ANNUAL REPORT 2018

PATIENT ASSOCIATION CMTC-OVM

WWW.CMTC.NL

COLOFON

This is a publication of CMTC-OVM

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

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

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

1 INTRODUCTION

1.1 Purpose of this Document

This document contains the 2018 annual report of the patient association CMTC-OVM. The purpose of this document is primarily to provide an overview of the activities performed in 2018.

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:

cmtc ovm

1.3 Administration

The board is composed as follows on December 31, 2018:
Mr. A.F.R. van der Heijden, Chairman;
Mrs. A. Fluijt, Secretary;
Mr. J. Schipper, Treasurer.

1.4 Medical Advisors

The medical 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.
Dr. M. Patel (Canada).
Mr. Dr. W.W. van der Schaar
Mr. Prof. Dr. M. van Steensel.
Mr. Prof. Dr. P. Steijlen.
Mr. Prof. Dr. Miikka Vikkula (Belgium).
Mrs. Dr. Maaike Vreeburg.

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

1.5 Ambassadors

At the end of 2018 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 40 volunteers active worldwide as of December 31, 2018, 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.

2 ACTIVITIES 2018

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 2018.
The most important activities that we carried out in 2018 are:

1. Organizing a family day for the patient and his / her immediate family.

2. Organize member conference in the Netherlands.

3. Participate in members meeting CMTC-OVM USA.

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. Start up 'patient advocate' initiative to reach more patients, families and caregivers.

15. Professionalize and automate the financial and member / donor administration.

16. Auditing and approvals

17. Marketing.

18. Implemention of General Data Protection Regulation (AVG)

19. Fundraising.

2.1 Family day

In 2018 we again organized a family day for the patients and their immediate family. This year we had selected the Efteling theme park in the Netherlands. The number of participants this year was around 80 people from 3 countries.

During the reception (new) members could meet and exchange experiences and also during lunch.

The report with photos can be found on our website.

2.2 Netherland Member meeting

Our worldwide meeting of members was organized this year on November 3, 2018 in Leusden (the Netherlands). The Friday evening before we hosted the foreign guests with a snack and a drink specifically intended to break the ice for the next day.

In total there were approx. 80 people present from Belgium, Germany, England, the Netherlands, Austria.

Patients could again receive personal medical advice and / or have the state of affairs reviewed. This year we offered both a simple medical diagnosis option during our conference and a complex one, the day before our conference in Rotterdam. A total of 11 people took advantage of these options!
We also offered the option again to receive a massage. The number of massages provided was 7.

Reports with photos and videos from a number of sessions are available on our website (only for members and doctors).

2.3 USA meeting

In 2018 we again attended the members' meeting of the American organization with a total number of participants around 30. At the USA meeting, just as in the Netherlands, there was the possibility of having a medical diagnosis made. Reports from this conference with photos and video material can be found on our website or via the American website.

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 2018:

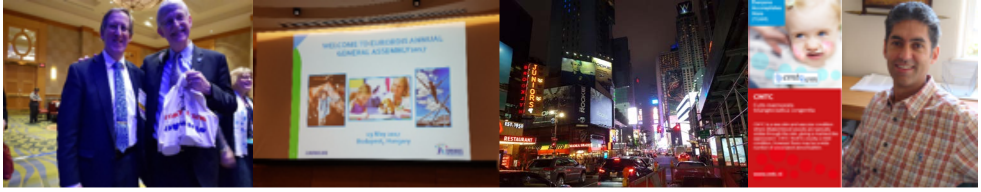
1. Facebook group (closed) for adults. This is mainly due to the privacy of the people in this group and to the extent possible that people abuse this group for all kinds of commercial purposes (such as selling sunglasses and shoes).
2. Facebook group (closed) for young adults (age approx. 15 - 25 years).
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 the NBC Congress Center in Nieuwegein.
In May we participated in the annual Eurordis conference organized this year in Austria (Vienna). The number of participants was around 800 people.
In June we participated in an international conference at the University in Groningen where we also participated in a panel.
In September we gave a guest lecture at the University of Groningen.
In October we participated in the annual NORD conference in the USA (Washington DC).
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 2018 we worked hard on our new website that can also be used well via smartphone and tablet ("responsive"). This website includes a knowledge base and a search function.

