

Patient Association
CMTC-OVM
www.cmtc.nl

Annual Report 2012



Date: 12 May 2013
Version: 1.0
Status: concept

Author: Lex van der Heijden
Owner: Board CMTC-OVM

Document History

Document location

The source document is stored on the computer of the President. A copy is available in the board area of the CMTC-OVM website.

Version control

Version #	Date	Summary changes	Changes marked (y/n)
1.0		First Version	Not applicable.

Approval

Name	Role
A. Fidder	Treasurer
A. Kerkvliet	Board Member
F. R. Kerkvliet	Secretary

Distribution

This is a public document.

Table of Authorities

Does not apply.

Table of Contents

1	Introduction	4
1.1	Objective Document.....	4
1.2	Introduction	4
1.3	Directors	4
1.4	Medical Advisors	5
1.5	Volunteers	5
1.6	Special Events	6
2	Activities 2012	7
2.1	Introduction	7
2.2	Family Day	7
2.3	Members Meetings.....	7
2.4	CMTC-OVM US	8
2.5	Medical Examination and Diagnosis	8
2.6	Marketing	8
2.7	Conferences	8
2.8	Newsletter	9
2.9	Website	9
2.10	Genetic Research	10
3	Financial.....	12
3.1	Introduction	12
3.2	Expenditure Overview	12
3.3	Income.....	12
3.4	Notes.....	12
4	Preview.....	14
5	People and Resources Available.....	16
6	CMTC-OVM and Environment.....	17
A.	Appendix – Terms and Abbreviations	18

1 Introduction

1.1 Objective Document

This document contains the annual report of the patient Association CMTC-OVM, formerly "Association for people with the Van Lohuizen Syndrome", concerning the year 2012. The purpose of this paper is primarily to provide an overview of the activities carried out in 2012.

1.2 Introduction

The patient 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, which is laid down in the statutes, is expressed in the text below.

The 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 in the broadest sense of the word.

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

The logo is:



1.3 Directors

The Board is composed as follows as of December 31, 2012:

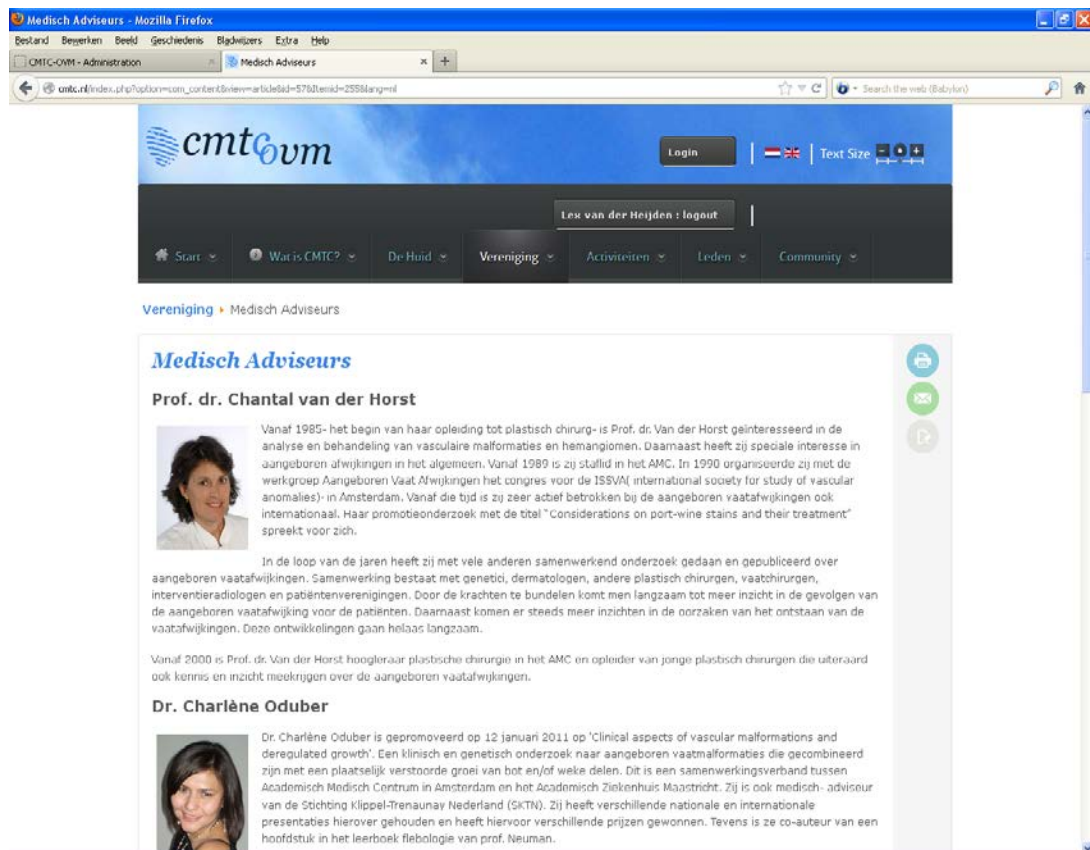
Mr. A.F.R. van der Heijden	President
Ms. F.R. Kerkvliet	Secretary
Mr. A. Fidder	Treasurer
Mrs. J. Kerkvliet-Molenaar	Board Member

