



# ANNUAL REPORT 2020

PATIENT ASSOCIATION  
CMTC-OVM  
[WWW.CMTC.NL](http://WWW.CMTC.NL)



*cmtovm*

# COLOPHON

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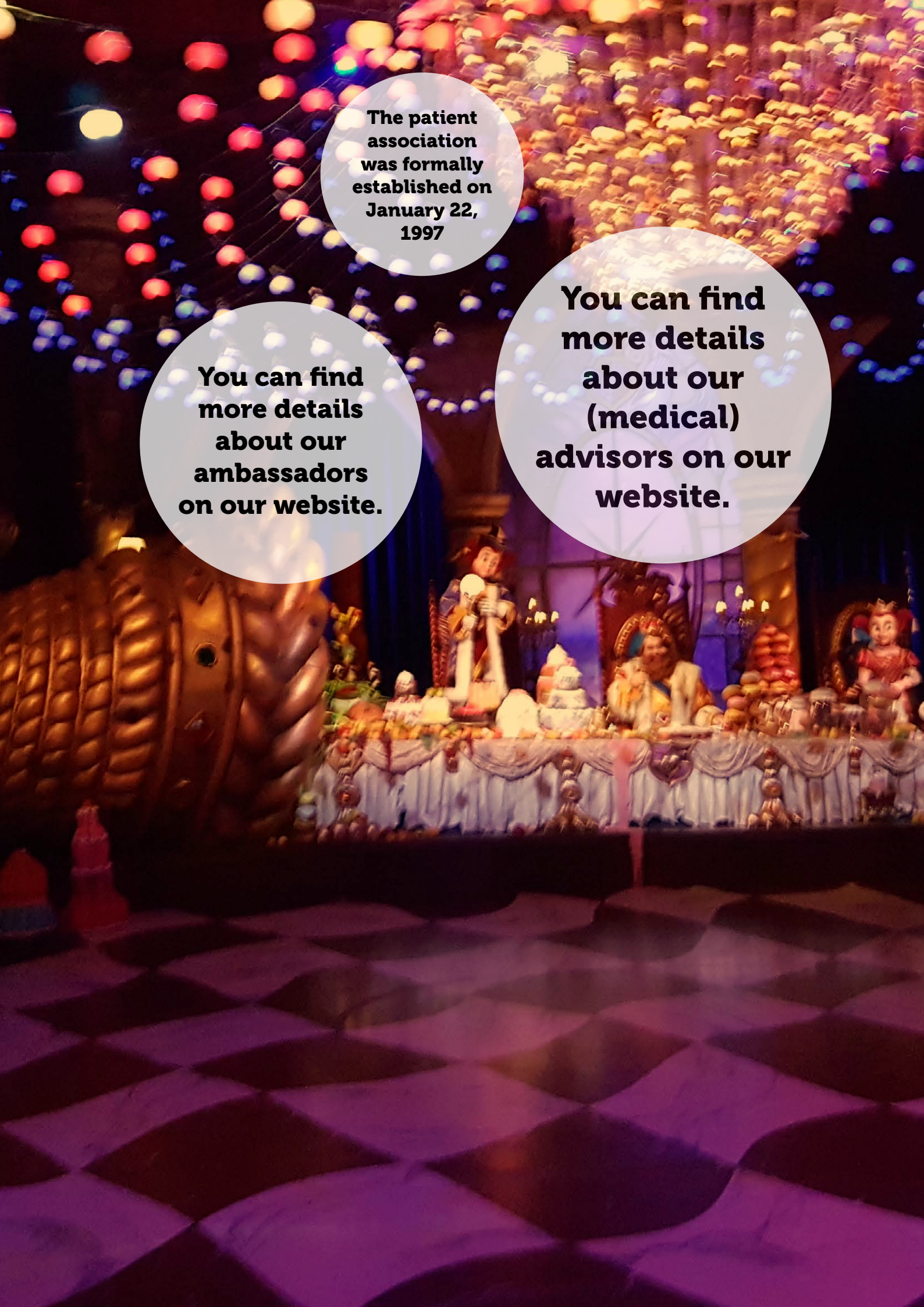
CMTCOVM

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The background of the entire page is a photograph of a festive stage display. On the left, a large, textured, golden-brown structure resembling a giant's foot or a large drum is visible. The stage is covered with a white cloth and is populated with several figures, including a man in a blue and white outfit holding a white object, and a woman in a red and white outfit. The stage is decorated with various items, including a large, ornate, golden-brown structure. The background is filled with numerous small, colorful lights in shades of red, yellow, and blue, creating a bokeh effect. The floor in the foreground is covered with a large, dark, checkered pattern.

