



ANNUAL REPORT
2019

PATIENT ASSOCIATION
CMTC-OVM
WWW.CMTC.NL



cmtovm

COLOPHON

This is a publication of CMTC-OVM
All rights reserved.

Chairman and author

Lex van der Heijden

Owner

Bestuur CMTC-OVM

Treasurer

Jacob Schipper

Secretary

Anja Fluijt

Graphic design

Rick Schurink, Design Delicious



@CMTCOVM



facebook.com/cmtcovm



linkedin.com/company/cmtc-ovm



CMTC-OVM

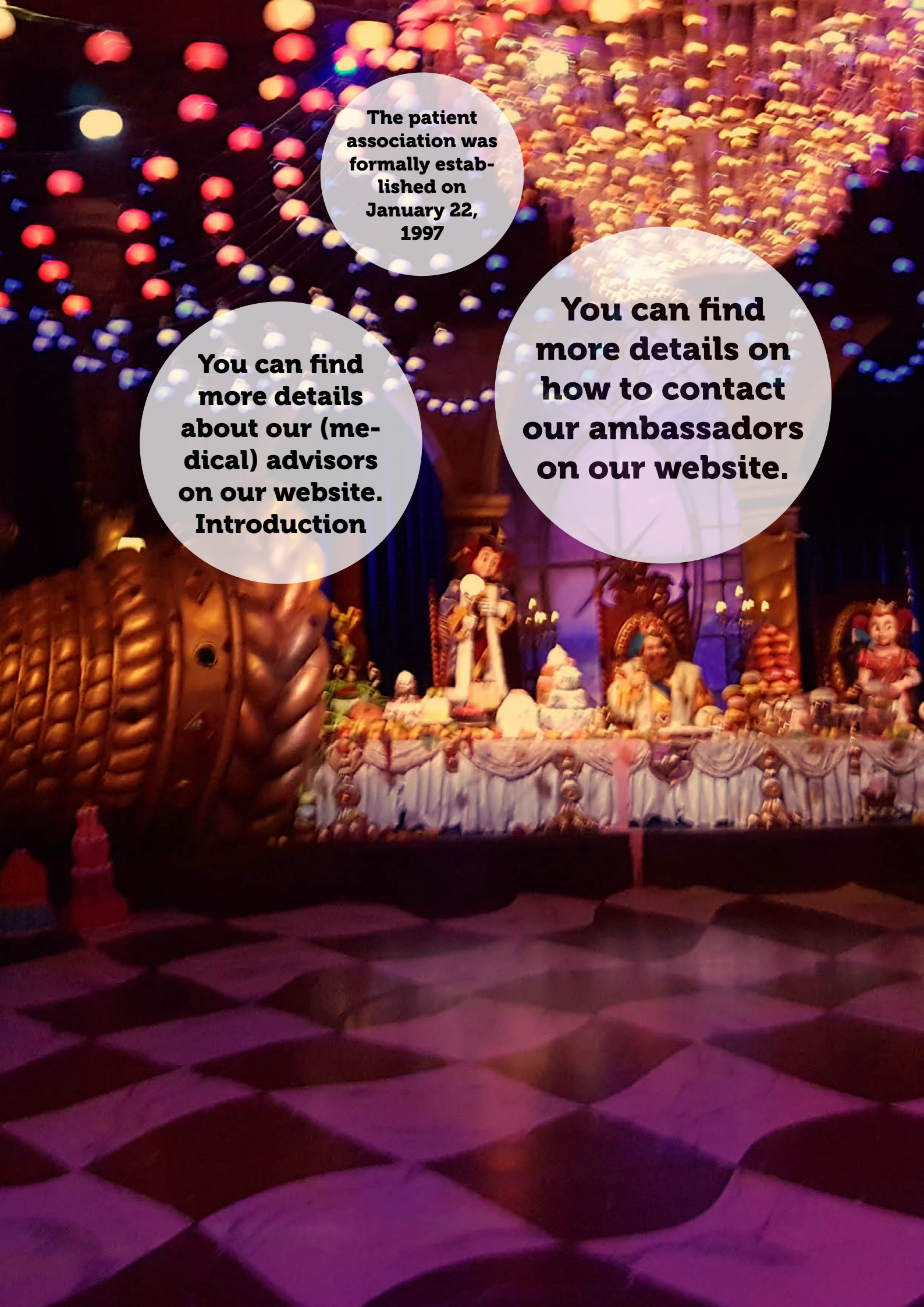


CMTCOVM

www.cmtc.nl

CONTENTS

1	Introduction	4
1.1	Purpose of this Document	4
1.2	Introduction	4
1.3	Administration	4
1.4	Medical Consultants	5
1.5	Ambassadors	5
1.6	Volunteers	5
2	Activities 2019	7
2.1	Family day	7
2.2	Members Conference Netherlands	7
2.3	CEO-Council	8
2.4	Personal Medical Advice	8
2.5	Personal Psychological Advice	8
2.6	Social Media	8
2.7	Conferences	8
2.8	Website	9
2.9	Information Folders	9
2.10	Genetic research in Belgium and Canada	9
2.11	Newsletter	9
2.12	Rare Connect Project	9
2.13	Cooperation with Other Organizations	11
2.14	Patient Advocates	11
2.15	Financial Administration	11
2.16	Quality marks	11
2.17	Marketing	11
2.18	General Data Protection Regulation	11
2.19	Fundraising	11
3	Financial	13
3.1	Introduction	13
3.2	Expenditure Overview	13
3.3	Income	14
3.4	Spending	15
4	Preview	16
5	Available People and Resources	19
6	CMTC OVM and Environment	16
A.	Appendix - Terms and Abbreviations	25



**The patient
association was
formally estab-
lished on
January 22,
1997**

**You can find
more details
about our (me-
dical) advisors
on our website.
Introduction**

**You can find
more details on
how to contact
our ambassadors
on our website.**

1 INTRODUCTION

1.1 Purpose of this Document

This document contains the 2019 annual report of the patient association CMTC-OVM. The purpose of this document is primarily to provide an overview of the activities performed in 2019.

1.2 Introduction

The patients' association 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, 2019:

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

Mrs. A. Fluijt, Secretary;

Mr. J. Schipper, Treasurer.

1.4 Advisors

The advisors are:

Mrs. Prof. C.M.A.M. van der Horst.

Mr. Dr. Patrick Kemperman.

Mr. Dr. P. de Laat.

Mrs. Dr. C. Oduber.

Mrs. Prof. Dr. S. Pasmans.

Mr. Dr. M. Patel (Canada).

Mr. Prof. Dr. M. van Steensel.

Mr. Prof. Dr. P. 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 2019 we have two ambassadors. These are Prof. Dr. Jan Peter Balkenende (former prime minister of the Netherlands) and Dr. Steve Groft (former director of rare diseases within the American National Institute of Health).

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, 2019, 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.