We refer you to our website for more information.

2.9 Information Folders

In 2018 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 2018 our CMTC information folder will be available in 16 languages.

We have also developed new leaflets such as practical tips for a conversation with a care provider and the psychological aspects of living with a rare disease.
In 2019, brochures with other topics will be added.

These folders can be downloaded from our website.

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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 Vikkula) 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 2019, 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 four times in 2018 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.


WORKAHOLIC
HOLLAND
HOPE

2.13 Cooperation with Other Organizations

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

1 LGDA-E. This organization focuses on people with Lymphangiomatosis & Gorham's Disease in Europe.

2 WEVAR team in the Erasmus Medical Center in Rotterdam.

3 The Hecovan working group, Center of Expertise for Hemangiomas and Congenital Vascular Malformations. This is a multidisciplinary team at the Radboud University Medical Center in Nijmegen (the Netherlands).

4 Noonan syndrome. The Noonan Syndrome Foundation represents the interests of every Dutch person with the Noonan Syndrome or the related CFC, Costello and Leopard syndromes.

5 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.

6 The European Organization for Rare Diseases (Eurordis).

7 National Organization for Rare Disorders (NORD, USA).

8 Genetic Alliance (USA).

9 The Dutch Organization Cooperating Parents / Patient Organizations (VSOP).

10 Global Skin Foundation (Canada).

11 During the NORD conference in 2016 in Washington in October, we made contact with "The Mighty" organization from which this collaboration ensues.

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 2018 we have patient advocates in 14 countries..

2.15 Financial Administration

In 2018 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.

2.16 Audits

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

2.17 Marketing

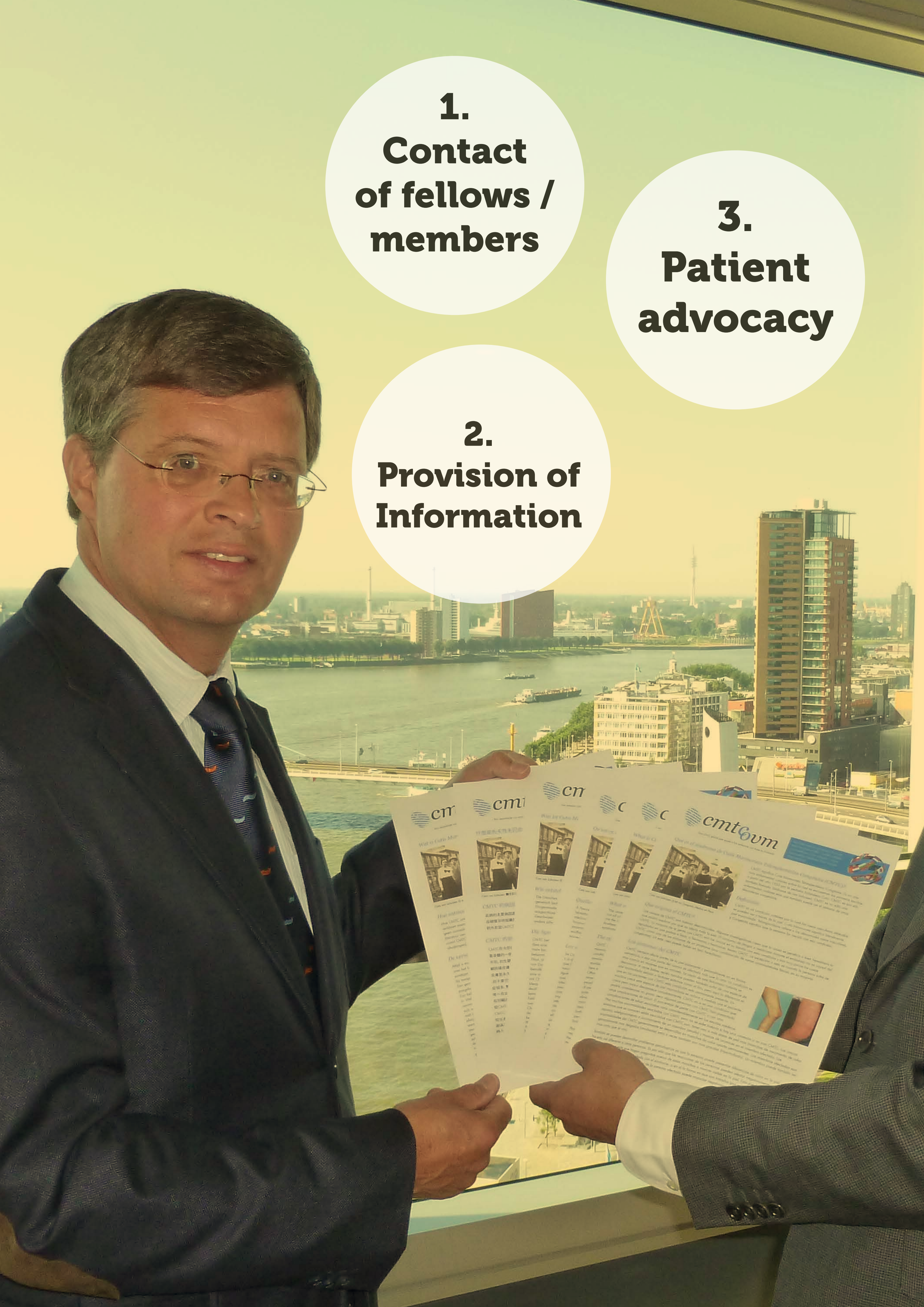
In 2018 we started using Google AdWords with the aim of reaching more patients, families and healthcare professionals. The number of visits to our website has increased enormously.
During the second half of the year, we conducted a paid campaign via an attachment from the daily newspaper "Trouw", the magazine "Arts and Car", and via the website My Health Guide and the newsletter from My Health Guide. We would reach over 400,000 people with this. The results were very disappointing (only 2 donors).