**The patient  
association  
was formally  
established on  
January 22,  
1997**

**You can find  
more details  
about our  
ambassadors  
on our website.**

**You can find  
more details  
about our  
(medical)  
advisors on our  
website.**

# 1 1 INTRODUCTION

## 1.1 Purpose of this Document

This document contains the 2020 annual report of the patient association CMTC-OVM. The purpose of this document is primarily to provide an overview of the activities performed in 2020.

## 1.2 Introduction

The patients' organisation was formally established on January 22, 1997 by notary "Van Helden" in Amsterdam and subsequently registered with the Chamber of Commerce in Amersfoort. The purpose of the association, which is laid down in the statutes, is expressed in the text below.

### The mission is:

**Promoting the well-being of people suffering from vascular malformations such as CMTC ("Van Lohuizen syndrome"), in particular its own members, and promoting and developing activities that can promote this well-being. The promotion of (scientific) research with regard to vascular malformations such as CMTC, the causes and treatment thereof, and everything related to it in the broadest sense of the word.**

The name is: CMTC-OVM which stands for: Cutis Marmorata Telangiectatica Congenita and Other Vascular Malformations.

The logo is:



## 1.3 Administration

The board is composed as follows on December 31, 2020:

Mr. A.F.R. van der Heijden, Chairman;

Mrs. A. Fluijt, Secretary;

Mr. J. Schipper, Treasurer.

## 1.4 Advisors

Our advisors in 2020 are:

Mrs. Prof. Chantal van der Horst.

Mr. Dr. Patrick Kemperman.

Mr. Dr. Peter de Laat.

Mrs. Dr. Margaret Lee (USA).

Mrs. Dr. Christianne van Nieuwenhoven.

Mrs. Dr. Charlene Oduber (Aruba).

Mrs. Prof. Dr. Suzanne Pasmans.

Mr. Dr. Millan Patel (Canada).

Mr. Prof. Dr. Maurice van Steensel.

Mr. Prof. Dr. Peter Steijlen.

Mr. Prof. Dr. Miikka Vikkula (Belgium).

Mrs. Dr. Maaïke Vreeburg.

You can find more details of our medical advisors on our website.

## 1.5 Ambassadors

At the end of 2020 we have three ambassadors. These are Prof. Dr. Jan Peter Balkenende (former prime minister of the Netherlands), Dr. Steve Groft (former director of rare diseases within the American National Institute of Health) and Eden Quine-Taylor (United Kingdom).

More details of our ambassadors can be found on our website.

## 1.6 Volunteers

The association is supported solely by voluntary staff, including the board. In addition to the board, various volunteers are active with different activities. As an example, translation work and social media. In addition to the board, there were around 50 volunteers active worldwide as of December 31, 2020, particularly in the field of translation work, recruiting members / donors, the audit committee, the complaints committee and during the members' meeting. We also include our medical advisers and ambassadors in this volunteer count.





Practical tips for a conversation  
with your healthcare provider

When your brother or sister is ill

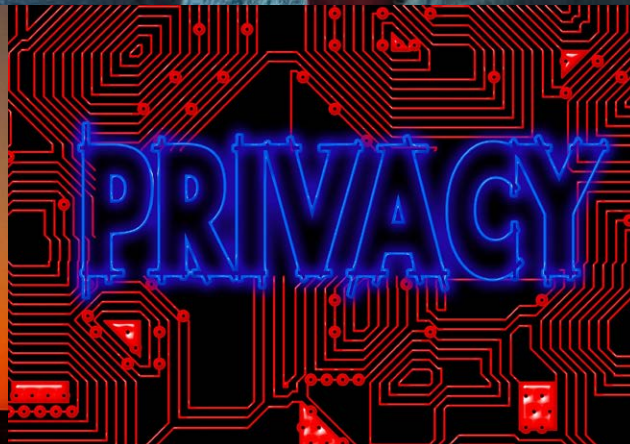
A sick child impacts the whole family, which sometimes



