



# **Annual Report**

# **2015**

**Care4BrittleBones Foundation**



# OI IN NUMBERS



## THE SHATTERING TRUTH

**0.5** MILLION

people worldwide have OI

(Germany: 5,000; UK, France and Italy: 4,000 each; Netherlands: 1,000; Austria: 500)

Some children break

**10** TIMES A YEAR

**50,000** BABIES

are born each year with OI

People worst affected with OI break over

**200** TIMES IN A LIFETIME

OI is just one of

**6,000** RARE DISEASES

**0** MEDICATION

has been developed specially for OI



## REACHING OUT IN 2015

**450** VOLUNTEERS

in Europe

**99,600** EUR

committed to research projects for OI

**25** FUNDRAISING EVENTS

in 2015

**97%** FUNDS FOR RESEARCH

Only 3% used to generate funds



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# The momentum keeps building

## Welcome note from Dagmar Mekking, Chairperson

Having set up the foundation in 2012, I am extremely pleased to see how it has developed over the years. From desperation to hope; from hope to a dream of a better future; from a dream of a better future to an action plan for how to get there. Now we are shifting gear again. We have many plans in the minds of many gifted people... and together this is really starting to form a bit of a movement in the OI community.

Key successes this year can be clustered into 3 areas: fundraising, research, and the OI community and networks.

**Fundraising** for OI research is what we are all about. Everyone in Care4BrittleBones at every level is engaged in it. Only if we all experience fundraising ourselves, can we continue to learn how to become even better at it. Key to our success is our strong linkage with the OI community. We are a very tight community that is connected through social media and other means. Not a day goes by without a fracture or pain for the people who we love. Our frustration, helplessness and compassion can be channelled into lasting value by fundraising for research. This year has again exceeded the 100,000 Euro mark through an energizing mix of individual activities, fundraising events and sponsoring obtained through other funds/foundations, and the number of people who are involved is growing.

In 2015 we have been very proud to be able to fund 3 important **research** projects:

1. An innovative project of the Free University of Amsterdam that is looking to identify collagen-enhancing compounds for the treatment of Osteogenesis Imperfecta targeting collagen deficiency.
2. An in-depth study of lung problems of people with Type 3 OI, utilising the latest available 3D technology and focusing on helping people to prevent life threatening pneumonias.
3. A practice oriented genetic research around the phenomenon of 'mosaicism' which should lead to a better understanding of some rare forms of OI and better genetic counselling. It may well help to explain why some people with OI show all the symptoms but could not yet be diagnosed.

Our advisory boards (page 9), which consist of the best and most committed OI researchers in Europe as well as some of the sharpest OI minds from the OI community, have signalled that the quality of the research proposals was very high. We are very much looking forward to hear more about these promising projects in the year to come.

When looking back on 2015, what I am most proud of is the momentum we have built, both within and together with the **OI community**. We have strengthened our board with a communications professional and have a very solid and extremely dedicated core team that is growing our foundation week by week. I am particularly grateful for our fantastic Care4BrittleBones ambassadors. We closed 2014 with 10 ambassadors in the Netherlands. By year-end 2015 we had 14 ambassadors and various strong contenders to lead Care4BrittleBones in other European countries, such as Germany, France, UK, Austria, Belgium and Cyprus! Many of these connections are emerging through our OI community network with OIFE (the OI Federation of Europe), which has been a strong partner, energiser, networker and collaborator all along. We have also made a giant step forward in creating OI awareness outside of the communities we live in by launching our first national poster campaign 'Stijnstory.nl', which has been a major success and generated a lot of reactions and support from people who had never even heard of the existence of OI before.

I am very grateful for what we've achieved together in 2015 and already looking forward to all the little and big things we can do in 2016 to make a significant positive difference to the lives of the people with OI who we love so much.