2.18 General Data Protection Regulation

In 2018, 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 2019.



1.
Contact of fellows / members

2.
Provision of Information

3.
Patient advocacy

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 Patient advocacy.

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3.2. Overview of Expenditure

ACTIVITY	EXPENSES 2018 (€)	EXPENSES 2017 (€)
CONTACT WITH FELLOW PATIENTS/ SUFFERERS	17.182	21.436
PROVISION OF INFORMATION	19.592	23.535
ENABLING ACTIVITIES	4.707	1.852
PATIENT ADVOCACY	3.799	10.777
TOTAL	45.280	57.600

3.3 Income

FINANCIAL SOURCES	INCOME 2018 (€)	INCOME 2017 (€)
MINISTRY HEALTH, WELFARE & SPORT	45.000	45.000
CONTRIBUTIONS / SUBSCRIPTIONS	2.622	2.380
DONATIONS / GIFTS / OTHER BUSINESS	2.606	9.437
TOTAL	50.228	56.817

3.4 Spending

	2018	2017
SPENDING PERCENTAGE OF EXPENSES (%)	91,13	96,78
BENEFITS OF SPENDING (%)	96,27	98,12

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 2019 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 2019.**
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. **Further develop the Facebook groups for young adults and children.**
6. **Fundraising so that we can develop additional activities and become less dependent on the Dutch government.**
7. **Members and donors recruitment via social media. For this we use Google AdWords and Facebook campaigns.**
8. **Active participation in the European Expertise Reference Networks (ERNs) and European Patient Advocay Groups (ePAGs)).**
9. **Organizing a personal contacts meeting and data exchange in the form of a global member conference in the Netherlands. Participation in the members conference of the CMTC-OVM organization in Canada.**
10. **Organizing a 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.**
11. **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.

12. Implementation of the "Impact" program consisting of a number of projects:
    a. Translation of the specially developed children's website into even more languages such as German, French and Spanish (currently in English and Dutch).
    b. Subtitling of available images.
    c. New folders / information material.
    d. Special CMTC booklet that covers practically all aspects of CMTC (English and Dutch).
    e. Expansion of new CMTC-OVM website.

