



CARE4BONES

Annual Report 2023

ANNUAL REPORT 2023

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Connecting the world of Rare Bone Diseases

The purpose

The purpose of CARE4BONES is to promote quality of life for people with rare bone diseases. In 2023 we focused on OI to develop and refine our approaches before we roll them out more widely. In 2024 we will include the full spectrum of Rare Bones Diseases as intended by our statutory purpose.

We work on Quality of Life by providing an innovative space for **networking** within and across communities in the Rare Bone area: the various patient communities dealing with Rare Bone conditions and the professional community caring for people with Rare Bone Diseases. We support **knowledge sharing** and make collaboration on research and healthcare improvement easy. An example of how we work is the virtual Conference QUALITYOFLIFE4OI, which brings together 500+ professionals and people with Rare Bone Diseases from 90 countries worldwide. Because the conditions are rare, we can **make a huge impact** by working together across the globe.



Networking



Sharing Knowledge



Making an impact

2 communities, 3 platforms

CARE4BONES operates across 2 communities and three separate yet related platforms:

- **CARE4BONES for Professionals working with Rare Bone Diseases:** A platform for any professional who cares for the quality of life of people with rare bone diseases (geneticists, biologists, basic scientists, radiologists, internists, orthopaedic surgeons, endocrinologists, physiotherapists, occupational therapists, psychologists, nurses / physician assistants, rehabilitation physicians, rheumatologists, dentists, nephrologists, pulmonologists, and many other disciplines).
- **CARE4BONES for OI and the Rare Bones Patient Community:** Two platforms with identical content and functionality. We established 2 separate platforms because OI currently stands out as the biggest, most established and active rare bone community. By choosing for a separate rare bone platform for everyone but OI a level playing field is established that will be more favourable for the development of the other organisations.

Importantly, the webinars in the Rare Bones Community and OI community are identical and all communities come together in 90% of all webinars. In most cases webinars for Professionals (eg a Basic Science Webinar) is also accessible for the patient community and vice versa. Professionals

can usually attend also webinars lead by the Patient community featuring an OI community Speaker (eg Parita D. about her work as communications professional with hearing impairment in a corporate environment).

Data privacy is key. Every participant is only visible with their first name and first letter of the last name. Every participant can change the visibility of information in the platform and adapt the communication preferences (eg if they want to receive the regular newsletter or not). The information on the platform is not shared with social media or third parties. On the platform, participants can indicate their interests and talents. Also, they can indicate in what ways they want to engage with others on the platform (eg coaching other people with the same rare bone disease).

Activities on CARE4BONES

On CARE4BONES professionals and members of the rare bone community can attend a broad range of activities supporting quality of life. The subject of quality of life is approached in a broad and integrated way. The diversity of topics enables everyone to build on each other's strengths. The available information also makes it possible to collaborate and learn together. The following functionalities are available:

1. Webinars for professionals (accredited) and people with rare bone conditions. Together and separate, depending on the topic and objective of the session.
2. Virtual Conferences (accredited)
3. Thematic collaboration in networks
4. Research projects and online focus groups
5. Round tables for the rare bones community to discuss topics of interest
6. A unique database of professionals supporting rare bone conditions and people with rare bone conditions.

Participants in 2023

By the end of 2023 **1304 people with OI from 93 different countries** were active on the platform. This is an increase of 19% compared to 2022. Also, there are **406 healthcare providers and researchers (of which 287 paid accounts) from 40 countries on the platform**. This is a steep increase compared to 2022. Both networks keep growing very much “triggered” by content, eg events like webinars or conferences people would like to attend.



Foundation CARE4BONES

CARE4BONES (www.care4bones.org) is a foundation that drives engagement with healthcare providers/researchers and people with rare bone conditions using an innovative IT platform. It is an open research and healthcare collaboration platform, in the widest sense of the word with the objective to support Quality of Life improvements for people with rare bones.

The statutory aim of CARE4BONES is to promote scientific research into rare bone disorders to improve the quality of life of people with these conditions.

The foundation works towards this goal by doing the following activities:

- setting up and maintaining a virtual collaboration platform (i.e. CARE4BONES)
- raising funds;
- funding research and activities related to research;
- contributing to impactful research by developing priorities and strategies for improving rare bone disorders and supporting research and research collaboration
- informing the communities, for example by publishing information.