2019 ACTIVITIES 2019

Thanks in particular to the subsidy from the Ministry of Health, Welfare and Sport, we were able to carry out a large number of (extra) activities in 2019. The most important activities that we carried out in 2019 are:

1. Organizing a family day for the patient and his / her immediate family.
2. Organize global member conference in the Netherlands.
3. CEO-Council
4. Offer personal medical advice.
5. Offer personal psychological advice.
6. Share information, support patients / parents, marketing through social media.
7. Participate in information sharing and networking conferences.
8. Expanding the website.
9. Develop different information folders in 5 languages.
10. Performing genetic research in Belgium, Canada and the Netherlands.
11. Publishing the newsletter.
12. Participation in the Eurordis RareConnect project.
13. Cooperation with other (non-profit patients) organizations.
14. Execute 'patient advocate' initiative to reach more patients, families and caregivers.
15. Professionalize our organization.
16. Auditing and approvals
17. Marketing.
18. Implementation of General Data Protection Regulation (AVG)
19. Fundraising.



2.3 CEO-Council

As a nonprofit patient organisation we are part of the CEO-council of the Ministerie van Volksgezondheid, Welzijn en Sport - VWS (Ministry of Health, Welfare and Sport). In this context, CEO-Council signifies 'Chief Experience Officers Council', i.e. experience experts in healthcare. Someone is an experience expert when they regularly provide healthcare, e.g. because they needed it themselves (or did so in the past), have a disability or are a caregiver. The CEOs offer a fresh, patient-oriented view of VWS policy and they put issues that they care about deeply on the agenda. Goal: join systems and living environment.

2.4 Personal Medical Advice

We have been offering personal medical advice for many years at our global meeting in the Netherlands. We have a number of our medical specialists, usually professors, available who provide free personal medical advice during the day.

In addition to the personal medical advice option during our worldwide conference, there is also the possibility of extensive personal medical advice at the Erasmus Medical Center in Rotterdam within the special multidisciplinary team WEVAR on the Friday preceding the Saturday conference in Leusden.

2.5 Personal Psychological Advice

We started with personal medical advice during our global members' meeting in the Netherlands in 2018. Participants could spend an hour with our medical psychologist Dr. Wouter van der Schaar asking all kinds of questions in a private conversation. Five families made use of this.