**Dagmar Mekking**  
Chairperson, Care4BrittleBones





# STRATEGIC REPORT





# Care4Brittle Bones

## What is OI (Osteogenesis Imperfecta)?

Brittle Bones, 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 problems, dental problems, blue sclera and heart problems.

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.

There are 5 main types of OI and 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 and some children will have a fracture every few weeks or months. This often has a big impact on the child as well as the family around him/her.

## Why more research for OI is needed



OI has been known for more than 100 years. However, to date there is no real treatment that can fundamentally address Brittle Bones disorder.

OI is a rare disorder. There are about 500,000 people worldwide with this condition (including 5,000 in Germany; 4,000 each in the UK, France and Italy; 1,000 in the Netherlands and 500 in Austria). Just as with many other rare diseases, there is hardly any funding available for research to change this situation. No funding for research means no progress to address the significant health challenges that these people are facing every day.

Children who ‘break’ every few weeks, adults who have chronic bone pain and face the threat of lethal pneumonia, scoliosis, severe hearing loss and more – they all call for a change!

People with OI are frequently challenged with pain and fractures. Yet they often also show a tremendous amount of willpower and an ‘unbreakable spirit’. We have allowed this spirit to inspire us and are fully committed to change things for the better.

## Who is Care4BrittleBones?

Care4BrittleBones is a fundraising organisation. It is an international charity with roots in the Netherlands. Founded in 2012 by family and friends of a child with OI, the foundation has quickly grown to become the biggest fundraising organisation for OI research in Europe. 97% of the funds raised by Care4BrittleBones is spent on research into OI. We



are recognised as charitable organisation in the Netherlands, which allows for tax deductibility of donations across the entire European Union.

By the end of 2015, more than 400 people had been involved in fundraising activities for the foundation and the momentum still continues to grow. Whilst most activities are currently organised in the Netherlands, we explicitly invite and would welcome more activities from other countries (particularly within the European Union). The only requirement for Care4BrittleBones: fundraising activities should be aligned with our core values: **Positive, Inspiring** and **Innovative**.

# Care4BrittleBones - vision





# The board and advisory boards

## Care4BrittleBones Board



**Dagmar Mekking**  
Chairperson and Secretary



**Peter M. Mekking**  
Vice Chairman



**Piet van Erk**  
Treasurer



**Jacqueline Hornman-Huberts**  
Member of the Board



**Dieuwke Swain**  
PR and Communication

The activities of the foundation are coordinated by the core team, which consists of 8-10 people, including the board. They meet on a monthly basis to discuss all matters concerning the foundation.

None of the board members, core team or volunteers receives a financial or other compensation. This also includes Ambassadors and Advisory Board members. The Foundation does not employ any staff.







## Members of the Scientific Advisory Board



**Fleur van Dijk**  
Clinical Geneticist,  
Vrije Universiteit  
Amsterdam,  
Netherlands



**Oliver Semler (MD,  
PhD)**  
Head of Skeletal  
Dysplasia Clinic,  
University, Children's  
Hospital University  
Cologne, Germany



**Outi Mäkitie**  
Pediatric  
Endocrinology and  
Metabolic Bone  
Diseases, Children's  
Hospital Helsinki  
University, Finland



**Lena Lande Wekre  
(MD, PhD)**  
Rehabilitation,  
University of Oslo,  
Norway



**Nick Bishop**  
Professor of  
Paediatric Bone  
Disease at University  
of Sheffield, UK

## Members of the OI Advisory Board



**Ute Wallentin**  
President OIFE (OI  
Federation Europe),  
Germany



**Therese Stutz-  
Steiger**  
Independent  
Consultant, Public  
Health Concepts,  
Basel, Switzerland



**Eero Nevalainen**  
Software Engineer,  
Eficode Oy, Finland



**Karsten Jensen**  
Head of Music, Radio  
Max, Esbjerg Area,  
Denmark



**Margriet Crezee**  
Project Coordinator,  
Nierstichting,  
Netherlands





# Our activities

## Making a difference through research

### Approach: 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 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. In this way, we can reach all OI specialists in Europe as well as some key experts outside Europe (US, Canada, Australia). Currently the scope is very open, enabling virtually all subjects to be proposed (orthopaedic, genetic, paediatric, psychological etc.).