What should CARE4BONES feel like:

Easy	Super user-friendly for admins and for users.
Safe	Only confirmed participants.
Quality	Curated information in general space. Healthcare providers allowed to publish in their own space
Affordable	No cost for patients and Meds from lower income countries. Small contribution for professional participants
Inclusive	Rules around inclusive culture and suspension/exclusion when breach
Sustainable	Supported by various parties and partnerships (eg patient organisations, expertise centers and others)
Agile	Layered service model. Learn as we go.
Global	Rare Bone Conditions have no boundaries.

The board of CARE4BONES

At the end of the year 2022 Care4Bones was formally led by its Board of 6 team members:



**Andreas
Matsangos**
President



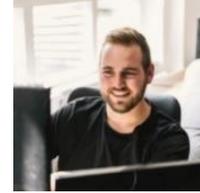
**Celine
Disch**
Vice president



**Dagmar
Mekking**
Director



**Dirk-Jan
Stegink**
Treasurer



**Nicklas
Teicke**
Fundraising



**Lidiia
Zhytnik**
Research



In 2023, Andreas Matsangos has been succeeded by **Vanja Zivkovic**, the new CARE4BONES President. Vanja was born in Serbia and moved to Switzerland as a teenager. She studied medicine and was Swiss delegate for OIFE for about 8 years. After her studies she specialized in pediatrics and worked for many years in the University Hospital of Zurich in the field of intensive care for children. Since July 2022 she is working as head of department of inpatient pediatrics at the Hospital of Winterthur in Switzerland.

The Board is ultimately accountable for all aspects of the foundation, with a strong focus on strategy, finance, risk and governance. The Board meets twice a year and more often if required. It approves the annual budget, operational plan, strategy document and (re)appointment of the director and monitors the performance against the plans. The Board formally reviews the performance of the director annually.

The CARE4BONES COMMUNITY LEADERS

The CARE4BONES Community is supported by 5 inspiring Community Leaders who support the 3 activities of CARE4BONES: Connecting, learning & sharing and making an impact on Quality of Life with Rare Bones. Each of the community leaders has a focus area they are active within, eg Emotional Wellbeing, Physical Wellbeing, Parenting, Adult life with rare bones etc.



**Dorna
Beyk**



**Tahné
van Wonderen**



**Sander
Colijn**



**Cynthia
Jacobs**



**Qusai
Al Rifai**

How CARE4BONES relates to Care4BrittleBones

The CARE4BONES Foundation was initiated by the Care4BrittleBones Foundation. It was set up as a separate legal entity to enable the platforms to develop independently and be shared with other stakeholders in the future. Care4BrittleBones is mainly focused on OI. CARE4BONES exists to support Quality of Life for everyone with rare bone diseases. The focus and activities of CARE4BONES are complimentary to the Care4BrittleBones Foundation:

- The Care4BrittleBones Foundation focusses on the **strategic** projects and takes a long-term perspective. It engages with multiple stakeholders, financially supports research projects and raises funds for research through the Care4BrittleBones Foundation.
- The strength of CARE4BONES is the **operational support** to knowledge exchange and communication across the communities. It organises networking sessions, webinars, focus groups and collaboration for research projects.

*“The reason we exist is to make **more impact** for quality of life for people with rare bone diseases. Occasional ad hoc webinars and conferences are just not enough. Today virtual collaboration platforms exist that are more **inclusive** and enable very **effective** ways to learn and work together amongst professionals and the rare bone community **around the world**”*



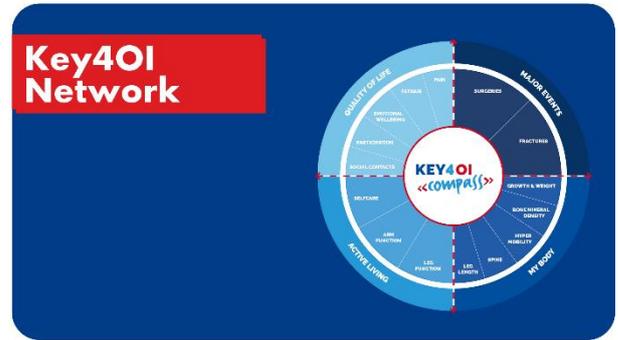
ACTIVITIES OF THE NETWORKS



*“On CARE4BONES it’s easy to present a **webinar** or to lead a **network**. Everyone receives support from our central team of “patient experts”.*

The CARE4BONES networks are open to people with rare bone conditions as well as professionals around the world at all career stages (early career, established or retired). The networks are the “heart” of CARE4BONES and each led by highly qualified professionals as well as patient experts.

