Patient Association
CMTC-OVM
www.cmtc.nl

Annual Report 2016

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Approvals

Name	Role
J. Schipper	Treasurer
M. de Vries	Secretary

Distribution

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Not applicable.

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1 Introduction

1.1 Document Purpose

This document is the CMTC-OVM Association Annual Report for 2016. The primary purpose of this document is to provide an overview of the activities carried out by the patient organization during the year.

1.2 Introduction

The CMTC-OVM Association was formally established on January 22, 1997 by notary Van Helden in Amsterdam and then registered at the Chamber of Commerce in Amersfoort. The purpose of the Association is laid down in the statutes and is expressed in the text below.

The Association mission is:

Promoting the well-being of people who suffer from vascular malformations such as CMTC ("Van Lohuizen syndrome"), in particular its own members and the promotion and development of activities that promote this welfare. Promoting scientific research on vascular malformations such as CMTC, the causes and treatment thereof, and all that this implies in the broadest sense.

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

The Association logo is:

1.3 The Board

As of 31st December 2016, the Board is comprised of the following members:

Mr. A.F.R. van der Heijden	Chairman
Mrs. M. de Vries	Secretary
Mr. J. Schipper	Treasurer

1.4 Medical Advisors

Our current specialist medical advisors are: Prof. Dr. C.M.A.M. van der Horst, Prof. Dr. S. Pasmans, Prof. Dr. M. van Steensel, Dr. W.W. van der Schaar, Drs. L. Siderius, Dr. C. Odubèr and Dr. M. Vreeburg.

Prof. Dr. A.P. Oranje who was also a medical advisor practically from the start of the organization unexpectedly passed away on 19th October 2016.

We also work closely with other doctors from several countries including Dr. Millan Patel in Canada for example, in the context of our genetic research activities.

Our website provides further details concerning the medical advisors.

1.5 Ambassadors

At the end of 2016 we can also count three new ambassadors in our midst: Prof. Dr. Jan Peter Balkenende, former Prime Minister of The Netherlands, Dr. Steve Groft, former Director of the Rare Diseases Research Office at the American National Institute of Health and Monique Kalkman, former paralympic champion athlete.

Our website also provides further details concerning these ambassadors.

1.6 Volunteers

In practice the Association including the Board is exclusively staffed by volunteers. In addition to Board membership our volunteers are engaged in a number of activities such as translation work or social media. As of 31st December 2016, in addition to the Board members we have around 30 volunteers active in many areas including translation, member and donor recruitment, fundraising, the audit committee, the complaints committee and providing assistance during meetings. Our medical advisors and ambassadors are also included in this total.

2 Activities in 2016

With the help of a grant from FondsPGO in particular we were able to carry out a large number of activities in 2016, the most important of which included:

1. Organizing a Family Day for patients and immediate family in The Netherlands.
2. Organizing the General Meeting in The Netherlands.
3. Participating in the General Meeting for CMTC-OVM USA.
4. Participating in the General Meeting for CMTC-OVM Canada.
5. Offering a medical diagnosis service.
6. Communication about our Association through social media.
7. Participation in conferences.
8. Expanding the website.
9. Translation of the information folder.
10. Genetic research in Canada.
11. Publishing a newsletter.
12. Taking part in the Eurordis RareConnect project.
13. Cooperation with other organizations.
14. Reorganization and professionalization of our financial administration.
15. Obtaining CBF certification.
16. Marketing.

2.1 Family Day

In 2016, we organized another Family Day for patients and their direct families. The Dolfinarium was chosen as the location and a total of around 60 people attended the event this year.

During the meet-up session and also during lunch we were able to get to know other members, and to swap experiences together.

You can find photographs from the day’s events on our website.

2.2 General Meeting Netherlands

Our worldwide General Meeting was held this year on the 12th of November 2016 in Leusden, The Netherlands. On the Friday evening before the event we held a drinks reception with snacks for our guests from abroad, to break the ice for the next day.

This year we had also invited another patent organization (LDGA) to take part at our meeting. Amongst other things they had organized two separate parallel sessions.

In total, there were around 130 people present from Belgium, Germany, England, Finland, Ireland, France, Japan, The Netherlands, Norway, Austria and Sweden.

