Patient support organisation
CMTC-OVM
www.cmtc.nl

Annual Report 2010

Date: 17 March 2011
Version: 1.0
Status: final

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Owner: Board CMTC-OVM

Document History

Document location

The document source has been stored on the computer of the chairman. A copy is available in the administration management section of the CMTC-OVM website and with the other members of the administration management team.

Version control

Version #	Date	Summary changes	Changes indicated (y/n)
1.0		First version	Not applicable

Approval

Name	Role
A. Fidder	Treasurer
A. Kerkvliet	Member of the board
F. R. Kerkvliet	Secretary

Distribution

This is a public document.

Source

Not applicable.

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1 Introduction

1.1 Goal of document

This document contains the annual report of the patient association CMTC-OVM, formerly the Association for People with the “Van Lohuizen Syndrome”. The purpose of this document is to give an overview of the activities performed in 2010.

1.2 Introduction

The patient association was formally established on January 22, 1997 by notary Van Helden in Amsterdam and was registered at the Amersfoort Chamber of Commerce. The goal of the association is enshrined in the statutes, as expressed in the text below.

The mission is:
“Improving the well-being of people suffering from the ‘Van Lohuizen syndrome’ (CMTC), specifically for its own members, and fostering and developing activities that may improve this well-being. Fostering (scientific) research on CMTC, its causes and treatment, and everything related to this in the widest sense of the term.”

The name has been changed into: CMTC-OVM, which stands for: Cutis Marmorata Telangiectatica Congenita en Overige Vasculaire Malformaties.

The logo is:

1.3 Board

As of 31 December 2010 the board consists of:

Mr. A.F.R. van der Heijden	Chairman
Ms. F.R. Kerkvliet	Secretary
Mr. A. Fidder	Treasurer
Mrs. A. Kerkvliet-Molenaar	Board member

1.4 Medical Advisers

The following people act as medical advisers to the association:

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 and Drs. C. Odubèr.

We also work very closely with a great many physicians from various countries.

1.5 Volunteers

Our association is solely run by volunteers, the Board inclusive.

In addition to the board, a number of volunteers provide services for the association including, for example, translation work. As from 31 December 2010, besides the Board, 7 volunteers are active as translators.

2 Activities in 2010

2.1 Introduction

Thanks to the grant from FondsPGO we were able to execute a great number of (extra) activities in 2010. In particular, in the area of professionalization, we were able to take some big steps.

The most important activities conducted in 2010 are as follows:

1. Organising a patient's day for the patient and his/her immediate relatives.
2. Organising a members day.
3. Offering free medical advice.
4. Professionalization of membership and financial administration.
5. Professionalization of image - attending events/conferences/etc.
6. Actively promote our organisation by means of marketing.
7. Setting up procedural policys.
8. Setting up volunteer policys.
9. Setting up organization General Assembly Netherlands scenario's.
10. Attending conferences.
11. Compiling a newsletter.
12. Extending the website.
13. Designing a new brochure and poster.
14. Designing a flag and banners.

2.2 Patients day

The second "Patient's Day", for patients and their close relatives was organised in 2010. Approximately 35 people attended the event held at the Avifauna Bird Sanctuary, which was a huge success thanks to great organization and helped along by the splendid weather!.

After a lovely cruise, while enjoying coffee, tea, soda and a nice pastry, the participants could visit the park.

Vogelpark Avifauna
ALPHEN AAN DEN RIJN

At midday, a tasty lunch was served with a magnificent view of the Flamingos. Then, while the children were playing, everybody had an opportunity to meet and get acquainted. After lunch a group photo was taken followed by an opportunity to see more of the park.

2.3 Membership meetings

Membership meetings were organized twice during 2010. The first one, in July, took place in Washington DC, where we were joined by Prof. Dr. Oranje and were we offered free diagnoses (17 people took advantage of this opportunity) and there was the opportunity to ask a wide variety of questions. Members from the USA and also Canada took advantage of this opportunity. Once again, we saw the number of attendees was double that of the previous year.

Note: Not all those present are on the photo.