**CMTC**

Cutis marmorata  
telangiectatica congenita

The psychological aspects  
of living with a rare disease



## 2 ACTIVITIES 2020

We are grateful in particular for the subsidy received from the Ministry of Health, Welfare and Sport, which enabled us to carry out a large number of (extra) activities in 2020.

Due to COVID-19, we were forced to cancel or reorganise several activities, especially our Family Day, our members' conference and participation in all kinds of other conferences. In close consultation with the Ministry of Health, Welfare and Sport, the earmarked budgets were allocated to other activities.

The most important activities that we carried out in 2020 are:

1. **Online members' conference.**
2. **New website.**
3. **Leaflet "After the diagnosis".**
4. **CMTC - GP leaflet.**
5. **CMTC patient journey.**
6. **ERN & ePAG.**
7. **External (online) conferences.**
8. **Genetic research.**
9. **Collaboration with organisations, e.g. nonprofit patient organisations.**
10. **Project 'patient advocates'.**
11. **Newsletter.**
12. **Eurordis RareConnect project.**
13. **Fundraising.**
14. **CEO Council.**
15. **Professionalisation of the organisation.**
16. **Certification marks.**
17. **Marketing.**

### 2.1 Online members conference

This year, our global members' conference was held online on 24 October 2020.

A total of over 30 people attended from Australia, Belgium, Canada, Germany, England, Japan, Kenya, the Netherlands, Norway, Poland and the USA.

Presentations were held by Prof. Dr. Miikka Vikkula (Belgium), Dr. Margaret Lee (USA) and Lex van der Heijden (the Netherlands). Prof. Dr. Suzanne Pasmans answered all kinds of medical questions. These questions and answers are included in our FAQ list on our website.

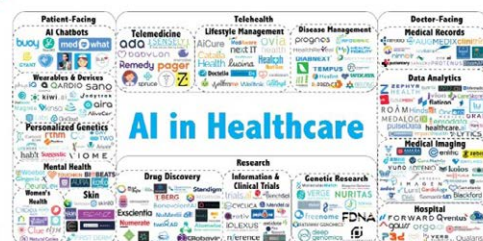
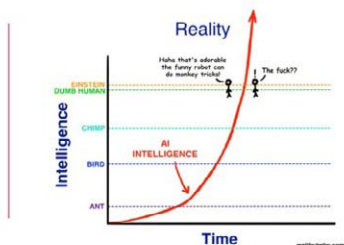
Reports and videos of the meetings are available on our website.



## Artificial Intelligence: Ready for Healthcare?

## Applied AI in Healthcare: Baby steps.....

"By far, the greatest danger of Artificial Intelligence is that people conclude too early that they understand it"  
Eliezer Yudkowsky



THE 10<sup>th</sup> EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS  
ONLINE on 14-15 May 2020

OUR VALUES, OUR RIGHTS, OUR FUTURE:  
SHIFTING PARADIGMS TOWARDS INCLUSION



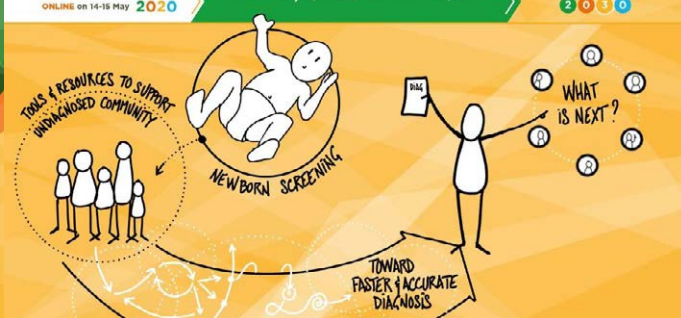
THE 10<sup>th</sup> EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS  
ONLINE on 14-15 May 2020