1.4 Medical Advisors

Our medical advisors are: Prof. Dr. C.M.A.M. van der Horst, Prof. dr. A.P. Oranje, Prof. dr. M. van Steensel, Dr. W.W. van der Schaar, Drs. Siderius en Dr. C. Odubèr.

In addition, we work closely with many other doctors from various countries such as with Dr. Millan Patel in Canada as part of our genetic research.

On our website there are more details of our medical advisors.



1.5 Volunteers

In fact, the association is exclusively driven by volunteers accompanying educators including the Board. In addition to the Board are various volunteers active with many activities. For example, in particular translation work. In addition to the Board, as of December 31, 2012, 15 volunteers that have been active in particular in the field of translations and members during the meetings.

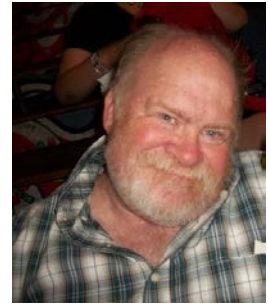
1.6 Special Events

In 2012 two of our members died.

On March 22, the Chairman of our American organization Ed Gallis died. He was the grandfather of all U.S. children with CMTC. His role has been taken over by his wife Becky.

Ed was also a beacon for many parents and has helped many people especially mentally. We lose in him an important person for our Organization and have at the same time, the confidence that his wife will fulfill this role well.

On September 13, a girl of four years died in the United States. This has become the sixth person, as far as is known, who has died of CMTC possible complications.



2 Activities 2012

2.1 Introduction

Thanks to the grant from the Dutch Government in particular, we had a large amount of (additional) activities in 2012.

The main activities in which we have done in 2012 are:

1. Organizing a family day for the patient and his/her immediate family in the Netherlands.
2. Organizing member meeting in the Netherlands and the USA.
3. Founding CMTC-OVM US.
4. Offering free medical examination both in the Netherlands and the USA.
5. Our organization actively propagating by means of marketing.
6. Participate in conferences.
7. Compose newsletter.
8. Rebuilding and expanding customers.
9. Start-up of genetic research in Canada.

2.2 Family Day

In 2012 we organized for the fourth time a family day for the patients and their immediate family. This was another great success! About 60 people came to Burgers's Zoo in Arnhem.



The responses were very positive and the members had both plenty of time to get to know each other and share experiences.

On our website are even more photos of this event and a report from one of our members.

2.3 Members Meetings

We have organized member meetings twice in 2012. In July in Washington D.C., Prof. Dr. van Steensel attended, taking with it the possibility to offer a diagnosis free (15 people made use of this) and the opportunity for most diverse medical questions to be asked. Members from both the USA and Canada were grateful to make use of this possibility. The number of participants was about 60 this year.



In November, the members' meeting in Netherlands was organized. Present were members from Germany, Hungary, Netherlands, and the United States of America. The number of attendees was about 70. Our members could receive a free medical diagnosis, of which full use was made. Present were two professors and two doctors so a vast resource of knowledge and experience.

Reports with photos are available on our website.

2.4 CMTC-OVM US

The creation of the American CMTC-OVM chapter has taken a long time and ultimately in 2012 has become a reality. They have their own website and logo where their and our website have strong links among themselves so that all knowledge and experience can be shared.



The Secretary and President of the worldwide Dutch organization are part of the American administration.