### Scientific and OI Advisory Boards

After the submission timeline, we are presenting 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. All 10 advisory board members have been chosen carefully based on their expertise and reputation for collaboration. The Scientific Advisory Board is composed of a variety of disciplines and has expertise in the areas of genetics, endocrinology, bone metabolism, paediatrics and physiotherapy. All members of the OI Advisory Board have OI themselves and have a good general knowledge of the disorder and a broad network.

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.

### Winners of Proposal Round 2015

We were very pleased to receive 7 very interesting proposals from 5 different countries requesting funding for OI research. Based on the advice of the advisory boards, the following 3 projects were chosen in October 2015:

#### **1. The Netherlands: VU Medical Center (Dr. Gerard Pals and Dr. Dimitra Micha): Identification of collagen-enhancing compounds for the treatment of Osteogenesis Imperfecta targeting collagen deficiency.**

This project is mainly focused on the most common OI type I caused by HI mutations in COL1A1, which lead to reduced collagen synthesis. Enhancement of collagen production is expected to be extremely beneficial in these patients. In addition, these compounds may also provide a therapeutic effect in OI type IV patients. Increased expression of normal collagen may also improve the phenotype in mild OI type IV.



VU medisch centrum

#### **2. Spain: University of Valencia (Prof. Juan Alberto Sanchis and Dr. Markus Bastir): 3D geometric morphometrics of the thorax and respiratory muscles of Osteogenesis Imperfecta patients.**

One of the least studied aspects of OI is the influence spine deformities and thoracic bone structure may have on the respiratory apparatus and its functioning. However, pulmonary complications are one of the main causes of death among OI patients. The respiratory problems of OI patients are usually attributed to the secondary effects of scoliosis and rib fractures, although they are also attributed to the





presence of severe restrictive pulmonary disease due to thoracic bone structure impairment. Severe ribcage deformation in Type III OI patients greatly impairs the function and coordination of their ventilatory muscles causing highly inefficient ventilation. Therefore an analysis with 3D geometric morphometrics comparing Type III OI patients and healthy control groups would be particularly advantageous for improving the understanding of different ways of thoracic and diaphragmatic respiration and how it is related to the shape of the thorax.

### 3. Spain: Hospital Clinic for Biomedical Research, Barcelona (Eva Gonzalez-Roca): Role of parental mosaicism in the transmission of disease causing mutations in patients with Osteogenesis Imperfecta.

The majority of Osteogenesis Imperfecta patients of European descent carry mutations in the collagen genes COL1A1 and COL1A2, which encode for procollagen  $\alpha 1$  and  $\alpha 2$  proteins. These mutations are usually inherited in the patient from an affected parent, but sometimes appear for the first time in the patient (a *de novo* mutation). There is an intermediate situation described in families where more than one affected child of OI type II has been described. In these cases, some parents harbored the mutation of their offspring but at low allele frequencies. Moreover, some of them presented mild features of OI suggesting that even the production of low amounts of abnormal collagen can lead to disease. Our research goal is to determine if somatic mosaicism plays a role in transmitting disease-causing variants from parents to their OI affected offspring OI types different from type II, and if it plays a role in causing OI when a mosaicism is present.