Some examples of networks:



Networks emerge and (occasionally) dissolve based on the need of the communities we serve. Other Networks are

- the Basic Science Network,
- the orthopaedic network,
- the hearing network,
- the pulmonary network,
- the teeth & jaw network.

The size of the networks varies. The activities are orchestrated by the network leaders on behalf of the community of interest they represent.

MULTIDISCIPLINARY CARE FOR RARE BONE CONDITIONS

Healthcare for rare bone conditions requires a multidisciplinary effort. CARE4BONES has been built with this in mind.



CARE4BONES for multidisciplinary teams

Hospitals can join CARE4BONES with their multidisciplinary team. In 2023 12 organisations had joined the platform with their teams (max 20 people per organization).



Sheffield Teaching Hospitals
NHS Foundation Trust



CARE4BONES for networks

Every specialist within a multidisciplinary team can reach out easily to specialists in other multidisciplinary teams around the world. In 2023 5 networks were active: The

Basic Science network, the orthopaedic network, the physical wellbeing network the emotional wellbeing network and the Key4OI Community.



Join the Key4OI Learning Community

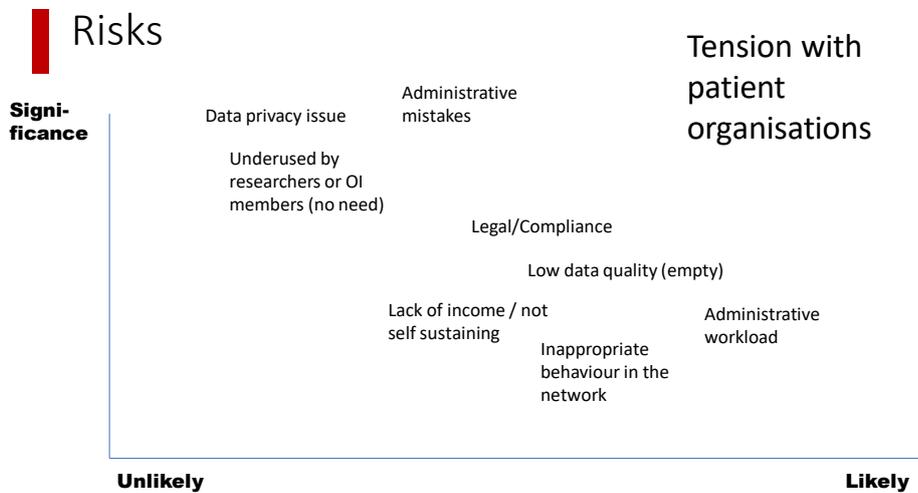
Key4OI is a standard set of outcome measures suitable for all people with OI, throughout a lifetime, anywhere in the world. Over time it will improve quality of life measurably for people with OI individually and collectively. It supports multidisciplinary care and research.

In 2023, CARE4BONES organized various activities related to Key4OI:

1. The Conference Quality of Life featured 4 Key4OI webinars
2. The monthly Pilot meetings were held on CARE4BONES and meeting recorded.
3. 1 Key4OI Affiliate meeting was organized on CARE4BONES.

Risk management

As any organisation, the CARE4BONES foundation needs review risks it may be facing on a regular basis. The risk overview below was created during a review in 2021 that helped the CARE4BONES board to discuss the risks and possible mitigations. The risk landscape has remained largely the same, as confirmed by a review of the CARE4BONES Board in 2023.



The key risk identified is related to potential tension with patient organisations. The CARE4BONES foundation recognises that many patient organisations struggle to keep members and find board members. They may find a global organisation a potential threat. We monitor this area closely. Fortunately, we are finding that most patient organisation appreciate the exitance of CARE4BONES. They value the access to good quality information material. They attend webinars and contribute webinars about their own best practices. Also, they like to connect their professionals with more experienced professionals in other countries. To our knowledge sensitivities remain mainly with OIFE and 3 OI patient organisations. We continue to listen to their concerns and trust that over time the benefits of the platform will speak for itself.