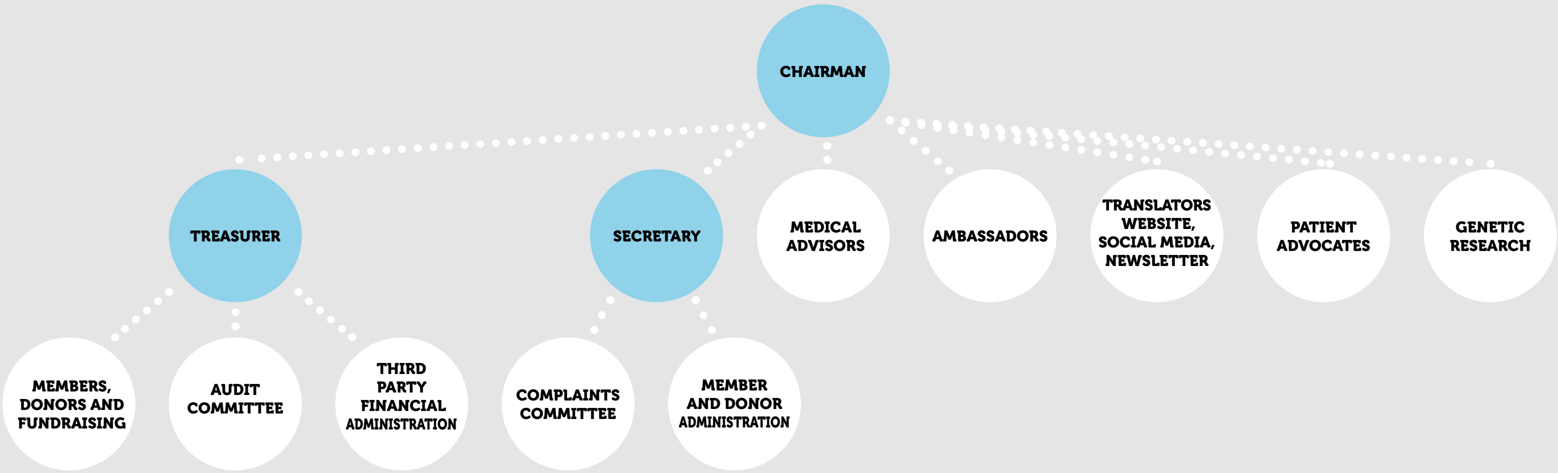
This program is funded separately.

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

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 2018.

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 2019 consists of the main items: contact with fellow sufferers, provision of information, advocacy and related activities. This budget comes to € 53,063

ACTIVITY (EXPENDITURE)	BUDGETED 2018 (€)
PATIENT CONTACT	22.400
INFORMATION PROVISION	18.500
PATIENT ADVOCACY	9.760
ENABLING ACTIVITIES	2.550
TOTAL	**53.210**

SOURCE (INCOMES)	BUDGETED 2018 (€)
GOVERNMENT SUBSIDY	45.000
SUBSCRIPTION (MEMBERS, DONORS, SPONSORS)	8.200
INTEREST	10
TOTAL	**53.210**

We carry out extra activities on a project basis which are financed 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.**

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.**


W
H&M
TIMES SQUARE
AMERICAN EAGLE OUTFITTERS
NYC
DWAYNE
SKYSC
IN THEAT
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PRETTY
W 49 St
9A
West Side Hwy
ONE WAY
OPRY
RESTAURANT & BAR

7 A. APPENDIX A - TERMS AND ABBREVIATIONS

Term/Abbreviation, Definition

ANBI	Formal status of a non-profit organization from the Dutch tax authority which implies that donations are tax deductible.
AVG	General Data Protection Regulation, GDPR.
CBF	Central Bureau on Fundraising.
CMTC-OVM	Cutis Marmorata Telangiectatica Congenita and Other Vascular Malformations, our organization.
Eurordis	European Organization for Rare Diseases.
NORD	National Organization for Rare Disorders, USA.
VSOP	The Dutch Genetic Alliance, a national umbrella organization of about sixty disease-linked parent and patient organizations.

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