### Ongoing research supported by earlier proposal rounds

Research is still ongoing in the following projects that were chosen during earlier proposal rounds:

1. **The Netherlands:** VU Medical Center (Dr. F. van Dijk): Therapy for patients with Osteogenesis Imperfecta (OI).
2. **Denmark:** Aarhus University Hospital (Prof. Bente Langdahl): Treatment of Osteogenesis Imperfecta in adults.
3. **Portugal:** University of Lisbon (Prof. Luísa Barros): Pain Less – OI youngsters take control.
4. **Italy:** University of Pavia - Biochemistry Unit (Prof. Antonella Forlino): Gene/cellular therapy.
5. **The Netherlands:** Isala Clinics (A. Harsevoort): OI and fatigue.
6. **Germany:** University of Cologne (O. Semler): an alternative for Biphosphonates Denosumab?
7. **Sweden:** Karolinska University Hospital Stockholm (Cecilia Götherström): Stem cell-research,

More information on these studies can be found on our website <http://www.care4brittlebones.org>.



Universität zu Köln





# How we work

## Strategy & Operating Plan 2015

### Statutory goal and strategy

The statutory goal of the Care4BrittleBones foundation is “To enable a better quality of life for people with Osteogenesis Imperfecta (OI) by enabling more medical scientific research”.

The long term goal of Care4BrittleBones is to find a cure for OI.

The idea for change is based on 3 simple truths:

1. The cause of OI is that the body is unable to 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 of someone with OI how to produce the right quality and quantity of collagen, this will over time improve the bone quality and strength, no matter how old or young the person with OI is.

The expectation is that the search for the cure could take many years. There is no ‘quick win’ to be expected. We will need improvements for the short and mid-term as well as continue to look for the long term game changer. We are fully determined to make this road to the cure as short as it can possibly be and collaborate with anyone who will be able to get us there in a way that is positive, innovative and inspiring.

The high level approach for the first 5 years:

	2012	2013	2014	2015	2016
Research		1 <sup>st</sup> Proposal round. Advisory Boards	2 <sup>nd</sup> Proposal round	3 <sup>rd</sup> Proposal round	4 <sup>th</sup> Proposal round
Fundraising		Events Products	Events Products Trustfunds	Events Products Trustfunds	Events Products Trustfunds
Communications & Networks		Website	Updated Website		
		Social Media (Facebook/Twitter)			
		Newsletters (quarterly)			
		Ambassadors			
		Friends of C4BB			
		International			
Workpractices	C4BB Strategy	Regular Meetings 1. Core Team	Regular Meetings 1. Core Team 2. Ambassadors	Regular Meetings 1. Core Team 2. Ambassadors 3. Medical  International Collaboration	Regular engagements with all stakeholder groups Strong International Collaboration





## Communications and networks

OI is a so called 'Orphan disease', meaning a very rare disease. Typically for these kinds of diseases and disorders, progress is hard to achieve for two main reasons. Firstly, research in the pharmaceutical industry is not commercially viable, as the number of people with OI is not high enough to make it profitable. Secondly, international collaboration between medical researchers is required to achieve progress as the number of people with OI with the exact same DNA deviation is too small to achieve critical mass for research. Therefore organisations such as Care4BrittleBones have to take a proactive role in enabling more research through fundraising and promoting collaboration amongst researchers internationally.

### OI Community

Care4BrittleBones strongly believes in a close collaboration with its sister OI organisations around the world. We need to learn from each other, build on each other and support one another.

Care4BrittleBones originally was 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 "making the best of today", Care4BrittleBones aims to bring change and create better opportunities for treatment for "tomorrow". Care4BrittleBones is present at formal meetings of the VOI 2-3 times a year, engages with VOI members throughout 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 part of the Care4BrittleBones core team.

In 2015, 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. The former OIFE President Ute Wallentin is a member of our OI Advisory Board.

Care4BrittleBones is keen to establish strong ties with as many OI communities worldwide as possible to enable fundraising for research anywhere where this is not yet happening.

To actively support exchange amongst the OI Communities worldwide, Care4BrittleBones is hosting a monthly teleconference for OIFE, Osteogenesis Imperfecta Foundation for OIFE (OI Federation of Europe, see above), the OIF (Osteogenesis Imperfecta Foundation, focusing on US and Canada) and the BBS (Brittle Bones Society, which supports people with Osteogenesis Imperfecta in the UK). The meetings are covering a wide range of topics like engaging our respective communities and working together for more research.





