Patients association
CMTC-OVM
www.cmtc.nl

Annual Report 2011

Date: *May 23 2012*
Version: 1.0
Status: Confirmed

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Owner: Board CMTC-OVM

Document History

Document location

The source document is stored locally on the computer of the President. A copy is available on the CMTC-OVM website and with the other committee members.

Version control

Version #	Date	Summary of Changes	Changes marked (y/n)
1.0		Initial version	N/A

Approvals

Name	Role
A. Fidder	Treasurer
A. Kerkvliet	Committee member
F. R. Kerkvliet	Secretary

Distribution

This is a public document.

Source

Not applicable.

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1 Introduction

1.1 Purpose of this Document

This document contains the annual report of the patients association of CMTC-OVM, formerly known as Association for people with the 'Van Lohuizen syndrome', relating to the year 2011. The main purpose of this paper is to give an overview of the activities carried out in 2011.

1.2 Introduction

The patients association was founded on January 22nd 1997 by van Helden, notary in Amsterdam, and then registered with the Chamber of Commerce in Amersfoort. The mission of the association, as documented in the bylaws, is copied in the text below.

The mission is:
To increase the well-being of people suffering from vascular malformations such as CMTC (‘Van Lohuizen syndrome'), in particular for its own members. Also to promote and develop activities that could advance that well-being. Stimulate (scientific) research regarding vascular malformations such as CMTC, its causes and its treatment, and everything that relates 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 Executive Committee

The executive committee is composed as follows per December 31st 2011:

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

1.4 Medical counselors

Our medical counselors are Mrs. Prof. dr. C.M.A.M. van der Horst, Mr. Prof. dr. A.P. Oranje, Mr. Prof. dr. M. van Steensel, Mr. Dr. W.W. van der Schaar and Mrs Dr. C. Odubèr.
We also work closely with many other doctors from various countries, such as a doctor in Canada regarding genetic research.

You can find more details on these medical counselors on our website.

1.5 Voluntary workers

The association is exclusively driven by volunteers, including the executive committee. Besides the committee, there are a number of voluntary workers engaged in various activities, such as translation work. Excluding the committee there were 15 other volunteers active per December 31st, 2011, in particular for translation activities and support during the general meetings.

2 Activities 2011

2.1 Introduction

Thanks to, in particular, the grant of the “PGO Fund”, we have been able to perform a large number of (additional) activities in 2011.

The main ones being:
1. Organize a family day for the patients and their immediate family.
2. Organize general meetings in the Netherlands and the USA.
3. Offering free medical examination.
4. Active promotion of our organization through marketing.
5. Participate in conferences.
6. Composing newsletters.
7. Reconstruction and expanding website (this will be deployed in 2012).
8. Startup of genetic research in Canada.

2.2 Family day

In 2011 we held our third family day for patients and their immediate family. Again it was a great success, even if the weather was not as good as in the last two years! Around 80 people came to the “Efteling”.

We had arranged special passes with which patients did not have to stand in line for the attractions. This would have been particularly difficult for a lot of patients because of, for example, blood circulation problems.

You can find more pictures of this event on our website.

2.3 General Meetings

Two general meetings were held in 2011. In July it was held in Washington DC. Prof. dr. van Steensel joined us, which enabled us to offer free diagnosis (14 people used this opportunity) and answer any medical questions that came up. Members from the USA and Canada took full advantage of this opportunity. The picture shows a subset of the people that attended the meeting.

In November our general meeting was held in the Netherlands. We had attendees from Brazil, Germany, United Kingdom, the Netherlands and the USA. This year we recorded the medical forum on video, amongst other things, in order to place it on the internet for members that were not able to attend. That way all could see and hear which medical questions were asked and what the answers were. The number of attendees was around 75.

The meeting was also broadcasted “live” on the internet to enable members who could not attend in the Netherlands, to also ask questions “live” and interactive, with sounds and pictures. As an example, this opportunity was taken by someone from the United Arab Emirates.

2.4 Free Medical Examination and Diagnosis

Thanks to the cooperation of Prof. Dr van Steensel we can offer our members free medical examination and diagnostic services at the University Hospital in Maastricht. Up until now approx. 30 members have made use of this opportunity. These were members from various countries (such as Aruba, Australia, Canada, Croatia, Denmark, England, Greece, Hong Kong, Italy, Norway, USA and Sweden).

2.5 Marketing

For some time we had the question on how to increase our reputation and how to reach more patients. So it was time to create a marketing plan which should contain a series of tools needed to provide this by use of modern (Internet) technology. During the year we implemented pieces of the plan and in 2012 we hope to deploy this even further.