Representatives from other patient organizations were also present including two people from France for Eurordis.

Participants could choose this year from 9 different parallel sessions and we could also offer our members the option to participate in a yoga workshop.

Patients were also of course able to obtain a medical diagnosis for their condition or a check on their situation. This year we could offer both a simple medical diagnosis option or a more complex diagnosis as an alternative. In total 10 people were able to make use of this facility.

Reports with photos and videos from a number of these sessions are available via our website. Available only for Association members and Doctors.

2.3 General Meeting USA

The CMTC-OVM USA organization held their 2016 General Meeting in Columbus (Ohio) and around 30 people attended the session.

On the Friday evening before the meeting the Family Day was held at a children’s fun park. Parents and carers also had the chance to get to know each other and good use was made of this opportunity.

There were various medical specialists present this year. They not only gave informative presentations but together could also provide a medical diagnosis.

A report for this conference can be found on our website together with photos from the event.

2.4 General Meeting Canada

The CMTC-OVM Canada organization organized their first ever General Meeting in Toronto with the total number attending being close to 50 people.

Just as at the meetings for CMTC-OVM in The Netherlands and in the USA a medical diagnosis could be obtained. A separate hall was also arranged with child-care so that parents could attend the conference and the children could be entertained.

Prof. Dr. Arnold Oranje and Lex van der Heijden from CMTC-OVM Netherlands took part in the conference and also gave a presentation.

A report for this conference can be found on our website together with photos and video material from the event.

2.5 Medical Diagnosis

We have already been able to offer a medical diagnosis facility for many years during our worldwide General Meeting in The Netherlands. A number of our advisors are available, mostly specialist professors, who can provide a free diagnosis during the day.

In the last few years the number of medical diagnoses that they provide has increased significantly. Following our conference in 2015, one of our advisors, Prof. Dr. Suzanne Pasmans, proposed that the diagnosis offering could be extended and professionalized even further. Starting in 2016 we now offer a basic diagnosis service during our conference event and an advanced diagnosis option at the Erasmus Medical Center in Rotterdam within the multidisciplinary team WEVAR on the Friday preceding the conference, held on a Saturday in Leusden.

2.6 Social Media

The use of social media has become an indispensable part of our society today. Having started in 2014 we currently make use of the following social media channels:

1. Facebook group: A closed group to maintain privacy for members of the group and to help prevent misuse of the group for commercial purposes.
2. Facebook page
3. Twitter
4. LinkedIn
5. YouTube

Thanks to the statistical information provided by the website and Facebook we are able to directly see the effect of our communications.

2.7 Conferences

Participation in conferences has a number of important goals especially for organizations which are active in the field of rare diseases. Cooperation is the key word in this context. Networking, brand awareness and learning from each other are also important themes.

In particular, we attend international conferences of large organizations such as Eurordis and NORD in order to generate and foster contacts at a high level

On the 10th of March the Dutch Genetic Alliance VSOP together with The Netherlands Federation of University Medical Centers NFU organized the National Rare Conditions Conference on the theme of ‘from expertise centers to expertise networks’. Nearly 200 people from many different countries took part in this conference. Lex van der Heijden was one of the speakers at a workshop with the title ‘Creating networks between expertise centers and regional care’ in which the central question was ‘what do the 1st line healthcare (GPs etc.) and 2nd line healthcare (hospitals etc.) services expect from the expertise centers?’. Lex has interpreted this question as meaning ‘what does the patient expect from the expertise centers?’.

The last day of February is the worldwide Rare Disease Day. In a number of countries such as The Netherlands this date is shifted slightly for practical reasons to be Saturday 27th February for 2016. Rare Disease Day was held this year at ‘The Netherlands Institute for Sound and Vision’ in Hilversum.

Jacob Schipper and Lex van der Heijden attended the event on behalf of our organization. Lex van der Heijden was invited as a speaker on the subject of ‘access to medical information’.

For reports from these conferences please do refer to our website.

2.8 Website

Our website is the main communication medium through which we share information. We can also link our social media to the website and through statistical analysis we can see how many people visit the site and from which countries following a specific message posting via these social media channels.