## Medical world

Collaboration in the medical world is paramount for achieving progress in OI research. Currently, true collaboration exists mainly on a country level. An example of a national network is the 'Linked clinical research centres' in the USA and Canada, which connect closely with each other. Another example is the Dutch OI Group in the Netherlands, which connects twice a year for an exchange on a broad variety of topics. Internationally, collaboration is up to the personal motivation of each individual researcher to share information and insight openly with other colleagues.

In 2015, Care4BrittleBone engaged with the following medical contacts:

1. **Netherlands:** Dutch OI Group: Group of 15 medical specialists who support OI. The experts of this group are associated with the Wilhelmina Kinderziekenhuis Utrecht (specialising in OI in children), Isala Klinieken Zwolle (specialising in OI in adults) and Vrije Universiteit Amsterdam (specialising in genetic research).
2. **Germany:** From the start of the foundation, Care4BrittleBones has engaged regularly with Oliver Semler of the University Children's Hospital in Cologne, who is leading the largest OI centre in Germany.
3. We are linked into the medical world of the **United Kingdom** (Nick Bishop), **Finland** (Outi Mäekiti) and **Norway** (Lena Lande Wekre) through the respective members in the Scientific Advisory Board.
4. Through our OI Advisory Board and OIFE connections, we are actively reaching into all **European** medical networks.
5. Our research proposal rounds have connected us to OI researchers from **Netherlands, Germany, Portugal, Brazil, Sweden, Italy, Switzerland, Denmark, United Kingdom, Estonia** and **Spain**.
6. We also have contact with various non-European medical OI experts, such as Prof. Francis Glorieux (**Canada**), and Prof. David Sillence (**Australia**).

Our 'Call4Proposals' are published online via OrphaNews, one of the main online news channels for the medical world specialised in orphan diseases: <http://www.orpha.net>.



## Newsletter "Good News from Care4BrittleBones"

Since the second quarter of 2013, Care4BrittleBones sends updates to its ever growing support community every quarter by means of a newsletter. The name of the newsletter is "Good news from Care4BrittleBones" and it covers all areas of interest; for example, fundraising, research or marketing. The distribution list of the newsletter began initially at 10 readers and, just within the space of 2 ½ years, grew to 116 by the end of 2015. This number is expected to continue to grow in 2016.

## Social Networks

We actively engage with our networks 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, YouTube and Twitter.



# Fundraising events and personal stories

## Our approach: FUNdraising

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 with 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 FUNdraising moments, as well as a high satisfaction and even stronger participation from our wonderful and highly motivated volunteers.

## 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 have OI themselves or have a relative with OI, and therefore know first-hand, how impactful OI is to the life of people with OI. We are open to anyone who cares for this group of people. Currently all ambassadors are based in the Netherlands, but strong networks are starting to emerge in Germany, France, UK, Austria and Cyprus. There is an expectation that by end 2016 there will be ambassadors in other European Countries.



Leonie Rouweler



Danielle de Bakker



Irma van der Hoek



Jessy van der Pol



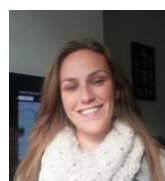
Rene van der Rijst



Tim Kroesbergen



Annemarie Visser  
and Kris Koendis



Marijke van Liempt



Welmoed Santema



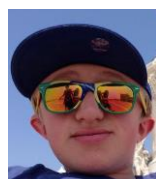
Rob en Rebecca van  
Berkel



Jeanette Chedda



Mira Thompson



Melvin Elderhorst



Karin Kragt-  
Vermolen

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





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

**Our heartfelt thanks for all of our amazing ambassadors – small and big!**

## Fundraising initiatives 2015

2015 has been another great year for fundraising. In total we raised €118,503. From duck races to cake sales, running challenges to car rallies, 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 hard-needed funds for research into OI.