2.6 Social Media

Nowadays, the use of social media is indispensable in our society. We used the following social media channels at the end of 2019:

1. **Facebook group (closed) for adults. This is mainly due to the privacy of the people in this group and to the extent possible that people abuse this group for all kinds of commercial purposes (such as selling sunglasses and shoes).**
2. **Facebook group (closed) for young adults (age approx. 15 - 25 years).**
3. **Facebook group (closed) for children (age approx. 8 - 14 years).**
4. **Facebook page for general affairs (global reach).**
5. **Facebook page for recruiting members / donors (usage in Netherlands).**
6. **Twitter.**
7. **LinkedIn.**
8. **YouTube.**
9. **Instagram.**

Thanks to the statistics from both our website and Facebook groups, we can immediately see the effect of a promotion.

2.7 Conferences

Participating in conferences has a number of important goals, especially for organizations active in the field of rare diseases. Collaboration is the keyword in this context. Networks, name recognition and mutual learning are also important key benefits.

In particular, we visit international conferences from major organizations such as Eurordis (European organization for rare diseases) and NORD (American organization for rare diseases). Important contacts are made here with other patient organizations with the aim of furthering cooperation. The last day in February is global rare diseases day.



This year the Dutch rare disease day was organized in Maastricht (the Netherlands) in cooperation with organisations, healthcare providers, etc. from Belgium and Germany. The theme was 'cross border healthcare'. Health care providers, hospitals and healthcare insurance companies collaborate in order to provide the best care.

In May we participated in the Canadian Organisation for Rare Diseases (CORD).

In May we participated in the annual Eurordis conference organized this year in Romania. The number of participants was around 270 people (members only this year).

In June we participated in the Global Skin conference in Italy with about 140 participants.

In June we participated in the Vascular Birthmarks Foundation conference in Greece.

In October we participated in the annual NORD conference in the USA (Washington DC).

In November we participated in the annual ICORD conference in Israel.

In December we participated in a panel during the Expert Reference Networks conference for doctors in Belgium.

For reports of the conferences please refer to our website.

2.8 Website

Our website is our most important medium for sharing information. We also link our social media channels to our website and can use statistics to see, for example, how many people and from which countries have visited our website as a result of a message via our social media channels.

In 2019 we worked hard on our new website that can also be used well via smartphone and tablet ("responsive"). Our new website includes a knowledge base, a search function, tons of new information and will be launched during the second quarter of 2020.

We refer you to our website for more information.

2.9 Information Folders

In 2019 we had our CMTC information leaflets translated into even more languages with the aim of reaching as many people as possible (in particular patients, parents of patients and caregivers).

At the end of 2019 our CMTC information folder is available in 17 languages.

We have also developed new leaflets such as 'if your brother / sister is ill'.

In collaboration with, among others, the Dutch General Practitioner Community, we have developed a brochure for general practitioners.

We will publish this brochure in 2020 in at least German, English, French, Dutch and Spanish.

These folders can be downloaded from our website.

2.10 Genetic research in Belgium and Canada

Thanks to many years of international networking, we have succeeded in starting a genetic research into CMTC.

This research is being conducted in Belgium (Prof. Dr. Miikka Vakkula) and Canada (Dr. Millan Patel) in collaboration with geneticists in the Netherlands and is coordinated from the Netherlands. In 2018 we again started collecting biopsies and performing sequencing of biopsies that have already been supplied. In 2020, we hope to find the genetic defect that could be the cause of CMTC.

2.11 Newsletter

In 2016 we started with a new style newsletter. We are working with a separate volunteer for this and a scientific journalist. The newsletter was published two times in 2019 in both the Dutch and English languages. The website contains an archive of these newsletters.

2.12 Rare Connect Project

We participate in the Eurordis Rare Connect Project where we have our own group and fulfill the moderator role.



2.13 Cooperation with Other Organizations

Below is a short summary regarding the most intensive ones (a full list is available on our website):

1. **WEVAR team in the Erasmus Medical Center in Rotterdam.**
2. **Department of Dermatology at the Academic Hospital Maastricht (MUMC). The Dermatology department of MUMC is recognized as the Genodermatoses Expertise Center (hereditary skin disorders) and is headed by Prof. dr. Dr. Peter Steijlen.**
3. **The European Organization for Rare Diseases (Eurordis).**
4. **National Organization for Rare Disorders (NORD, USA).**
5. **Genetic Alliance (USA).**
6. **The Dutch Organization Cooperating Parents / Patient Organizations (VSOP).**
7. **Global Skin Foundation (Canada).**

2.14 Patient Advocates

To provide local support to our members who come from many different countries, we are working to appoint a contact person or "patient advocate" for each country. At the end of 2019 we have patient advocates in 15 countries.