2.6 Conferences

Participating in conferences plays an important role, especially for organizations active in the field of rare diseases. Collaboration is the key word in this context. Networking, branding and learning from each other are also important key words. We visit important international conferences, especially from large organizations such as Genetic Alliance and Eurordis. They lay the basis for important contacts at high levels.
The experience has been that the time between sowing and harvesting can take years, and that you should keep sowing even if you do not see immediate results. In 2011 we participated in the following international conferences:

1. Eurordis in Amsterdam.
2. Genetic Alliance in the USA.

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

2.7 Newsletter

The CMTC OVM-newsletter is published, in principle, around four times a year in both Dutch and English. This newsletter is also available to physicians and third parties, but made anonymous to ensure the privacy of our members.
The newsletter includes medical papers, translated in different languages to make them accessible to everyone. They include personal stories as well as reports of conferences.

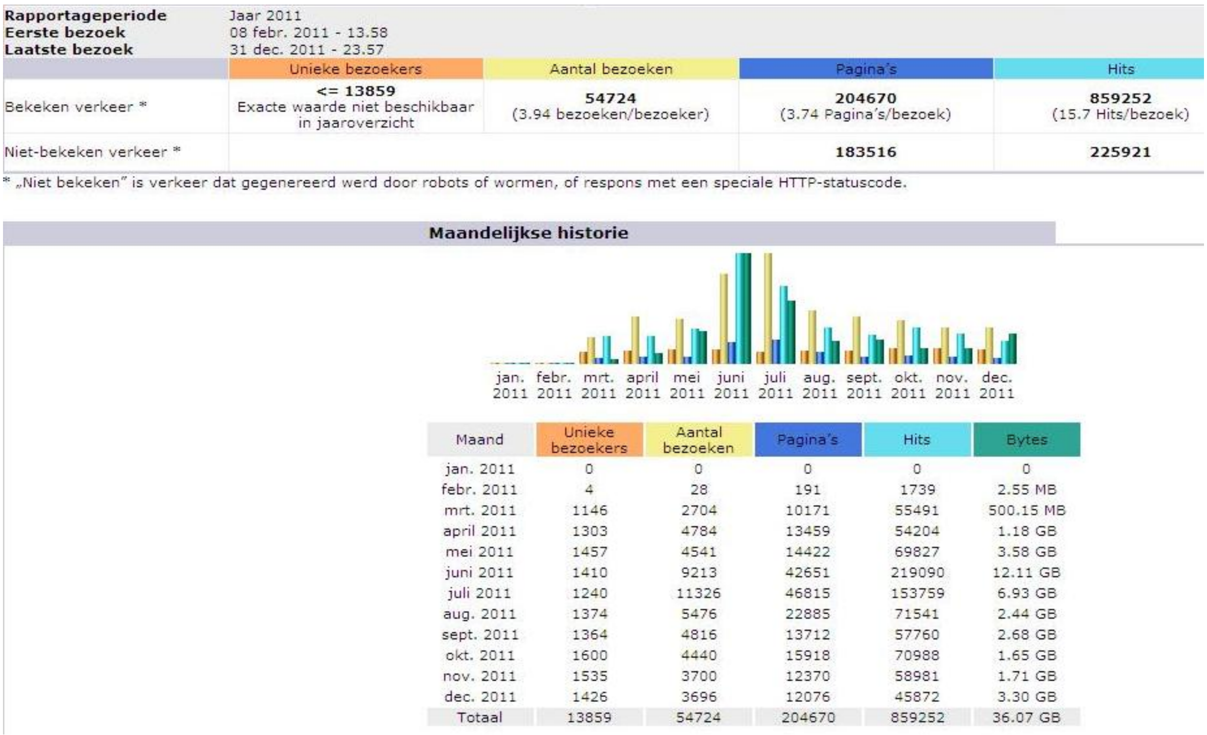
2.8 Website

Our website is our primary medium for sharing information. In 2011 we started a graphic redesign of our new website which offers lots of extra functionality. In 2012, this new website will be deployed and even more new features will be added. We are also anticipating on the increasing use of social media and smart phones.
The new website is also enabled for use on ‘smart phones’, which requires a different approach because the screen is considerably smaller than a computer screen.

As an example, almost all reports can be found of the conferences we have attended. We created separate pages for donors, volunteers and sponsors. The 'homepage' has also changed in the course of the year together with the integration of social media into our website.

The security of the site was expanded to ensure the privacy of our members even further.

The statistics we use to determine the effect of certain actions is an important tool in our marketing. Below an example of our statistics (in Dutch).



Rapportageperiode Jaar 2011
Eerste bezoek 08 febr. 2011 - 13.58
Laatste bezoek 31 dec. 2011 - 23.57

	Unieke bezoekers	Aantal bezoeken	Pagina's	Hits
Bekeken verkeer *	**<= 13859** Exacte waarde niet beschikbaar in jaaroverzicht	**54724** (3.94 bezoeken/bezoeker)	**204670** (3.74 Pagina's/bezoek)	**859252** (15.7 Hits/bezoek)
Niet-bekeken verkeer *			**183516**	**225921**

* „Niet bekeken" is verkeer dat gegenereerd werd door robots of wormen, of respons met een speciale HTTP-statuscode.