SHARE, CARE, CURE:  
TRANSFORMING CARE FOR RARE DISEASES BY 2030



THE 10<sup>th</sup> EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS  
ONLINE on 14-15 May 2020

THE FUTURE OF DIAGNOSIS  
NEW HOPES, PROMISES AND CHALLENGES



THE 10<sup>th</sup> EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS



ONLINE on 14-15 May 2020

#ECRD2020

THE JOURNEY OF LIVING WITH A RARE DISEASE IN

2030



## 2.2 New website

In March 2020, we started working with a new supplier to develop our new website. Through the good teamwork of approximately 30 people from different countries, our new website was launched on 26 May 2020.

By the end of 2020, our website contains over 3,000 photos, over 100 videos, over 900 articles and over 350 presentations/leaflets/etc.

In addition, new functions are available such as:

1. **Search tool (also supported by pdf files).**
2. **Read text aloud.**
3. **Being able to chat with us directly on the website using the chat function.**
4. **Translating the website directly into over 100 languages using machine translation.**

Members have access to all of our information on our website.

In 2021, we will further expand both the functionality and the content.

## 2.3 Leaflet "After the diagnosis"

In collaboration with the author of "After the diagnosis", we have not only updated our website with this practical and disease-independent information, but also developed a separate leaflet in five languages.

This leaflet can be downloaded from our website.

## 2.4 CMTC - GP leaflet

In cooperation with Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (VSOP, Dutch Patient Alliance for Rare and Genetic Diseases) and Nederlands Huisartsen Genootschap (NHG, Dutch College of General Practitioners), we have developed a leaflet about CMTC in five languages for general practitioners.

This leaflet can be downloaded from our website.

## 2.5 CMTC patient journey

In collaboration with the European Organisation for Rare Diseases (Eurordis), we have developed a 'patient journey' for patients with CMTC and their families.

The aim of this patient journey is to improve a patient's treatment by involving them.

With rare diseases, the patient often knows more about his condition than his doctor, which is exactly the opposite of what the patient needs.

Patients and their families face many challenges during their time in treatment. This process starts with the medical diagnosis, then the actual treatment and follow-up steps. The

patient will experience a lot of uncertainty and there will be many questions left unanswered. There are often no effective medical treatments.

The details of the patient journey is communicated via a poster and a table describing all kinds of details during all stages of life.

This information can be downloaded from our website.

## 2.6 ERN & ePAG

We actively participate in the European Reference Networks (ERN), the SKIN European Patient Advocacy Groups (SKIN ePAG) and VASCERN.

## 2.7 External (online) conferences

Because of COVID-19, practically all conferences have been replaced by online conferences.

Among others, we have participated in the following conferences:

1. **European Organisation for Rare Diseases) Eurordis.**
2. **International Society for the Study of Vascular Anomalies (ISSVA).**
3. **Canadian Organization for Rare Diseases (CORD).**
4. **European Reference Network Vascular Malformations.**
5. **European Academy of Dermatology and Venereology (EADV).**
6. **National Organization for Rare Disorders (NORD).**
7. **Asia Pacific Patients Congress.**
8. **Patient Academy (Novartis).**

On 28 February 2020, we participated in the international Rare Disease Day.

## 2.8 Genetic research

Genetic research into CMTC, which is mainly carried out in Belgium, is moving slowly because we are still unable to find enough patients with 'classic' CMTC who are willing to have a biopsy specimen (skin sample) taken.

## 2.9 Collaboration with organisations, e.g. nonprofit patient organisations

During 2020, we established new partnerships with a number of umbrella organisations in different countries.

These organisations focus on rare diseases in their respective countries.







We have established partnerships with umbrella organisations in the following countries:

1. **Australia.**
2. **China.**
3. **Kenya.**
4. **Austria.**
5. **South Africa.**

In 2021, we plan to establish even more partnerships. On our website, you will find a complete and up-to-date list of all organisations we work with.