The second membership meeting, in November, took place in the Netherlands. Members from Aruba, Cyprus, Germany, England, Hong Kong, The Netherlands, Russia and the USA also attended this membership meeting. This year we recorded the medical forum on video, which members were able to access later via Internet, allowing people who where unable to attend the meeting to the ability to see and hear which medical questions where asked and which answers where given. For this session we had record attendance: there where close to 100 people present!

The meeting was also broadcasted “live” via internet, and members had the opportunity to ask questions “live” and interactive with sound and video. A number of people from regions such as the USA made use of this opportunity.

2.4 Free Medical Examination and Diagnosis

Thanks to the cooperation of Prof. Dr. van Steensel we are able to offer free medical examination and diagnoses in Maastricht University Hospital. Until now more than 20 members from various countries (including Aruba, Australia, Canada, Croatia, Denmark, England, Greece, Hong Kong, Italy, Norway and Sweden) took advantage of this opportunity.

2.5 Membership and Financial Administration

For many years we mainly used MS-Excel for our membership and financial administration, this cost us a lot of time, especially when we had to make our financial annual report.
It was time to buy a new software package that would make this task simpler and quicker. We choose for the Davilex Club. A number of licences where purchased and during the last year we switched, in collaboration with our supplier, to improve the professionalism of our membership and financial administration.

2.6 Marketing

For a long time our question was: how do we enlarge our brand awareness and how can we reach more patients.

It was time for a marketing plan that could make us more accessible, in particular using modern (Internet) technology. During the year we implemented the first part of our marketing strategy and in 2011 we will continue with further phases of that strategy.

2.7 Procedure policy

Drafting a procedure policy was not only necessary from a professional point of view but also from a vulnerability point of view. In the event of something happening to our chairman the survival of our organisation would be in great danger. During the course of several years we built a lot of procedures that need to be anchored in a procedure policy book. The procedure policy book is a dynamic document which needs to be updated regularly.
At this moment the policy book consists of about 70 pages.

2.8 Volunteer policy

Drafting a volunteer policy was also very important to us. This document outlines how we want to treat our volunteers as an organisation, and what expectations we have of our volunteers.
At this moment the policy document consists of about 30 pages.

2.9 Script Membership meeting Netherlands

Organising the membership meeting in the Netherlands has become a significant activity, to ensure that we are effective it is necessary to script this quite carefully.

The first version of the script was tested during our meeting in November 2010 and subsequently updated. This way we can guarantee the high quality and continuation of our membership meetings.

2.10 Conferences

Attending conferences contributes to a number of important goals for organisations who are active in the area of rare diseases.

Working together is the key in this context. Networks, brand awareness and learning from each other are just some of those key important goals.

We visited named international conferences and big organisations, for example Genetic Alliance and Eurordis. Here we establish important contacts for our own organisation.
In the meantime, it is our experience that it takes years between sowing and harvesting, and we have to keep on sowing.

In 2010 we attended the following internationale conferences:

1. ICORD in Argentina.
2. Eurordis in Poland.
3. Genetic Alliance in the USA.
4. Genodermatology in Maastricht (the Netherlands).

For a report of these conferences we refer to our website.