Maandelijkse historie

Maand	Unieke bezoekers	Aantal bezoeken	Pagina's	Hits	Bytes
jan. 2011	0	0	0	0	0
febr. 2011	4	28	191	1739	2.55 MB
mrt. 2011	1146	2704	10171	55491	500.15 MB
april 2011	1303	4784	13459	54204	1.18 GB
mei 2011	1457	4541	14422	69827	3.58 GB
juni 2011	1410	9213	42651	219090	12.11 GB
juli 2011	1240	11326	46815	153759	6.93 GB
aug. 2011	1374	5476	22885	71541	2.44 GB
sept. 2011	1364	4816	13712	57760	2.68 GB
okt. 2011	1600	4440	15918	70988	1.65 GB
nov. 2011	1535	3700	12370	58981	1.71 GB
dec. 2011	1426	3696	12076	45872	3.30 GB
Totaal	13859	54724	204670	859252	36.07 GB

We use these statistics to determine which search keys are used to visit our website and to determine the impact of certain activities.

We also wanted to know the countries where our visitors came from (below a partial list):

Bezoekers domeinen/landen

Domeinen/landen		Pagina's	Hits	Bytes
Commercial	com	65160	157870	6.31 GB
Network	net	53386	182098	6.98 GB
Onbekend	ip	28883	103717	2.07 GB
Netherlands	nl	26847	274251	14.16 GB
Germany	de	8491	23235	839.37 MB
Russian Federation	ru	6831	15852	277.56 MB
Non-Profit Organizations	org	6256	9299	134.35 MB
Belgium	be	1186	17783	324.60 MB
Sweden	se	597	1646	74.61 MB
Australia	au	542	7474	265.32 MB
United Kingdom	uk	509	4808	173.38 MB
Italy	it	409	5030	632.62 MB
Brazil	br	390	4405	1.67 GB
Onbekend	sjdc	330	330	13.55 MB
Czech Republic	cz	319	1914	9.67 MB
France	fr	296	3114	116.29 MB
Finland	fi	259	1136	207.23 MB
Argentina	ar	241	1292	119.91 MB
Spain	es	238	1703	47.64 MB
Poland	pl	208	7132	402.38 MB
Mexico	mx	190	450	111.75 MB
USA Educational	edu	186	2521	18.90 MB
Denmark	dk	182	1985	38.11 MB
Canada	ca	170	2518	30.54 MB
Ukraine	ua	153	403	5.56 MB
New Zealand	nz	144	2106	7.05 MB
China	cn	135	468	2.31 MB
Hungary	hu	122	1654	7.28 MB
Israel	il	113	1575	10.07 MB
Switzerland	ch	109	1748	24.43 MB
Romania	ro	95	2154	87.77 MB

Below is a list of some of the pages visited. It should be noted that the promotional video was published in June 2011. This video is a collection of photographs of various activities which we have implemented or attended. The set-up makes them appear as if they are moving images.

Mark Knopfler of the Dire Straits, has given permission to use his music on our site.

Pagina's/URL's

Totaal: 1471 verschillende pagina's	Bezoeken	Gemiddelde grootte	Binnenkomst	Vertrek
/	53266	8.52 KB	16687	14596
/Public/Jaarverslagen/NL/	13139	1.25 KB	4773	4925
/Public/Jaarverslagen/EN/	13107	1.20 KB	5672	5732
/Public/Jaarverslagen/	4458	1003 Bytes	513	518
/Public/EN/en_index.html	4178	7.57 KB	1685	1212
/Private/Artsen/Vergadering/EN/	3240	1.11 KB		
/Public/NL/watiscmtc_beschrijving.html	3128	7.56 KB	802	932
/Public/Video/CMTCOVMPromo.mp4	1974	8.44 MB	695	875
/Public/EN/en_activiteiten_ledenvergadering.html	1941	9.29 KB	714	855
/Public/EN/en_watiscmtc_beschrijving.html	1850	6.89 KB	309	378
/Public/NL/dehuid.html	1814	8.33 KB	511	619
/Public/NL/watiscmtc_fotogalerij.html	1567	7.47 KB	239	443
/Public/Folder_CMTC_ES.pdf	1532	844.04 KB	930	935
/Public/NL/ovm_beschrijving.html	1466	7.48 KB	206	306
/awstats/awstats.pl	1454	4.26 KB	103	310
/logsoud/	1315	4.48 KB	285	401
/Public/NL/vereniging_organisatie.html	1314	9.12 KB	261	297
/Public/NL/activiteiten_agenda.html	1252	8.46 KB	231	273
/Public/EN/en_watiscmtc_fotogalerij.html	1184	7.75 KB	240	326
/Public/EN/en_dehuid.html	1173	8.11 KB	291	348
/Public/NL/watiscmtc_complicaties.html	1137	8.10 KB	123	234
/Public/EN/en_ovm_beschrijving.html	1039	7.09 KB	168	207
/Public/EN/en_activiteiten_genetischonderzoek.html	1031	8.59 KB	416	430
/logsoud/augustus2005/webalizer.current	1031	12.03 KB	91	102
/Public/EN/en_watiscmtc_complicaties.html	1013	7.86 KB	171	208
/Public/NL/watiscmtc_psychologischeaspecten.html	998	9.47 KB	311	315
/Public/Folder_CMTC_EN.pdf	980	1008.46 KB	458	485
/Public/EN/en_activiteiten_agenda.html	957	7.97 KB	227	281
/Public/NL/vereniging_medischadviseurs.html	941	10.00 KB	439	438
/Public/NL/vereniging_lidworden.html	886	10.43 KB	226	247
/Public/NL/vereniging_sponsorworden.html	883	12.05 KB	210	286