The current website is available in both Dutch and English at present and as of the end of 2016 contains around 2000 photos, 50 videos and a very large number of articles. We publish reports from nearly all the conferences that we have attended for example.

Please do visit our website for more information.

2.9 Information Folders

In 2016, we translated our existing information folders into several more languages with the aim of being able to reach as wide a public as possible. As of the end of 2016 the folder is currently available in 15 different languages.

In 2017, we will start a program to develop a new folder which will also be published and made available in many different languages.

Please see our website for more information.

2.10 Genetic Research in Canada

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

This research is being conducted in Canada in collaboration with some of our medical advisors. Dr. Millan Patel pictured here is leading the research program in Canada.

That the research costs are not being charged to our organization can be seen as quite a unique situation! In the region of € 35,000 to € 50,000, these costs could not normally be borne by a relatively small organization such as ours.

In 2012, a number of patients that met certain criteria had given biopsies, or pieces of skin tissue, which were to be examined in Canada. The process of obtaining biopsy samples has been on hold for a long time now and in the second half of 2016 we submitted a new request to the Medical Ethics Committee in order to be able to obtain biopsies again for genetic research. During 2017, we do expect to be able to obtain sufficient biopsies so that the research work will finally be able to start.

The current status of these activities can be followed via our website.

2.11 Newsletter

In 2016, we started with the production of a new style newsletter. For this work we have been able to find a dedicated volunteer with a background in scientific journalism. The new newsletter has been published six times in 2016 in both Dutch and English language versions.

The website has a special archive section for these newsletters.

2.12 Rare Connect Project

We are participating in the Eurordis Rare Connect for which we have our own online group and carry out a moderator role for the community.

2.13 Cooperation With Other Organizations

In 2016, we started a number of new cooperation initiatives. A brief summary is provided here following:

1. *Hart en Vaatgroep Nederland*. As indicated by the name, this concerns a Netherlands based cardiovascular disease organization for which the website and information provided are only available in the Dutch language.

2. LGDA-E. This organization is focused on people in Europe with Lymphangiomatosis and Gorham's Disease.

3. *De Hecovan-werkgroep*, An expertise center for hemangiomas en congenital vascular malformations. This is a multidisciplinary team at the Radboud University Medical Centre in Nijmegen, The Netherlands.

4. *Noonan Syndrome Foundation.* This organization represents the interests of everyone in The Netherlands with Noonan Syndrome or the related syndromes CFC, Costello and Leopard.

5. CMTC-OVM will work together with the Department of Dermatology at the Maastricht University Medical Centre (MUMC). The Department of Dermatology is recognized as a center of expertise on Genodermatoses or inherited genetic skin conditions, and is led by Prof. Dr. Peter Steijlen

6. In the last quarter of 2016 our CMTC-OVM Association started a new cooperation with *The Mighty.* During the October NORD conference in Washington we made contact with this organization from which an agreement to work together arose.

   The Mighty is an American based website with a large worldwide readership and on which there are all sorts of personal stories from people with some kind of disease, (mental) condition, or disability. For example, there are personal stories from people with diabetes, autism or hemangioma. Our cooperation means that a CMTC-OVM home page will be created on their website. Personal stories from people with CMTC and other vascular malformations will shortly be available on this site.

   Many people in the world suffer from one form of (serious) medical problem or another. These individuals not only seek information about their condition but are also looking to be inspired. This could mean reading stories from people that have the same medical problems and describe how they have learned to live with these for example, or what they experience as a result of having their condition. *The Mighty* presents '*real stories from real people that have real challenges*' as they say themselves. Because there is now a home page on *The Mighty* for CMTC-OVM we hope to be able to help more people as we will have a much wider reach.

During the Eurordis conference in Scotland in May 2016 we have again been able to add several new organizations to our list of contacts for international cooperation. These were from a number of different countries:

1. Luxembourg
2. Ukraine
3. Austria
4. Russia
5. South-Africa

2.14 Financial Administration

Under the ongoing theme of professionalization in financial administration we have continued to round off the process overall. We now have a monthly report of actual operational costs compared to their budgeted funds. We also have a dashboard for invoices showing available payment methods together with status details. We have also started with electronic payment processing for donations and subscriptions. From the beginning of 2016 we started sending electronic invoices to members and donors which can easily be settled using electronic payment systems via several methods.