2.11 News letter

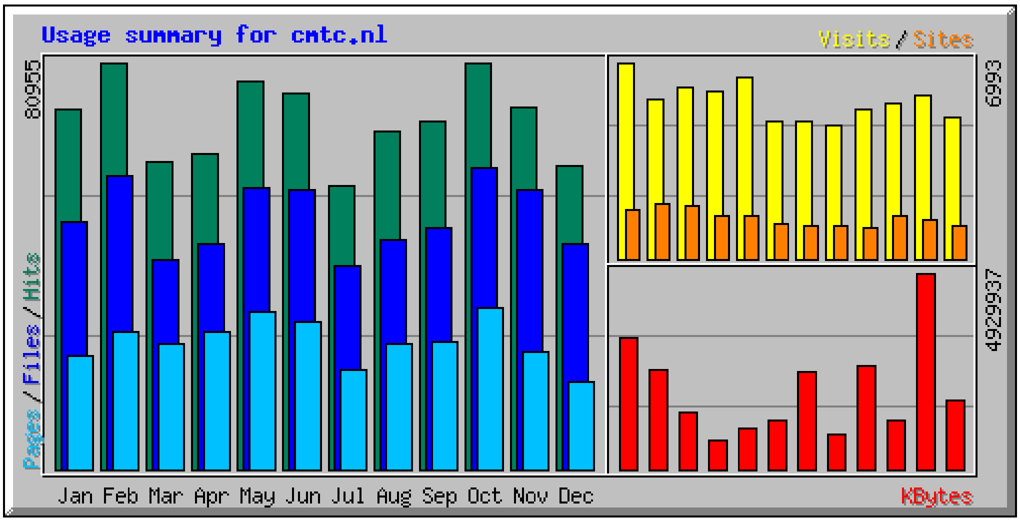
The CMTC-OVM news letter is published four times a year, both in Dutch and in English. This news letter is also available for physicians and third parties but in an anonymous form to guarantee the privacy of our members.
The news letter contains, among other things, medical articles, and translated in layman's language, personal stories as well as reports of conferences.

2.12 Website

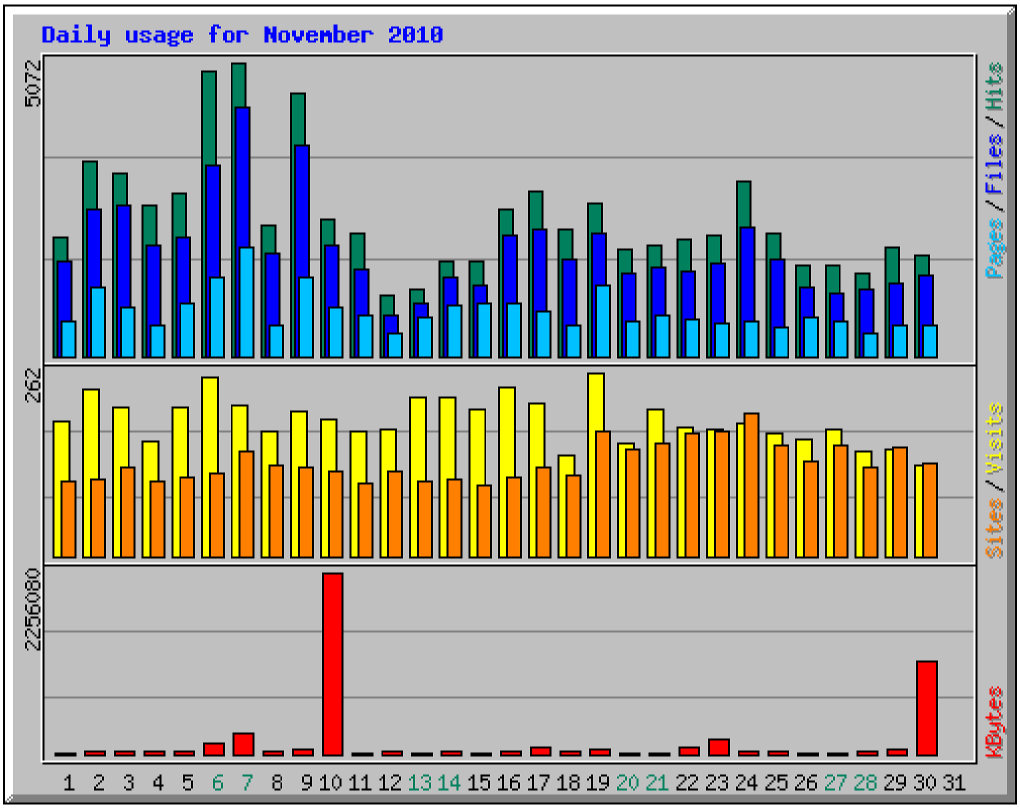
Our website is our most important medium for sharing information. In February 2010 our new website went 'live' and during the year 2010 a lot of information was added mainly to the public part of the website. You will find, for instance, reports of practically all the conferences we attended and reports of various membership meetings. Furthermore we added separate pages on behalf of donators, volunteers and sponsors. The "homepage" was changed during the course of the year and the use of social media is now integrated in our "homepage".