**RUNNING FOR Care4BrittleBones:** 2015 was an amazing year for fundraising through running challenges. One such motivated fundraiser was Arjan Harsevoort, a transition coordinator of the Dutch OI Group and clinical nurse specialist at the Isala Hospital in Zwolle, which houses the expertise centre for Osteogenesis Imperfecta in adults. Already committed for many years to the care of people with OI, Arjan (pictured far left) ran the Zwolle half marathon together with Erik Meinen, father of Sara Avelin (who has OI). The achievement raised an impressive 3,300 EUR for much needed OI research, which far exceeded their goal amount.

Diane Blacow (right) made her debut in the world of organised running events after recovering from breaking a bone in her foot. She ran the '15 of Wassenaar', a 15 km course, and succeeded in raising 1025 EUR for people with OI, for "those who aren't able to run themselves". Another debut came from Care4BrittleBones Chairperson, Dagmar Mekking. The City Pier City run in The Hague was her very first half marathon, which delivered a superb amount of 2,539 EUR.



One of the biggest events each year for our foundation is the Dam to Dam run. As always, Care4BrittleBones was there to cheer on the runners this year while they enjoyed the fun challenge of running the famous 16 km course from Amsterdam to Zaandam. The participants raised a total of 3.330 EUR for the foundation.

All the runners that raise funds for Care4BrittleBones do so via Just Giving, one of the leading providers of fundraising websites. Care4BrittleBones has created an account free for anyone to use for fundraising for OI (<https://www.justgiving.com/Care4BrittleBones>). 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 of their action page by e-mail and social media with their networks, inviting them to support their personal and charity goals.





**SCHOOL CHARITY RUNS FOR Care4BrittleBones** – Our network of ambassadors continues to reach out to partners around them to help with fundraising. As a result, many schools have started to support Care4BrittleBones through organising a ‘charity run’ for OI research. By spreading awareness, children learn more about the child in their school who has “something with fractures”. They are then sponsored by family and friends to run as many ‘rounds’ of a circuit as possible. This is a great way to allow children to do something for others! Raising between 1,000 EUR and 10,000 EUR per school, these charity runs often engage several hundreds of people and lead to very welcome media attention.

Benthe, daughter of Care4BrittleBones ambassador Welmoed Santema, organised a fantastic sponsored run together with her school OBS Slingerbos in Diepenveen. The proceeds raised by Benthe (pictured centre) and her classmates reached a very admirable 3,500 EUR.

**WOESTIJNRALLY** – Following the resounding success of 2013, the second WoeSTIJNRally took place this year. The ‘Desert Rally’ is named after Stijn Rouweler, a child from Wesepe with OI. It is a ‘puzzle tour’ by car and motorbike whereby the 275 participants have to perform tasks during the scenic route around Wesepe.

This very special and fun event hosted by our ambassador Leonie Rouweler, husband Wijnand, their sons Daniel and Stijn, and all their friends resulted in an overwhelming response and a cheque for the incredible amount of 8,008 EUR for OI research.





**NATIONAL POSTER CAMPAIGN 'STIJNSTORY'** – Launched in March 2015, the nationwide poster campaign with Stijn Rouweler has resulted in many reactions from the general public. The triple-sign posters placed throughout the length and breadth of The Netherlands invite people to visit [www.stijnstory.nl](http://www.stijnstory.nl) and learn Stijn's story about living with OI.

Aside from raising donations and creating visibility for our foundation, the campaign has contributed to the much needed increase in awareness about OI in society. The campaign continues into 2016 and will be augmented by an additional campaign.





# FINANCIAL REPORT





# Treasurer report

## 2015 review

During the fourth year since the start of the Care4BrittleBones foundation, the level of fundraising activities remained high. This has resulted in a stabilisation of our income compared to 2014. Noticeable activities include charity runs, school and club activities, a rally, a few large donations from funds and a large number of donations from companies and individuals. Bottle deposit actions at supermarkets have also made a significant contribution to our income.