2.15 Professionalization

In 2019 we took another major step towards simplifying and streamlining our financial administration. This is visible to members and donors in that when they receive an invoice it can be paid directly in many ways.

For example, we also want a monthly overview of the budgets by mail and the current costs so that we can quickly see our current financial status.

In addition, we can give the members of the Financial Audit Committee secure access to our financial data so that they can prepare the audit for the most part from home.

2.16 Audits

We have both the ANBI (Dutch Tax Authorities) and the Central Fundraising Agency (CBF) certification marks.

2.17 Marketing

In 2018 we started using Google AdWords with the aim of reaching more patients, families and healthcare professionals. The number of visits to our website has increased enormously.


2.18 General Data Protection Regulation

In 2019, our organization, processes and website have been set up in such a way that we meet the requirements laid down in the European Privacy Act General Data Protection Regulation.

2.19 Fundraising

In 2018 we started a new fundraiser. We hope to reap the first benefits of this in 2020.





**1.
Contact of
fellows /
members**

**3.
Representation
of interests**

**2.
Provision of
Information**

3 FINANCIAL OVERVIEW

3.1 Introduction

Again this year we have been able to develop many activities in diverse 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. Conditions-creating activities.

3.2 Overview of Expenditure

ACTIVITY	EXPENDITURE 2019 (€)	EXPENDITURE 2018 (€)
CONTACT WITH FELLOW PATIENTS / SUFFERERS	17.270	17.182
PROVISION OF INFORMATION	15.237	19.592
ENABLING ACTIVITIES	2.736	3.799
PATIENT ADVOCATES	13.971	12.490
TOTAL	49.214	53.063

3.3 Income

FINANCIAL SOURCES	INKOMSTEN 2019 (€)	INKOMSTEN 2018 (€)
MINISTRY HEALTH, WELFARE & SPORT	43.604	45.000
CONTRIBUTIONS / SUBSCRIPTIONS	3.079	2.622
DONATIONS / GIFTS / OTHER BUSINESS	3.306	2.606
TOTAL	49.989	50.228

3.4 Spends

	2019	2018
SPENDING PERCENTAGE OF EXPENSES (%)	94,44	91,13
BENEFITS OF SPENDING (%)	92,98	96,27

4 FORWARD LOOKING

In practice, it appears that it takes many years before a patient organization enjoys any (name) recognition. When it concerns a rare condition, this requires extra efforts in all respects, especially financially. International contacts will also increase further, as will the number of foreign members. With Internet technology we want to strengthen our network worldwide and act as a link between doctors and patients and doctors. Contacts through Eurordis, NORD and Genetic Alliance remain very important and they offer us the inputs and

possibilities that would not have been possible for our small organization if we wanted to achieve this on our own. Working together and sharing knowledge and experience is also crucial with the ultimate goal of improving the lives of patients and their loved ones.

In the year 2020 we want the following, among others to develop activities:

- 1. Maintain and expand contacts and collaborate with both patients and other patient organizations, both at home and abroad.**
 - 2. Maintain and expanding contacts with medical specialists such as dermatologists, both at home and abroad.**
 - 3. Research into vascular malformations such as CMTC. We are thinking in particular of genetic testing of DNA material from patients. Our aim is to find the genetic cause of CMTC in 2020.**
 - 4. Further development of social media strategy and implementation of this social media strategy taking into account the changing strategies of search engines such as Google and Facebook.**
 - 5. Launch our new website.**
 - 6. Further develop the Facebook groups for young adults and children. Extension via Instagram, YouTube, Pinterest and LinkedIn.**
 - 7. Fundraising so that we can develop additional activities and become less dependent on the Dutch government.**
 - 8. Members and donors recruitment via social media. For this we use Google AdWords and Facebook campaigns.**
 - 9. Active participation in the European Expertise Reference Networks (ERNs) and European Patient Advocacy Groups (ePAGs)).**
 - 10. Organizing a personal contacts meeting and data exchange in the form of a global member conference in the Netherlands.**
 - 11. Organizing an international family day in the Netherlands in an informal environment, so that the thresholds are as low as possible, with the focus on doing business together with patients and their immediate family. This also offers the opportunity to become acquainted and to exchange knowledge / experiences.**
- Organize an additional event in the Netherlands for our members.**



12. Supporting other (small) patient organizations in the field of organization development and cooperation. We can act as an umbrella organization for smaller organizations in the field of vascular malformations and growth disorders. These organizations can “piggyback” with us in terms of website, social media, etc.