The security of the website was extended in 2010 to protect the privacy of our members

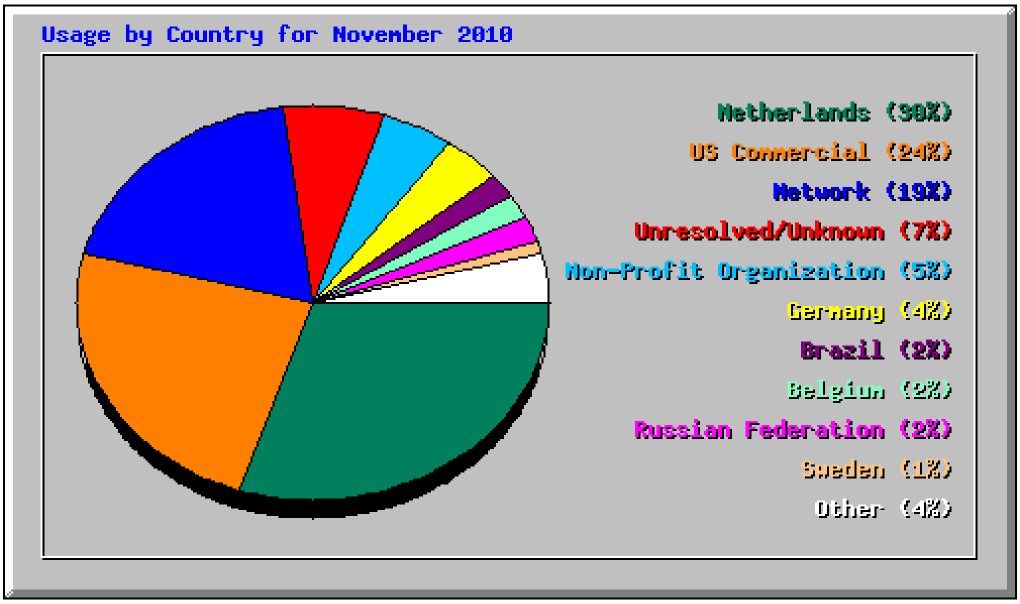
Statistics are used with the aim to help us determine the effect of association activities on visits to the site, this is important to help our marketing strategy. You will find an example of these statistics in the section below.



We use these statistic to determine which searchkeys were used to find our website and to determine the effect of certain activities on website activity.
Below is an example from the statistics that shows the effect of the membership meeting in November in the Netherlands.



We also want to know the geographical distribution of our visitors:



Since our attendance to the Eurordis congres in Poland, the amout of visitors from the Russian Federation has been in the top 10, and the first Russian member has signed in. This is clearly a result of one of our activities.

Maintenance of the webite demands a lot of time. For this we bought a specific software package . At the moment the graphic designer ,who built the website it is responsible for maintenance. He makes all changes and extensions.

In 2010 we made the first step towards the integration and use of “social media”, according to one of the suggestions from our marketingplan, which will continue in 2011.

2.13 Brochure and Poster

Because our website, logo etc. were changed, it was also necessary to adapt the style that is being used in our brochure and our poster.

The brochure is now available in 6 languages as shown on the image on the right.

Informatiefolder

>> Download de Nederlandse folder (pdf bestand)
>> Download de Engelse folder (pdf bestand)
>> Download de Duitse folder (pdf bestand)
>> Download de Franse folder (pdf bestand)
>> Download de Spaanse folder (pdf bestand)
>> Download de Russische folder (pdf bestand)

Our poster is only available in Dutch, in English and in various qualities to guarantee a good quality when printed on a larger format.

Poster

>> Download de Nederlandse poster (pdf bestand - zeer hoge kwaliteit)
>> Download de Nederlandse poster (jpg bestand)
>> Download de Engelse poster (pdf bestand - zeer hoge kwaliteit)
>> Download de Engelse poster (jpg bestand)

2.14 Flag and Banners

We improved our apprearances and visability during meetings and congresses by designing a CMTC flag and banners. The flag was flying for the whole week at the conference centre/hotel were we organised our membership meeting in The Netherlands. We also used our banners there for the first time.