Cost related to Fundraising and Governance has been kept to an absolute minimum and no remunerations or any other compensation for cost incurred has been paid to any volunteer associated with the foundation. The total costs of fundraising and governance activities were less than 2.5% of the generated income, which is far below the maximum recommended by CBF (Centraal Bureau Fondsenwerving – the Central Bureau of Fundraising – which is the quality seal for charities in the Netherlands). Governance costs mainly consist of insurance premium, cost of banking, (promotion) materials and some web development costs.

Three research projects have been funded for a total amount of over EUR 56,000 and another EUR 100,000 has been committed to 3 different research projects during 2015. From the general reserves of some EUR 116,000 there is EUR 66,000 available for further funding of projects. The remainder of the General Reserves will be held for continuity reasons. These surplus funds are being held in risk-free savings accounts.

The Income Statement, Balance Sheet and Cash Flow Statement have been prepared in line with “Directive 650 for Fundraising Institutions”. An overview of the status of project commitments as at 31st December 2015 has been added.

## Future Plans

A wide range of fundraising activities are planned to take place during 2016. Further commitments to research programmes that meet the goals of the foundation are intended to be made during 2016. The foundation has no fixed cost and does not intend to make such commitments going forward. Costs of fundraising activities will be kept as low as possible, with the aim to spend at least 95% of funds raised on research activities over time.

**Piet van Erk, Treasurer, Care4BrittleBones**





# Financial statements

## Income statement:

INCOME	Budget 2015	2015	2014	2013
Donations	100.000	63.076	99.331	25.077
Sponsoring		3.116		10.897
Sale of Products / Auctions	1.000	95	1.026	2.064
other Fundraising (Incl. JustGiving)	19.000	49.976	17.938	38.844
Interest Income		2.240	398	
<b>Total Income</b>	<b>120.000</b>	<b>118.503</b>	<b>118.693</b>	<b>76.882</b>

EXPENDITURE	Budget 2015	2015	2014	2013
Cost of Fundraising activities	1.500	1.082	1.309	2.184
Cost of purchase products			-	
Governance costs	2.000	1.781	2.078	918
<b>Total Expenditure</b>	<b>3.500</b>	<b>2.863</b>	<b>3.387</b>	<b>3.103</b>

PROJECTS AND EVENT FUNDING	Budget 2015	2015	2014	2013
Research projects funded		56.114	6.000	
sponsoring events			1.227	
movement in project commitments		60.768-		
New projects committed	150.000	102.622	103.739	
<b>Total Project and event funding</b>	<b>150.000</b>	<b>97.968</b>	<b>110.966</b>	<b>-</b>
<b>Balance carried forward</b>	<b>33.500-</b>	<b>17.672</b>	<b>4.340</b>	<b>73.779</b>





### Balance Sheet:

<b>Current Asset</b>	<b>2015</b>	<b>2014</b>	<b>2013</b>
Debtors	51.887	-	10.100
ABN AMRO Current Account	8.842	2.370	4.189
ABN AMRO Savings Account	201.292	200.000	80.000
<b>Total Assets</b>	<b>262.021</b>	<b>202.370</b>	<b>94.289</b>

<b>Liabilities &amp; Reserves</b>	<b>2015</b>	<b>2014</b>	<b>2013</b>
General reserves	116.303	98.631	94.289
Projects committed	145.593	103.739	
Creditors	125	-	-
<b>Total liabilities and Reserves</b>	<b>262.021</b>	<b>202.370</b>	<b>94.289</b>