13. Development of a general practitioner brochure in Dutch, English, French, German and Spanish.

This activity is financed separately.

14. Publishing a newsletter. The aim is to actively bring news and readers to our website for more information.

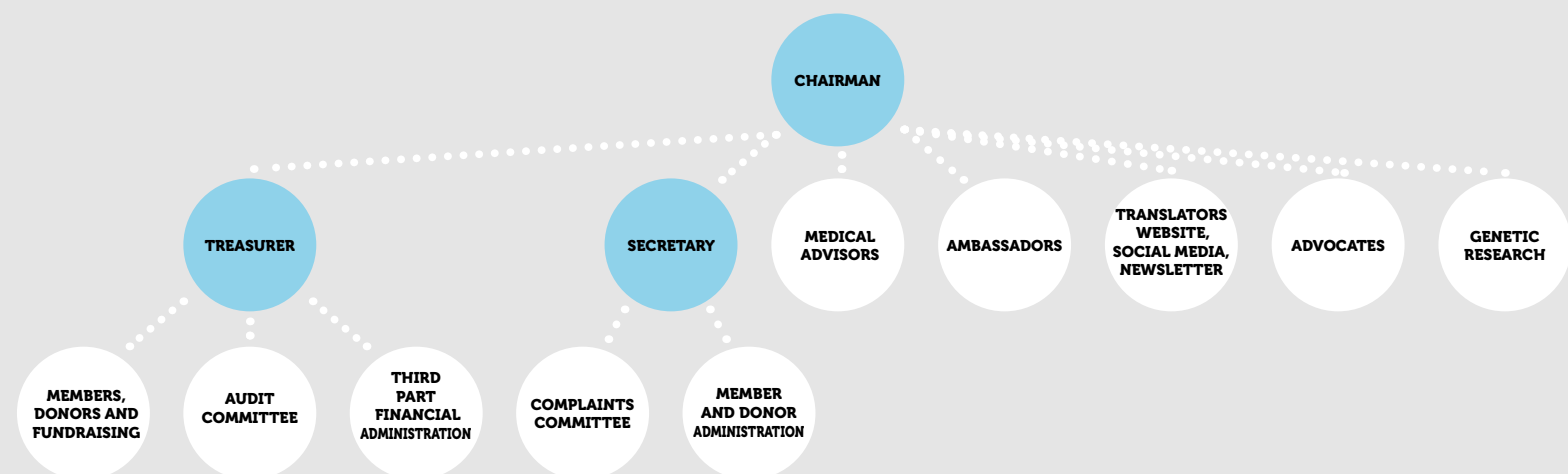
15. Board extension from 3 to 5 persons.



5 AVAILABILITY OF PEOPLE AND RESOURCES

The amount of available people is quite limited in a small association. However, the amount of work is not proportional to the size of an association, which means that a considerable amount of work needs to be done. The board consisted of three people during 2019.

Below is the organization chart of our organization 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 diverse activities. Members even sign up spontaneously to perform activities.

The budget for 2020 consists of the main items: contact with fellow sufferers, provision of information, advocacy and related activities. This budget comes to € 60,000 (excluding projects).

ACIVITIES (EXPENDITURE)

BUDGET (2020)

CONTACT WITH FELLOW SUFFERERS

18.500

PROVISION OF INFORMATION

13.000

PATIENT ADVOCACY

17.400

ENABLING ACTIVITIES

2.200

TOTAL

51.100

INCOME SOURCES

BUDGET 2019 (€)

MINISTRY OF HEALTH, WELFARE & SPORT	45.000
SUBSCRIPTIONS (MEMBERS AND DONATIONS) SPONSORS INTEREST	8.200
TOTAL	51.300

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



6 CMTC-OVM AND THE ENVIRONMENT

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

- 1. Newsletters etc. are made available via the website.**
- 2. Double sided paper printing happens as much possible.**
- 3. Traveling by car is shared as much as possible with other people. If possible, public transport is used as much as possible.**
- 4. Computers are only switched on if they are being actually used.**
- 5. If possible, a meeting is held by telephone (eg via Skype). We do this, for example, with our board meetings.**
- 6. e-mail 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 as much as possible recycled and reused.**



7 APPENDIX A TERMS AND ABBREVIATIONS

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

ANNUAL REPORT
2019

PATIENT ASSOCIATION
CMTC-OVM
WWW.CMTC.NL



cmtovm