We first used our banner externally at the Worldwide Genodermatology convention in Maastricht in November 2010.

Looking around us at other (professional) exibitors, we came to the conclusion that we made a positive impression with our professional image. This was confirmed by the people visiting our stand.

3 Financial

3.1 Introduction

The year 2010 has been a good year for us, also from a financial point of view. We were able to develop many activities in various regions and were able to strengthen our position.
The summary below will give you the various key items (expenditure and income).

The key items are largly the same with the structure which FondsPGO uses, namely:

1. Member contacts.
2. Education.
3. Advocacy.
4. Enhancing activities.

3.2 Expenditure Member Contacts

Activities	**2010 (€)**
Membership meetings	12.740
Medical diagnosis in the Netherlands	254
Patients day	1.263
Small gift fund	619
Office- and computer articles	2.365
Total	**17.241**

3.3 Expenditure Education

Activities	**2010 (€)**
Website	9.613
Marketing & Public Relations	3.887
Total	**13.500**

3.4 Expenditure Advocacy Activities

Activities	**2010 (€)**
Collaboration external organisations	11.469
Expense allowance medical advisors	1.200
Support medical research	500
Total	**13.169**

3.5 Expenditure Conditional Activiteities

Activities	2010 (€)
Board expenses	4.279
Banking costs	97
Chamber of Commerce	37
Software licenses	1.606
Accountant/notary	593
Education	31
Memberships	57
Total	**6.700**

3.6 Expenditure Overview

Activities	Expenses 2010 (€)	Expenses 2009 (€)
Member contact	17.241	11.376
Education	13.500	3.045
Advocacy	13.169	15.176
Enhancing activities	6.700	3.087
Professionalization (integrated in 2010)	In other activities	8.070
Total	**50.610**	**40.754**

3.7 Income

Source	Income 2010 (€)	Income 2009 (€)
FondsPGO subsidy	40.700	40.600
Contribution	1.039	1.475
Donation/gifts/etc.	2.825	4.675
Total	**44.564**	**46.750**

3.8 Explanation

The book year 2010 was the first year in our history in which we didn’t have to worry about our financial position and our survival. This was largely thanks to a grant from the FondsPGO (Dutch Government).
Major contributors in the category “member contacts” are caused by two membership meetings.
During the membership meeting in The Netherlands, child care was organised in a separate room so that the parents were able to attend the meeting. The children were occupied in all sorts of ways, befitting their age.
In 2010 we also organised a patient’s day with the purpose of not only bringing patients together, but also their close relatives, in an informal environment to have fun together and share experiences.

The major expenditure in the category “education” is caused by the office computer supplies, which are spread across different categories.

The major costs in the category “advocacy” are mainly from attending conferences.

The major costs in the category “enhancing activities” are from the expense allowances for the board members. These expenses meet the Dutch tax regulations in close consultation with our accountant.

The major cost in the category “professionalization” was our new website, which, after about 10 years, badly needed to be replaced.

Other costs that deal with professionalization were divided over various other categories that were more relevant to the spent - therefore this item is relatively small.

4 A look ahead

It is our experience that it takes a patient organisation years to build up a (name) reputation. Where it concerns a rare disease it takes an even larger effort, including a financial one.

A number of organization’s address guides are updated only once a year, so it takes at least a year before a new organisation is to be found in guides like this. Given the rarity of the disease we expect a slow progression these coming years.

International contacts will increase further as will the number of international members.
We aim to expand our networks globally by means of Internet technology, and to strengthen our pivotal roll among physicians and between patients and physicians.

Contacts through Eurordis, NORD en Genetic Alliance are expected to be increasingly important and will open doors for a small organisation such as ours. Making the right contacts is very difficult without their help. Collaboration, sharing knowledge and experience is crucial to improving the lives of patients.

In the year 2011 we want to accomplice the following activities:

1. Issuing a quarterly news letter for members. A special anonymous version will go to an number of physicians in various diciplines in a number of (academic) hospitals. All newsletters will be translated in English. Of special interest are the personal experiences of patients, these are enormously appreciated by other members.