CARE4BONES in 2023

The CARE4BONES Platform was started in January 2021. 2023 was therefore “year three” of our operations. We have focused this year on further establishing our processes and ways of working. Also, we have put dedicated volunteer resources in place to lead activities on the platform (eg the OI Community leaders and faculty of the networks). The following end results have been achieved:

1. Growing the community

Community Platform*

*In 2023 CARE4BONES focused on OI. Starting 2024 other rare bone diseases will be included.

1. Data Base

- # of accounts
 - 1205 (vs 1011 in 2022)
 - 55 requests pending
 - 99 (vs 74 in 2021, vs 94 in 2022) people indicate that there are 2 more people with OI in the family.)
 - All together about 1304 people are connected into Care4Bones.
- 93 countries (vs 80 in 2021 and 88 in 2022)
- 64% are not part of a patient organization (vs 58% in 2022)

2. Webinars (about the same as in 2022)

- 11 community related events
- 21 health / key4OI / skill related events
- 13 internal meetings with OI Community leaders, of which 1 F2F
- Attendance patchy
- VOI and OIF ok to post their activities on CARE4BONES

3. Projects supported

- Energy4OI – Fitness app
- Key4OI
- Qualityoflife4OI 2023 Conference
- Wishbone Day – Global OI Awareness Day

Professional Platform

1. Data Base

- # of accounts
 - 406 (vs. 271 in 2022).
 - 2 requests pending (same)
 - 287 paid (vs 38 in 2021, 165 in 2022), 68 complimentary access for people in lower income countries (vs 54 in 2022), 52 uncompleted registrations
- 40 countries (vs 38 in 2022)

2. Webinars

- 90% same as OI community platform

3. Networks / Projects

- Same as above

2. Robust operations

CARE4BONES established its own infrastructure from scratch to ensure information could be shared and communities could be reached.

- A separate e-mail was established (eg info@care4bones. Or dagmar.mekking@care4bones.org)
- 3 Hivebrite -websites with three separate licenses.
- YouTube Channel
- Facebook
- Instagram
- Data privacy agreements for everyone involved in CARE4BONES work
- CARE4BONES board meetings
- Annual report
- Zoom
- Dropbox / Teams

FINANCIAL REPORT 2023

From a financial point of view, we continue to ensure we cover the platform costs with the recurring income from membership contributions of (professional) individuals and institutions. In 2023 we had 12 institutions contributing (vs 10 in 2022) and individual contributions of EUR 3.900 (vs 2.304 in 2022). This puts us in a slightly better position to cover the platform costs and some other minor expenses, like payment and banking fees.

On top of these basic run and maintain activities (and associated costs), we also continued to work on the Care4Bones Academy, sponsored by the Agis Innovation Fund. This grant was already recognized as income in 2021, yet activities (and costs) continued into 2023, as planned. Roughly EUR 27.000 of our expenses were related to this project and hence covered by the reserves booked in 2021. The remaining expenses, roughly EUR 8.000, were more than covered by our income from membership contributions.

Another key item for a young foundation like ours is our cash position. Like in 2022, we managed to have a positive operational cashflow. While the amount of EUR 11.588 was a steep improvement from the EUR 1.481 in 2022, we again also increased our creditor level on our balance sheet. However, this latter increase was EUR 8.254, so even taking this into account, our liquidity improved.

It is good to note our creditor position is being carefully managed and has not led to any payment issues. Thanks to our improved cash position, we plan to significantly reduce our debt levels in 2024.

Furthermore, in 2024 we'll be looking to further professionalize our organization and broaden the reach of our platform to other rare bone diseases in line with our statutory purpose. Financially this will only be possible with (a) new source(s) of funding, since our current recurring income will only sustain the current operations. We look forward to raising more funds for new projects that contribute to our goal of promoting quality of life for people with rare bone diseases, with a focus on knowledge exchange and communication across all communities related to Rare Bone Conditions -professionals and patient communities- worldwide.