## **2.10 Project 'patient advocates'**

The biggest problem that patients and parents of patients (our target groups) face is getting the correct medical diagnosis. This actually applies to all rare diseases. Our idea is to appoint Patient Advocates (PAs) in countries where patients with CMTC and Other Vascular Malformations (OVM) reside. A PA is an expert by experience, such as a patient or a direct family member, who knows the language and culture in a particular country and knows which doctors have knowledge of or experience with vascular malformations, e.g. to make a medical diagnosis. They can initiate and maintain peer-to-peer contact, they know the local health care services, can spread information, know how to use local social media platforms, etc. This project aims to have PAs from various countries come to the Netherlands at our expense and train them by means of a workshop. This workshop ties in with our global conference in the Netherlands.

We have been granted subsidies for this project by the Dutch government and started in July 2020. Due to COVID-19, the date on which the subsidies cease has been moved up to February 2022 because of its link to our conference in the Netherlands in 2021.

## **2.11 Newsletter**

In 2020, our newsletter was published three times in both Dutch and English. Our website provides an archive of these newsletters.

## **2.12 Eurordis RareConnect project**

We participate in the Eurordis Rare Connect Project where we have our own group and serve as moderators.

## **2.13 Fundraising**

In 2020, we have successfully done our own fundraising. In addition to the institutional subsidy from the Ministry of Health, Welfare and Sport, we received another project subsidy for our 'patient advocate' project and our leaflet on CMTC for general practitioners (GP leaflet).

## **2.14 CEO Council**

As a nonprofit patient organisation, we are part of the CEO Council of the Dutch Ministry of Health, Welfare and Sport (VWS).

In this context, CEO Council means 'Chief Experience Officers Council', i.e. experienced experts in health care. We call someone an expert by experience when they regularly need care, e.g. because they need care themselves (or did so in the past), have a disability or are an informal carer. The CEOs offer a new, patient-oriented look at the policy of VWS and put topics on the agenda that are particularly important to them. The goal is to bring the systems and the living environment together.

## **2.15 Professionalisation of the organisation**

In 2020, we managed to take a number of steps towards further professionalisation, especially by the launch of our new website.

For example, after registering as a member or donor via our website, an invoice is automatically generated by our external invoicing tool. The member or donor can subsequently gain access to a complete overview of their own invoices.

The majority of this professionalisation itself is not directly visible to our members and donors.

## **2.16 Certification marks**

We have been awarded several certification marks:

1. **ANBI (Algemeen Nut Beogende Instelling (Public Benefit Organisation)).**
2. **CBF (Centraal Bureau Fondsenwerving (The Netherlands Fundraising Regulator)).**
3. **NORD (USA, Platinum status).**

## **2.17 Marketing**

In this context, we interpret marketing as making our organisation and information more visible with the aim of reaching patients with CMTC-OVM, their families, care givers and donors or sponsors.

In addition, we want to improve the awareness of the general public of what people with CMTC-OVM may have to deal with in both their daily lives and their future.

We use various social media platforms such as Facebook, Instagram, Twitter, LinkedIn and YouTube.

We also run campaigns through social media platforms such as Google AdGrants and Facebook.







**1.  
Fellow  
Patients**

**3.  
Enabling  
Activities**

**2.  
Provision of  
Information**

**4.  
Patient  
Advocacy**

**5.  
Backoffice**

# 3 FINANCIAL OVERVIEW

## 3.1 Introduction

Again this year, we have been able to develop many activities in various areas and to further strengthen our position. Below is an overview of the various main items (expenditure and income).

The main items largely correspond to the structure which the Ministry of Health, Wellness and Sport uses, namely:

1. Contact with fellow patients/sufferers;
2. Information provision;
3. Patient advocacy;
4. Back office.

The back-office activity is new to us in 2020 and is intended to cover tasks that are not part of our core business, such as hosting our website, setting up or managing social media campaigns, preparing financial statements and creating graphic designs.

We have to pay for 'enabling activities' ourselves and it consists of, for example, board travel expenses, bank fees and education.