2. To maintain and expand our contacts and work together with both patients and other patient associations, in the Netherlands and abroad.

3. Set up a daughter organisation in the USA. This is a slow process because it requires research on legal, tax and financial aspects.

4. Maintenance and expansion of our contacts with medical specialists such as dermatologists in the Netherlands and abroad.

5. Research of vascular malformations like CMTC. With a focus on genetic research of DNA material of our patients.

   In September 2010 we were asked to participate in genetic research in Canada. In 2011 we will, in cooporation with our medical advisors, carry on with this project.
   We will “deliver” the people who want to participate in this research, we will communicate with both members as well as physicians, about this research.

6. Organising a meeting enabling people to meet and share information, both in The Netherlands and in the USA.

7. Organising a patient’s day in the Netherlands in an informal environment where the focus lies on sharing activities with the patients and their close relatives. This also provides an opportunity to get acquianted and share knowledge and experiences.

8. To build and extend the website including a list of questions and answers which we accumulated over the years. Also adding to the website a feature to create a personal profile, giving patients the choice of what information is shared and with whom.

9. Attending (international) rare disease conventions. In particular the conventions of: ICord, Eurordis, NORD and Genetic Alliance.

10. Participating in medical (international) conventions with a stand displaying our promotion materials.

11. Raise funding to strengthen our fianancial base and to spread risks. To be completely dependent on only one sponsor is a risk to the continuation of our organisation.

12. Recruting members and donors and obtaining grants in order to be able to give our organisation a better brand awareness, thus helping more people and gathering more information about the disease.

13. Design patient information brochures about Other Vascular Malformations and publish these in various languages, the CMTC brochure is now available in 6 languages (Dutch, German, English, French, Russian and Spanish).

14. Making better use of the Internet. This can help to realise a considerable time and cost reduction in an environment where both time and financial means are in short supply. By offering information such as patients information brochures in digital form, the workload of the organisation is greatly reduced because people can download their information direct from our website. Another big (financial) benifit of sharing information digitally is minimization of costs incurred when making changes.

15. Maintaining internet security. Of the dangers present on the Internet, the most important are viruses and hackers when the members of the board are using the internet. Few people realize the risks involved when using the internet. Since our computers contain the (medical) data of our members, security is a top priority.

16. Further implementation of the marketing plan.

5 Available people and resources

The amount of people available is quite limited in a small organization like ours. However the amount of work to be done is not proportional to the size of the organisation. This means that a considerable amount of work has to be done by few people. The board consisted of four people in 2010. Because of the effort put in by volunteers for tasks such as translations, a huge amount of work has been done and a large number of tasks were completed.

Thanks to a new structure of grants, we now have substantial funds at our disposal, this enables us first of all to improve the lives of the CMTC patients and their close relatives and secondly we will be able to professionalize our organisation.

6 CMTC-OVM and the Environment

Like other businesses, our activities can have a negative effect on the environment. We took the following measures to minimalize these negative environment effects:

1. News letters etc. are only available on the website, only by exception will we print them and send them through the post.
2. We print documents on both sides of the paper as much as possible.
3. When we have to travel by car, we try to share a car as much as possible.
4. Computers will only be switched on when we actually use them.
5. Where ever possible we hold our meetings using conference call (for instance via Skype). This applies mainly to board meetings.
6. Using e-mail is preferred over paper mail.
7. Empty cartridges are collected and delivered to the appropriate collection points. Per cartridge we receive € 2 discount on new Hewlett Packard cartridges.
8. Paper, plastic and chemical waste are separated from the rest of the waste.
9. We recycle materials as much as possible.

A. Appendix – Terms and Abbriviations

Term/abbriviation	explanation
ANBI	General Benefits Analysis Institution
CMTC-OVM	Our organisatian.
Eurordis	European organisation for rare diseases.
Fonds PGO	Dutch government fund (Patients, Disabled and Elderly)
NORD	National Organisation for Rare Disorders (USA).
VSOP	United Parents and Patients Organizations.