Income Statement

Income & Expenses	Notes	Actual 2023	Budget 2023
Income			
Income from Individuals		3.900	3.000
Income from Companies		11.438	12.000
Income from Grants from Government			-
Income from other Non-Profit Organizations			-
Total Acquired Income		<u>15.338</u>	<u>15.000</u>
Income as compensation for the delivery of:			
- Products and/or Services		0	
Total Income		<u>15.338</u>	15.000
Expenses			
Spent on Goals			
- Information sharing & Collaboration		21.840	29.940
- Platform related costs		<u>11.000</u>	<u>11.000</u>
		32.840	40.940
Fundraising costs		0	7.200
Management & Administration costs		<u>2.621</u>	<u>2.538</u>
Total Expenses		<u>35.460</u>	<u>50.678</u>
Balance before Financial Income & Expenses		-20.122	-35.678
Balance Financial Income & Expenses		0	0
Balance Income & Expenses		<u>-20.122</u>	<u>-35.678</u>
Assignment Balance Income & Expenses			
Addition to / Withdrawal from:			
- Other Reserves		16.397	
- Earmarked Funds		-	
		<u>16.397</u>	

Balance Sheet

	Notes	31/Dec/23	
		EURO	EURO
Assets			
Receivables & Accrued Assets	1	34.678	
Cash & Cash Equivalents	2	24.205	
			<u>58.883</u>
			<u>58.883</u>
Liabilities			
Reserves & Funds			
- Reserves			
- Earmarked Reserves	3		
- Other Reserves	3	<u>16.397</u>	
			16.397
- Funds			
- Earmarked Funds	4		<u>0</u>
			16.397
Long Term Debt	5		0
Short Term Debt	6		<u>42.486</u>
			<u>58.883</u>

Note 1

	2023	2022
Receivables & Accrued Assets	EURO	EURO
Receivables from Individuals	-	-
Receivables from Companies	5.479	2.826
Grants from Government	-	-
Interest/BTW	401	1.309
Receivables from Non-Profit Organizations	29.600	54.000
Total	34.678	58.135

Note 2

	2023	2022
Cash & Cash Equivalents	EURO	EURO
ABN AMRO Current Account	24.205	12.570
ABN AMRO Savings Account	-	-
SNS Bank Savings Account	-	-
Total	24.205	12.570

Note 3

	2023	2022
Reserves	EURO	EURO
balance 1/1	36.519	68.270
Additions	0	0
Withdrawals	-20.122	-31.750
Balance 31/12	16.397	36.519

Note 4

	2023	2022
Earmarked Funds	EURO	EURO
balance 1/1	0	0
Additions	0	0
Withdrawals	0	0
Balance 31/12	0	0

Note 5

	2023	2022
Long Term Debt	EURO	EURO
Project Commitments	0	0

Note 6

	2023	2022
Short Term Debt	EURO	EURO
Project Commitments	-	-
Creditors	42.486	34.232
Total	42.486	34.232

Cash Flow Statement:

	2023	2022
<i>Cash collected from:</i>		
donations	14.685	10.938
Income from Grants from Government	-	-
Income from other Non-Profit Organizations	22.400	22.000
Products & Services	-	-
Interest / BTW received	1.710	(968)
Total cash collected	38.795	31.971
<i>Cash paid for:</i>		
- Information sharing & Collaboration	13.586	13.558
- Platform related costs	11.000	11.000
Governance costs	2.621	4.732
Fundraising activities	-	1.200
Total cash paid	27.207	30.490
Net cash from operations	11.588	1.481
Cash Balance:	2023	2022
Opening balance ABN AMRO	12.616	11.135
Closing balance ABN AMRO	24.205	12.616
Net cash from operations	11.588	1.481

Thanks

We would like to thank everyone who has been involved in the third year of operations of CARE4BONES. We look forward to building an engaged and impactful online community in 2024 and beyond.

Our special thanks go to the Agis Innovation Fund. Thanks to a generous donation assigned to us. This has made a big difference in our ability to organize activities that matter to people with OI and other rare bone diseases!



e-mail info@care4bones.org

Internet www.care4bones.org

 www.facebook.com/care4bones

 https://www.youtube.com/channel/UCDd737sMgQ1mkY_Mk0hrPcA