2.5 Medical Examination and Diagnosis

Thanks to the collaboration of Prof. Dr. van Steensel we are able to offer our members free medical examination and diagnosis in the academic hospital Maastricht. Up to this moment, 35 members from various countries (such as Aruba, Australia, Canada, Croatia, Denmark, England, Italy, Greece, Hong Kong, Norway, USA and Sweden) have made use of this opportunity.

2.6 Marketing

How we increase our brand awareness and how do we thereby achieve more patients was our question for quite some time. We have developed a marketing plan which enables us to increase our visibility using modern (Internet) technology. We measure the effects of actions by means of website statistics so that we can determine the extent to which the action for us has had sufficient results. In 2012 we have again created unique CMTC-OVM pens with the new logo.

2.7 Conferences

Participating 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. Networks, brand awareness and learning from each other are also important keywords.

We visit particular international conferences of large organizations in order to make and maintain important contacts (networking).

The experience has been that the time between planting and harvesting years and that you have to keep seeding.

In 2012 we have participated in the following international conferences:

1. Eurordis in Brussels. This year a record number of participants (plm. 680) and also several large pharmaceutical companies were present.
2. NORD/DIA in the United States. It was not only the global Netherlands Organization represented but also the American CMTC-OVM organization.

For a report of the different conferences we refer to our website.

2.8 Newsletter

The CMTC-OVM Newsletter, in principle, written four times a year in both Dutch and English. This year the newsletter was published three times for the first time which was caused by the large amount of work on the new website.

This newsletter is also available for doctors and third parties but then is anonymous to ensure the privacy of our members. The newsletter contains among others, medical articles for everyone in a readable translation, a personal story, as well as reports of conferences.

2.9 Website

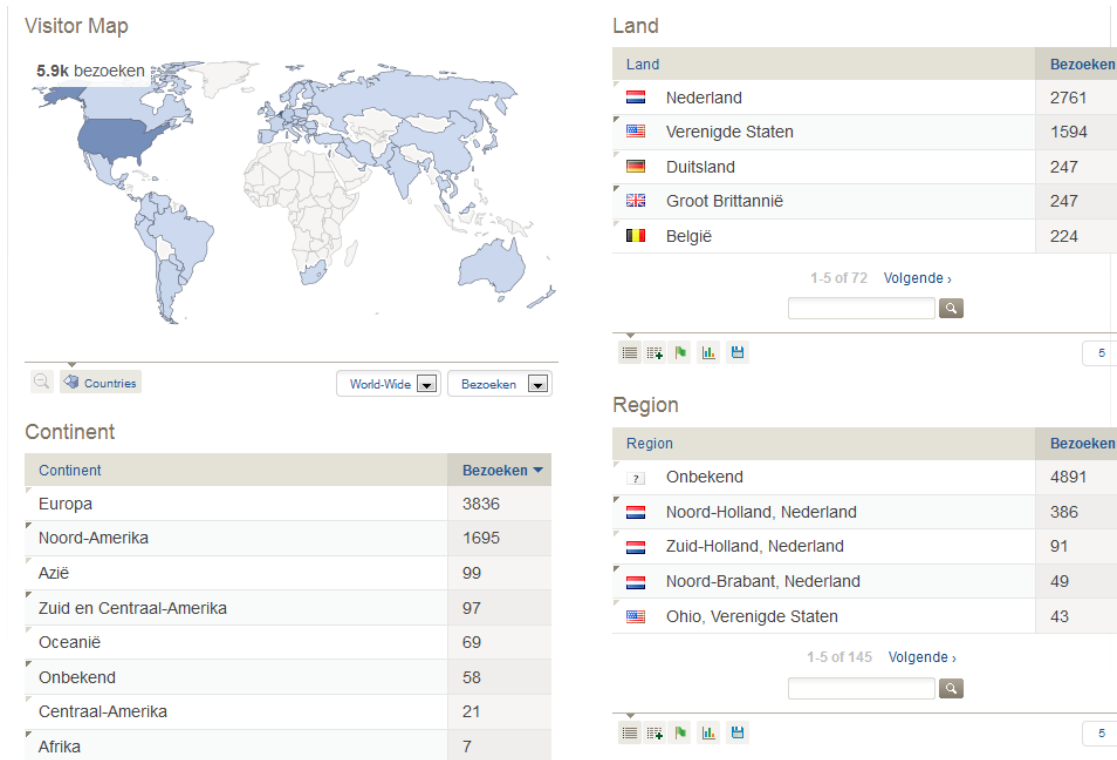
Our website is our main medium to share information. In 2011 we launched a graphic redesign of our new website and with the construction of this new website a lot of additional functionality. In 2012, the new website has been activated on May 23.