## 3.2 Overview of Expenditure

ACTIVITY	EXPENDITURE 2020 (€)	EXPENDITURE 2019 (€)
1. FELLOW PATIENTS	5.873	17.270
2. PROVISION OF INFORMATION	31.428	15.237
3. ENABLING ACTIVITIES	2.736	496
4. PATIENT ADVOCACY	9.815	13.971
5. BACKOFFICE 2020	10.794	0
TOTAL	62.253	49.214



We have received subsidy of our Patient Advocates project by ZonMW in 2020. This is not included in the income from projects of 2020 because this project has moved to 2021 due to the COVID-19 pandemic.

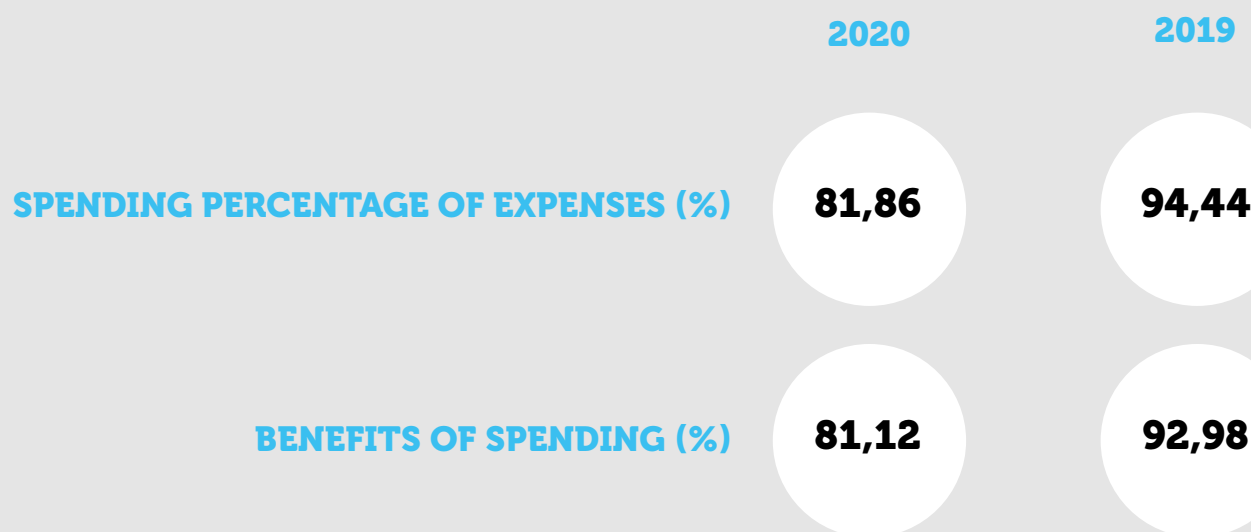
### 3.3 Income

FINANCIAL SOURCES	EXPENDITURE 2020 (€)	EXPENDITURE 2019(€)
MINISTRY HEALTH, WELFARE & SPORT	53.800	43.604
CONTRIBUTIONS / SUBSCRIPTIONS	3.375	3.079
DONATIONS / GIFTS / OTHER BUSINESS	1.800	2.614
PROJECTS	3.850	0
TOTAL	62.825	49.989





### 3.4 Expenditure



# 4 LOOKING AHEAD

The world is changing rapidly, and COVID-19 has played a crucial role in this.

In the past, it was very uncommon for patients and doctors to speak to each other via an online meeting; the patient really had to travel to see the doctor. In a very short time, care at a distance was forced to become our reality.

We expect care at a distance to become more frequent in the future.

Another thing we see and have experienced is that conferences will be held online more often. In 2020, this really took off and a huge number of online conferences were held.

It is clear that online conferences have many advantages, such as no time or money is spent travelling, they're easy to organise and cost less.

However, human contact and being able to look each other in the eye is something that is often missed.

Where international conferences are concerned, time zones are also a factor, e.g. when attending online conferences in Asia and the USA from Europe.

There are several possibilities, such as a hybrid conference (both physical and online) or one physical conference and one online conference a year (spread across the year).

The current tendency for people not wanting to become members of an organisation so readily is something that hasn't changed.

Through social media platforms, especially Facebook groups, it is possible to get in touch with other patients and families.