2.15 CBF Certification

On the 1st of July in 2016 we obtained CBF recognition. The Central Bureau on Fundraising (CBF) has provided recognition for fund raising institutions since 1996. The CBF logo shows that the organization conforms to the applicable rules of the independent Central Bureau on Fundraising. Recognized good causes are able to demonstrate clear goals, have established organizational controls and are able to explain their processes in an open and understandable manner. The CBF will revalidate an organization at least every three years and interim assessments can also take place.

2.16 Marketing

During the year, we were also able to make a start on making marketing, fund raising and recruitment of members and donors more professional. For this we have enlisted the help of an external professional organization and the implementation of this in 2017 should be visible in our income level and our membership and donors lists.

3 Financial Information

3.1 Introduction

This year we have again been able to move forward and strengthen our position in a number of different areas.

The following sections provide an overview of various items concerning income and expenditure.

The main activity items largely correspond to the structure which the government organization *FondsPGO* uses. These are as follows:

1. Patient contact
2. Information provision
3. Enablement activities

3.2 Expenditure

Activity	**Expenditure 2016 (€)**	**Expenditure 2015 (€)**
Patient Contact	23.366	22.205
Information Provision	12.908	12.833
Enablement Activities	2.868	2.916
Total	**39.142**	**37.954**

3.3 Income

Source	**Income 2016 (€)**	**Income 2015 (€)**
FondsPGO Grant	35.000	35.000
Membership Fees	4.554	1.911
Donations/Gifts/Miscellaneous	4.084	4.494
Total	**43.638**	**41.405**

3.4 Notes

During the General Meeting in The Netherlands there are also children's activities and entertainment organized in a separate room so that parents can attend the meeting and the children can be kept amused in all kinds of ways and which allow for their varying age groups.

This year we again organized a Family Day with the aim of bringing not only patients but also their direct family together in one environment to have an enjoyable time, to get to know each other and to share experiences.

	2016	**2015**
Utilization Rate Expenditure (%)	92,67	92,31
Utilization Rate Income (%)	83,12	84,62

4 Looking Ahead

Experience shows that it takes many years for a patients’ organization to gain visibility. When this concerns a rare condition, the challenge can be even harder and is one which requires a significant effort in many areas including financial aspects.

International contacts will also continue to increase as well as the number of foreign members. Through internet technology, we want to strengthen our network worldwide and act as a central point of communication between doctors and their patients.

Contacts via NORD, Eurordis, and Genetic Alliance are expected to become more and more important for a small organization like ours in terms of providing introductions and opportunities because it would not be possible to achieve these on our own. Working together and sharing knowledge and experience is also crucial with the ultimate aim of improving the lives of patients.

In 2017, we would like to be able to develop the following activities:

1. On January 22nd 2017 our organization will have been established for 20 years and we plan to celebrate this event during our global AGM on November 4th in The Netherlands.

2. Maintain and expand our contacts and work with both patients and other patients' associations, both at home and abroad.

3. Maintain and expand our contacts with medical specialists such as consultant dermatologists, both at home and abroad.

4. Promote research into vascular malformations such as CMTC. Towards genetic research into the DNA material of patients.

5. Further development and implementation of a Social Media strategy taking into account any changes in approach of search engines such as Google and Facebook.

6. Fundraising to be able to develop extra activities and become less reliant on funding subsidy from the Dutch Government.

7. Organizing an annual meeting for personal contacts and exchange of information in the Netherlands. Taking part in the AGM for our sister organizations in the USA and in Canada.

8. Organizing a Family Day in The Netherlands, in a casual setting so that people feel easily able to participate and where the attention is focused on working together with patients and their immediate family. This also provides the opportunity to gain knowledge and exchange experiences.

9. Provide support for other small patient organizations regarding development and cooperation. We can act as an umbrella organization for vascular malformation and growth related medical conditions. These organizations could piggyback with ours in some areas such as websites or the use of social media for example.