For example, reports from practically all conferences which we have attended can be found. Separate pages are created for donors, volunteers and sponsors. Also the 'homepage' is changed in the course of the year and the use of 'social media' is integrated into our website.

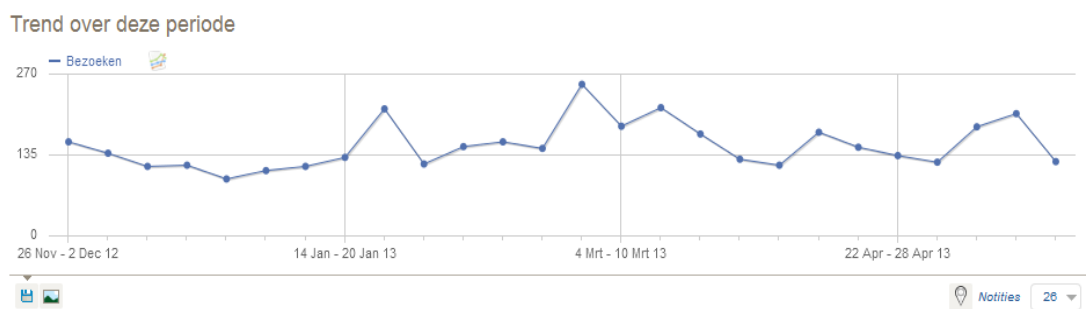
The security of the website is further expanded to further protect the privacy of our members.

We are paying a lot of attention to security partly because we saw that in 2012 approximately 7000 attempts per month were made to break into our website! We want to prevent personal information of members, donors, etc. from getting in the hands of people with wrong intentions.

The statistics which we use in order to determine the effect of certain actions, among others, is an important tool in our marketing. Below an example of our statistics.



We use these statistics to determine which search keys are used to find our Web site and to determine the effect of certain activities.



Mark Knopfler, Dire Straits, has given approval to use his music for the videos that have been made (which have been composed of single pictures).

2.10 Genetic Research

Thanks to many years of international networking we managed to start a genetic research program to the cause of CMTC. This research is being conducted in Canada in collaboration with some of our medical advisors. Dr. Millan Patel on the picture leads this genetic research program in Canada.

This research is free of charge for our organization which would not have been possible if we need to fund this program ourselves. The costs of such a program are between € 35,000 and € 50,000.



In 2012, a number of patients that meet certain criteria, have given biopsies (piece of skin), which will be examined in Canada. It is expected that during the second half of 2013 a step can be made in unraveling the genetic cause of CMTC.

3 Financial

3.1 Introduction

The year 2012 was a pretty good financial year for us as well. We could perform many activities in various areas and can further strengthen our position. Unfortunately, we lost a lot of grant in 2012 due the new Dutch Government grant legislation but by the generosity of IBM this was well compensated.

Below an overview of the different main items (expenditure and income).

The main items largely correspond to the structure which the Dutch Government organization FondsPGO uses, namely:

1. Contacts.
2. Information.
3. Advocacy.
4. Capacity-enhancing activities.

3.2 Expenditure Overview

Activity	Expenditure 2012 (€)	Expenditure 2011 (€)
Contacts	22.845	26.305
Information	16.694	5.633
Advocacy	6.553	8.465
Capacity-enhancing activities	4.465	4.625
Total	50.557	45.028

3.3 Income

Source	Income 2012 (€)	Income 2011 (€)
FondsPGO grant	34.850	41.300
Membership fee	1.825	1.584
Donation/gift/miscellaneous	11.362	1.317
Total	48.037	44.201

3.4 Notes

The main posts in the category 'Contact' are formed by two members' meetings (Netherlands and United States). During the Assembly of members in Netherlands there is also in a separate hall with children's entertainment organized so that parents can attend the meeting and the children will be kept busy in all kinds of ways, taking into account the age of the children.

