Genetic, Amsterdam</td>
<td>Gerard Pals and Dimitra Michi</td>
<td>ongoing</td>
<td>47.250</td>
<td>20.000</td>
<td>47.250</td>
<td>47.250</td>
<td>0</td>
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<tr>
<td>Physical rehabilitation in children with OI</td>
<td>Physiotherapy</td>
<td>Germany</td>
<td>University of Cologne</td>
<td>Oliver Semler and Brigitte Muller</td>
<td>ongoing</td>
<td>22.500</td>
<td>0</td>
<td>22.500</td>
<td>20.000</td>
<td>2.500</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical rehabilitation in children - Implementation</td>
<td>Physiotherapy</td>
<td>Germany</td>
<td>Care4BB</td>
<td>Various</td>
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<td>Vitamin K</td>
<td>Clinical research</td>
<td>Netherlands</td>
<td>Wilhelmina Kinderziekenhuis</td>
<td>Bea Zoer and Attie van Dijk</td>
<td>ongoing</td>
<td>24.120</td>
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<td>Fatigue and sleep disturbances in OI – Prevalence, characteristics, and impact on the quality of life</td>
<td>Clinical research</td>
<td>Finland</td>
<td>University of Helsinki</td>
<td>Heidi Arponen</td>
<td>ongoing</td>
<td>20.000</td>
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<td>Dental and craniofacial characteristics of adult patients with OI</td>
<td>Clinical research</td>
<td>Denmark</td>
<td>Aarhus University</td>
<td>Dorit Haabeck</td>
<td>ongoing</td>
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<td>Towards a therapy for OI - Next Steps</td>
<td>Basic science</td>
<td>Netherlands</td>
<td>Isala / UMC Groningen</td>
<td>Fleur van Dijk</td>
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<td>Eat, breathe, sleep with OI</td>
<td>Clinical research</td>
<td>Italy</td>
<td>Politecnico di Milano Dipartimento di Elettronica</td>
<td>Antonella Lo Mauro</td>
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<td>Targeting Gene Repair to Bones</td>
<td>Basic science</td>
<td>Australia</td>
<td>The Centre for Children's Bone and Musculoskeletal Health Australia</td>
<td>Craig Munns, Aaron Schindeler etc</td>
<td>Allocated</td>
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<td>Assessment Bone Strength with Zebrafish</td>
<td>Basic science</td>
<td>Belgium</td>
<td>Universiteit Gent</td>
<td>Andy Willaert</td>
<td>Ongoing</td>
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<td>Psychosociale zorg bij Osteogenesis Imperfecta</td>
<td>Psychology</td>
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<td>Care4BB</td>
<td>Various</td>
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<td>Events, conference, collaboration etc</td>
<td>Care4BB</td>
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<td>spent</td>
<td>32.713</td>
<td>6.863</td>
<td>25.850</td>
<td>32.713</td>
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</table>

**General information:**
- **Total:** 254,039
- **Committed:** 405,193
- **Actualcy:** 659,232
- **To be paid / reserved:** 82,212

**Financial information:**
- **Total actual to date:** 29,530
- **To be paid / reserved:** 214,784
- **444,448**
Notes on the role and remuneration of the Director

<table>
<thead>
<tr>
<th>Name:</th>
<th>Dagmar Mekking</th>
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<tbody>
<tr>
<td>Other roles:</td>
<td>- Director/owner of DM Consultancy</td>
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<tr>
<td>Contract of Service:</td>
<td>- Self employed</td>
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<tr>
<td></td>
<td>- 2 year contract</td>
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<tr>
<td>Actuval 2017:</td>
<td></td>
</tr>
<tr>
<td>period 1/1/2017 - 22/09/2017:</td>
<td>32 hours per week</td>
</tr>
<tr>
<td>23/09/2017 - 31/12/2017:</td>
<td>40 hours per week</td>
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<tr>
<td>Total Remuneration:</td>
<td>€ 61,200</td>
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<td>VAT *</td>
<td>€ 12,852</td>
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<tr>
<td>Total</td>
<td>€ 74,052</td>
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The total remuneration of the Director (self employed) remains within the maximum of €90,500 (1 FTE/12 months) as per 'regulation for remuneration of directors of Charity Organizations job grade ‘D’ from Goede Doelen Nederland applicable in 2017. * VAT is not recoverable as our foundation is exempted

Accounting Control Statement

The Auditing Committee in the person of Mr. C.A. Braber and D. Dwarwaard have, on Tuesday May 15, 2018 in the presence of the treasurer Mr. P. Van Erk and Mrs. I. Juza-Parfus checked the books of the Care4BrittleBones Foundation for the 2017 financial year.

The committee states that:

The annual accounts give a correct representation of the income and expenditure for the year 2017
The Balance Sheet as at 31 December 2017 gives a true and fair view of the Reserves

Gouda, May 15, 2018

The auditing committee:

D. Dwarwaard

C.A. Braber
Thank you

Without our generous donors, fundraisers and ambassadors we would not be able to achieve any progress in research into OI. These individuals, institutions and corporations have relentlessly realised opportunities to raise funds in a way that was more impactful and more inspiring then we could have ever imagined! A sincere and very big thank you goes to everyone who has supported our cause and believes that together we can make a difference for people with OI.

Many thanks too to the core team for the numerous passionate and committed discussions about how we can make a positive difference and for the powerful actions that flow from these. You are the “pacemakers” for the entire organisation and without you there would be no Care4BrittleBones.

We also would like to thank our partners in OI research, working in hospitals, universities and other health related institutions around the world. Your deep expertise and true dedication to improve the lives of people with OI are an inspiration to us. We admire your new ideas and your courage to think of and try out new approaches in responsible ways to take away pain and fractures. Your work gives us hope for a better future.

Last but not least we would like to thank our OI Community network, all people with OI, their families and friends who have supported us in 2017! A very special thank you is for our network partners, who work shoulder to shoulder with us on research approaches and projects, on raising awareness and funds to improve the quality of life of people with OI! We are extremely proud to be associated with you and thankful for the active role you take together with us 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 (RSIN 851392854; www.kennisbankfilantropie.nl/anbi/care4brittlebones) since 12 June 2012.

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.