For the past two years, the Ministry of Health, Welfare and Sport has been changing the eligibility criteria for the institutional subsidy, where there is a move from the number of

In 2021, we intend to undertake various activities, including the following (depending on the implications of COVID-19):

- 1. Organising two international members' conferences, one online and the other on location in the Netherlands.**
- 2. Organising an international family day in the Netherlands in an informal setting, so that the threshold is as low as possible, with a focus on getting involved with patients and their families.**  
**This also provides an opportunity to get acquainted and to exchange knowledge and experiences.**
- 3. Reaching the 15-25 target age group in collaboration with, for example, JongPIT!**
- 4. Organising webinars that are publicly available.**
- 5. Expanding our new website with both higher functionality and more content.**
- 6. Maintaining and increasing connections and collaborations with other patient organisations, both domestically and internationally.**
- 7. Maintaining and increasing relations with medical specialists such as dermatologists, both domestically and internationally.**
- 8. Researching vascular malformations such as CMTC. In particular, we are thinking of genetic research of DNA material from patients. Our ambition is to find the genetic cause of CMTC in 2021.**

members or donors towards impact and reach. The outline of this new policy framework was put up for discussion at the end of 2020 and we also contributed to it.

This new policy framework will be implemented in 2023.

In the Netherlands, the involvement of experts by experience is seen as valuable and required by all kinds of discussion groups (a “nothing about us without us” attitude). This also means that experts by experience are appreciated more and more financially-speaking.

Reaching patients in the 15-25-year age group is proving to be difficult. We would also like to know what their concerns and needs are.

International relations will also continue to increase, as will the number of foreign members.

Through the Internet, we want to strengthen our network worldwide and act as a pivot between doctors themselves and between patients and their doctors.

Relations through international umbrella organisations such as Eurordis, NORD and Genetic Alliance continue to be very important as they provide us with connections and opportunities that would not have been possible for our small organisation if we had tried to achieve this on our own.

Teamwork and exchanging knowledge and experience is also crucial, with the ultimate goal of improving the lives of patients and their families.

At the moment, approximately 7000 rare diseases have been identified and the number of patients with rare diseases is low.

The result of this is that it takes many years for a patient organisation to become relatively well-known, and it requires continuous promotion through marketing.

This requires a lot of extra work, not just in terms of time spent, but also financially.

**9. Expanding social media campaigns, taking into account the ever-changing strategies of search engines.**

**10. Increasing our Facebook, Instagram, YouTube, Twitter and LinkedIn activities.**

**11. Fundraising so that we can undertake additional activities and become less dependent on the Dutch Government.**

**12. Recruiting members and donors through social media. We use Google AdWords and Facebook campaigns to achieve this.**

**13. Participating actively in the European Expertise Reference Networks (ERNs and ePatient Advocacy Groups (ePAGs)).**

**14. Publishing a newsletter. The idea is to actively cover news and refer readers to our website for more information.**