### Cash Flow Statement:

	<b>2015</b>	<b>2014</b>	<b>2013</b>
<i>Cash collected from:</i>			
donations	11.899	109.433	34.624
Sales of Products	95	1.026	2.064
Other Fundraising	52.507	17.938	38.844
Interest received	2.240	398	-
<b>Total cash collected</b>	<b>66.741</b>	<b>128.795</b>	<b>75.532</b>
<i>Cash paid for:</i>			
Research projects	56.114	6.000	-
Sponsoring events		1.227	-
Governance costs	1.781	2.078	1.055
Fundraising activities	1.082	1.309	2.184
<b>Total cash paid</b>	<b>58.977</b>	<b>10.614</b>	<b>3.239</b>
<b>Net cash from operations</b>	<b>7.764</b>	<b>118.181</b>	<b>72.293</b>

<b>Cash Balance</b>	<b>2015</b>	<b>2014</b>	<b>2013</b>
Opening balance ABN AMRO Bank	202.370	84.189	11.897
Closing balance ABN AMRO Bank	210.134	202.370	84.189
<b>Net cash from operations</b>	<b>7.764</b>	<b>118.181</b>	<b>72.292</b>

<b>Key Performance Indicator:</b>	<b>2015</b>	<b>2014</b>	<b>2013</b>
% Cost of Fundraising activities / Income	2,42	2,88	2,11



## Committed Projects

31 december 2015

Project title	Institution / Lead Researcher	Total committed	Total Paid	To be Paid
<b>Proposal round 2013</b>				
Ol and fatigue	The Netherlands: Isala Clinics (A. Harsevoort):	3.000	0	3.000
<b>Proposal round 2014</b>				
Therapy for patients with Osteogenesis Imperfecta (OI)	The Netherlands: VU Medical Center (Dr. F. van Dijk)	30.483	0	30.483
Pain Less - OI Youngsters take control	Portugal: University of Lisbon (Prof. Luisa Barros):	12.602	10.114	2.488
Gene/cellular therapy	Italy: University of Pavia - Biochemistry Unit (Prof. Antonella Forlino):	26.000	26.000	0
Treatment of Osteogenesis Imperfecta in Adults	Denmark: Aarhus University Hospital (Prof. Bente Langdahl):	30.000	20.000	10.000
<b>Total 2014</b>		<b>99.085</b>	<b>56.114</b>	<b>42.971</b>
<b>proposal round 2015</b>				
Identifiation of novel therapeutic compounds for the treatment of Osteogenesis Imperfecta (OI) targeting collagen deficiency	The Netherlands Vumc, Clinic Genetics, AMS, NL, Gerard Pals and Dimitra Micha	47.250	0	47.250
Role of Parental Mosaicism in the Transmission of Disease Causing Mutations in Patients with Osteogenesis Imperfecta	Fundació Clinic per a la Recerca Biomèdica, Barcelona, Spain, Eva Gonzalez-Roca	23.872	0	23.872
3D geometric morphometrics of the thorax and respiratory muscles of Osteogenesis Imperfecta patients	Department d'Anatomia i Embriologia Humana, Spain, Juan Alberto Sanchis and Markus Bastir	28.500	0	28.500
<b>Total 2015</b>		<b>99.622</b>	<b>0</b>	<b>99.622</b>
<b>Overall Total</b>		<b>201.707</b>	<b>56.114</b>	<b>145.593</b>







# Thank you

Without our generous donors, fundraisers, ambassadors and sponsors 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 fun and creative than we could have ever imagined! A sincere and very big thank you goes to everyone who has supported our cause and believes with us that we can make a change for people with OI.

Many thanks too to the core team for the numerous inspiring discussions about how we can make a positive difference and for the powerful actions that flow from these. We had a very successful 3<sup>rd</sup> year of fundraising for OI research, which has given us a huge amount of additional energy, learning, and inspiration to continue on this long journey to improve the lives of people with OI and ultimately to find a cure.





# 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.

Since 12 February 2013, Care4BrittleBones is recognised as a charitable organisation in the Netherlands (RSIN 851392854; [www.kennisbankfilantropie.nl/anbi/care4brittlebones](http://www.kennisbankfilantropie.nl/anbi/care4brittlebones)).

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



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