10. Implement the NewPatients! program that consists of several separate projects:

    a. Translate the specially developed website for children into more languages such as German, French and Spanish, currently only available in Dutch and English.
    b. Create subtitles for the available video material.
    c. Prepare new folders and information material.
    d. Modernize the current website.

    This program will be financed separately.

    a. Extension of the special website for children for learning about rare conditions. This could take the form of additional languages or additional content for school projects and subject talks.

11. Publish a newsletter. The aim would be to actively provide news updates and to direct readers to our website for more information.

12. Attend national and international conferences in the field of rare diseases. Conferences such as Eurordis and NORD for example.

13. Recruiting new members and donors and obtaining additional grants to increase the visibility of the Association. The main goals being to be able to support more people and to gather information on the medical conditions. We do now have a dedicated volunteer assigned to this role.

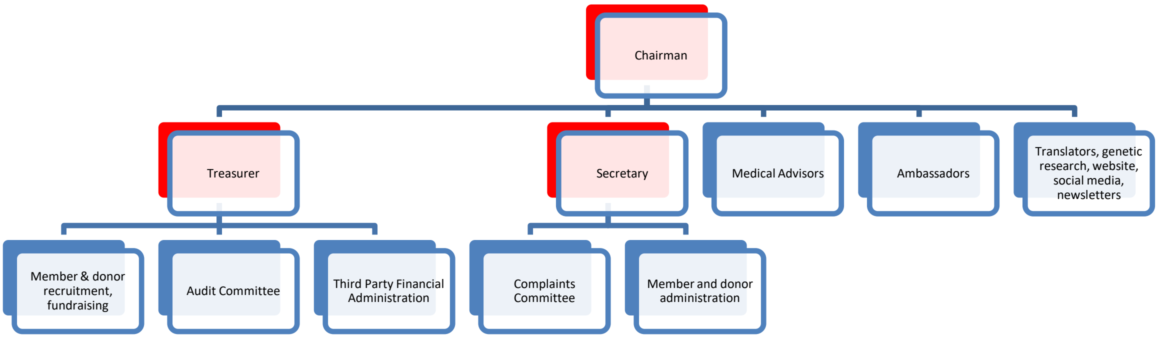
14. Ongoing professionalization of our organization such as through development and implementation of the fund-raising strategy.

15. Provide local representation for our organization in other countries through a liaison construction (so not via a separate new local CMTC-OVM organization). An example of this has been established in Germany.

5 People and Resources

The number of people available is quite limited in a small Association such as ours. The amount of effort required however is not proportional to the size of the organization which means that there is still quite a considerable quantity of work to be done. During the year 2016, the Board consisted of three people.

The organogram of our organization is shown here with the Board members indicated in a red marking:



Through the use of extra volunteers for translation work and various other activities a lot of additional work has also been carried out.

We actively involve increasing numbers of our existing members in activities such as the recruitment of new members and donors, other fundraising efforts and attending conferences.

A number of members have themselves generously volunteered to help out with some of these activities

The 2017 budget contains the key items Patient Contact, Information Provision, Advocacy (new for 2017) and Enabling Activities. This budget amounts to approximately € 55,000.

Extra activities on top of this are carried out on an individual project basis and these are funded separately.

6 CMTC-OVM and the Environment

Just like any commercial organization our activities can have also have a negative impact on the environment. We have taken the following measures to limit any adverse environmental impact:

1. Newsletters are generally made available via the website and only exceptionally printed on paper and sent by post.
2. Printing on paper is double-sided where possible.
3. When necessary, travel by car is shared with other persons.
4. Computers are only switched on when they are actually used.
5. Meetings are held by telephone if possible, for example via Skype.
6. Communication via e-mail is preferred above physical post.
7. Empty inkjet cartridges are collected and submitted at drop-off points.
8. Paper, plastic and chemical waste are separated from other waste.
9. Material is reused as much as possible.

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.
CBF	Central Bureau on Fundraising.
CMTC-OVM	Cutis Marmorata Telangiectatica Congenita and Other Vascular Malformations, our organization.
Eurordis	European Organization for Rare Diseases.
FondsPGO	Arranges subsidy from the Dutch government for disabled people and patient organizations.
NFU	The Netherlands Federation of University Medical Centers
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.