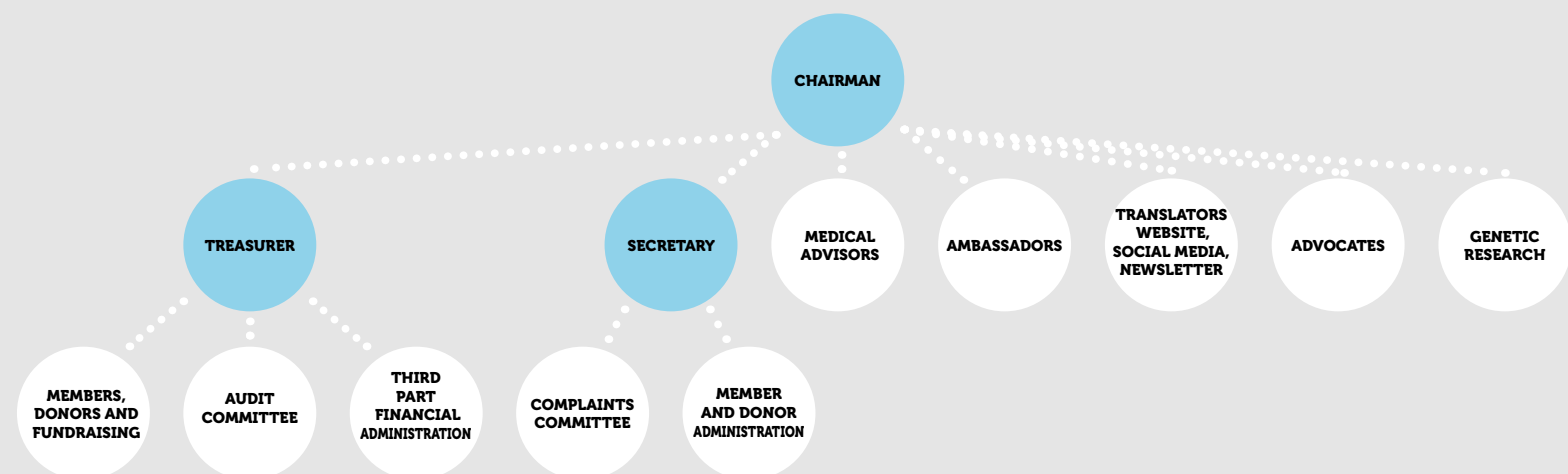


## 5 AVAILABILITY OF PEOPLE AND RESOURCES

The amount of available people is quite limited in a small organisation. However, the amount of work is not proportional to the size of our organisation, which means that a considerable amount of work needs to be done.

During 2020, the board consisted of three people and in total around 50 volunteers.

Below is the organisation chart of our organisation where the board members are marked separately.



A lot of work, for example, has been done through the use of extra volunteers for translation work and other various activities.

Members even sign up spontaneously to perform activities.

The budget for 2021 consists of the main items: contact with fellow sufferers, provision of information, advocacy, back office and related activities. This budget comes to €59.900,- (excluding projects).

## ACTIVITIES (EXPENDITURE)

## BUDGET (2021) (€)

CONTACT WITH FELLOW SUFFERERS

23.700

PROVISION OF INFORMATION

10.600

ADVOCACY

14.850

ENABLING ACTIVITIES

750

BACKOFFICE

10.000

**TOTAL**

**59.900**



## INCOME SOURCES

## BUDGET 2021 (€)

**MINISTRY HEALTH, WELFARE & SPORT**

55.000

**SUBSCRIPTIONS (MEMBERS, DONATIONS, SPONSORS)**

4.900

**TOTAL**

**59.900**

We carry out extra activities on a project basis, which are funded separately.







## 6 CMTC-OVM AND THE ENVIRONMENT

Just as with other companies, our activities can have a negative environmental impact. We have taken the following measures to limit any negative environmental effects:

1. Newsletters etc. are made available via the website.
2. Printing on paper is done double-sided as much as possible.
3. We carpool whenever we can. However, if possible, we use public transport.
4. Computers are only switched on if they are being actually used.
5. If possible, a meeting is held online or by telephone (e.g. via Skype). We do this, for example, with our board meetings.
6. Email is preferred to physical mail.
7. Empty inkjet cartridges are collected and returned to the designated collection points.
8. Paper, plastic and chemical waste are separated from the other waste and are disposed of separately.
9. Materials are recycled and reused as much as possible.





## 7 APPENDIX A TERMS AND ABBREVIATIONS

<b>Term/abbreviation</b>	<b>Explanation</b>
<b>ANBI</b>	<b>Algemeen Nut Beogende Instelling (Public Benefit Organisation).</b>
<b>AVG</b>	<b>Algemene Verordening Gegevensbescherming (General Data Protection Regulation).</b>
<b>CBF</b>	<b>Centraal Bureau Fondsenwerving (The Netherlands Fundraising Regulator).</b>
<b>CMTC-OVM</b>	<b>Our organisation.</b>
<b>Eurordis</b>	<b>Europese organisatie voor zeldzame ziekten (European Organisation for Rare Diseases).</b>
<b>Fonds PGO</b>	<b>Subsidie vertrekker vanuit Nederlandse Overheid (Subsidy provider by the Dutch government) for patients, disabled people and elderly.</b>
<b>NORD</b>	<b>National Organization for Rare Disorders (USA).</b>
<b>VSOP</b>	<b>Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (Dutch Patient Alliance for Rare and Genetic Diseases).</b>

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