In 2012 we had a family day organized with the aim to bring together not only patients but also their immediate family in an environment and have fun together, get to know each other and share experiences.

The post 'Happy Together' is formed by the relatively sudden death of the President of the American organization. The President of the worldwide Dutch organization went to America and unfortunately came just too late but was then able to provide the family support.

Furthermore, we have purchased new hardware in 2012 as a laptop and a private 'cloud' so that more members and doctors can share big files easily and securely.

	2012	2011
Implementation rate charges (%)	91.17	89.73
Implementation rate income (%)	95.11	91.41

4 Preview

It turns out that it takes many years for a patient organization to become visible. For rare condition organizations this is even harder which requires a lot of effort also financially.

All kinds of address guides are updated once a year so that it takes at least a year before a new organization is to be found in such guides. Given the rarity of the condition, we expect slow growth over the next few years.

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 focal point between doctors and patients.

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

In the year 2013, we want to include the following activities:

1. Our quarterly newsletter, which was published at the time, will be replaced by articles within our website.
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 like dermatologists, both at home and abroad.
4. Research on vascular malformations such as CMTC. We are thinking in particular of DNA genetic research material of patients.
5. Organizing a meeting for personal contacts and exchange of information in the form of a meeting in both the Netherlands and USA.
6. Organizing a family day in Netherlands in a casual setting where the attention is focused on the business together with patients and their immediate family. This also provides the opportunity to make gain knowledge and knowledge and exchange experiences.
7. Building and expanding the website including:
 - a. Other vascular malformation information.
 - b. Psychological information (e.g. how to deal with bullying).
 - c. Special part for children (child language use, etc.).
 - d. The website for the use of different modes of access. The tipping point will come when in 2013 more users view websites with 'smartphones' and 'tablets' than 'normal' computers. The presentation on smaller monitors e.g. should be different than on large displays.

For these different extensions we define projects which will be funded separately.
8. Attending national and international conferences in the field of rare diseases. We think in particular of conferences of Eurordis and NORD.

9. Participate in medical (International) conferences with for example a 'stand' with promotional material.
10. Raise funds in particular to broaden our financial basis and to spread risk. Totally dependent on only one sponsor is a risk to the continuity of our organization.
11. Recruiting members and donors and obtaining grants to increase the visibility of the association with as main goals to be able to support more people and to gather information on the condition.
12. Patient information folders for Other Vascular Malformations designed and published in different languages. Meanwhile the CMTC folder available in 6 languages (Dutch, German, English, French, Russian and Spanish).
13. Develop a leaflet for donors, in particular Dutch donors.
14. Further development of our website such as integration of member administration and financial administration and all sorts of other articles.
15. Development of our own community within our website.
16. Maintaining the security of the dangers which come from the Internet. The main dangers are viruses and intrusion into the computers used by the board members and illegal access to our website. In 2012 we had about 7000 intrusion attempts in our website per month.

5 People and Resources Available

The amount of available people is quite limited in a small association. The amount of work, however, is not proportional to the size of an association which means that there is still considerable work to be done. The board existed during the year 2012 of four people. For example, through the use of additional volunteers for translation work and other various activities a lot of work is done.

6 CMTC-OVM and Environment

Our activities can have negative environmental impacts. We have taken the following measures to limit any adverse environmental impact:

1. Newsletters etc. are made available via the website and at high exception printed on paper and sent by post.
2. Printing on paper is done as much as possible, double-sided.
3. Travel is done by car as much as possible, combined with other persons.
4. Computers are only switched on when they are actually used.
5. Conferencing by telephone if possible (e.g. via Skype).
6. The medium email is preferred over physical post.
7. Empty inkjet cartridges are collected and submitted on the aforementioned drop-off points. We receive per cartridge € 1 discount when buying new Hewlett Packard cartridges.
8. Paper, plastic and chemical waste are separated from the other waste.
9. Material is reused as much as possible.

A. Appendix – Terms and Abbreviations

Term/acronym	Statement
ANBI	Our organization has received from the Dutch Taks a formal status of non-profit which implies that donations are tax deductible.
CMTC-OVM	Our organization.
Eurordis	European Organisation for Rare Diseases.
Fonds PGO	Arrange sufficient subsidy from Dutch Government (patients, disabled and elderly people).
NORD	National Organization for Rare Disorders (USA).
VSOP	United Together working parents and patients' organizations.