2.9 Genetic Research

Thanks to many years of international networking, we have succeeded to start a genetic investigation into CMTC.

This research is conducted in Canada in collaboration with a number of our medical advisors.
Free of charge, which can be described as unique!
Being a small association we could have never afforded such costs (€ 35,000 - € 50,000) on our own.

Dr. Millan Patel from Canada also attended our meeting in the USA on his own expenses. Dr. Millan Patel is the person leading this research.

3 Finance

3.1 Introduction

The year 2011 was also financially a good year for us. We have been able to develop many activities in various areas and further strengthen our position. Below an overview of the various key items (expenses and revenues).

The key items are very similar to the structure which “PGO Fund” uses, namely:
1. Fellow-sufferers contact.
2. Counseling.
3. Advocacy.
4. Stimulating activities.

3.2 Expenses Fellow-sufferers Contact

Activity	**2011 (€)**
Meetings	18.533
Family day	3.821
Joys and Sorrows	1.025
Office and computer supplies	2.926
Total	**26.305**

3.3 Expenses Counseling

Activity	**2011 (€)**
Website	5.633
Marketing & Public Relations	0
Total	**5.633**

3.4 Expenses Advocacy

Activity	**2011 (€)**
Cooperation external organizations	6.670
Expenses medical advisors	1.000
Travel expenses for committee members	795
Total	**8.465**

3.5 Expenses Stimulating Activities

Activity	2011 (€)
Expenses Committee members	2.835
Chamber of Commerce	38
Software licenses	448
Accountancy	863
Cost of money transfers	232
Memberships	57
Expenses volunteers	35
Other	117
Total	**4.625**

3.6 Expenses Overview

Activity	Expenses 2011 (€)	Expenses 2010 (€)
Fellow-sufferers	26.305	17.241
Counseling	5.633	13.500
Advocacy	8.465	14.628
Stimulating activities	4.625	5.991
Totaal	**45.028**	**51.360**

3.7 Revenue

Bron	Revenue 2011 (€)	Revenue 2010 (€)
PGO Fund grant	41.300	40.700
Membership fee	1.584	1.039
Donations/gifts/ miscellaneous	1.317	2.825
Totaal	**44.201**	**44.564**

3.8 Explanation

The major items in the category 'fellow-sufferers contact' consist of two member meetings. During the meeting in the Netherlands a separate children's entertainment room was created to enable parents to attend the meeting, while their children were entertained in a number of ways, also taking the age of the children into consideration.
In 2011 we also organized a family day with the aim not only to enable patients to get mutually acquainted and to share experiences, but also for their immediate family members. All in an environment which also enabled to have fun together.

Another major item in this category is formed by the office- and computer supplies

The major items in the category 'advocacy' are formed mainly by participation in conferences.

The major item in the category 'stimulating activities' is formed by the expenses of committee members. They are in accordance with the Dutch association rules as well as tax rules after consultation with an accountant.

The major item in the category 'Counseling' is formed by costs for our new website that after approx. 10 years urgently had to be redesigned.

Various other items relating to professional development are scattered throughout the other categories because it makes more sense. As a result, this item is relatively small.

Utilization rate expenses	**89.73%**
Utilization rate revenue	**91.94%**

4 Preview

From past experiences it has become clear that it takes years before a patient organization gets name recognition. Especially when it concerns a rare disorder it requires extra effort in all respects, including financially.

All kinds of address guides are updated only once a year, so it takes at least a year before a new organization can be found in these guides. Given the rarity of the condition we expect slow growth in the coming years.

International contacts will increase further as the number of foreign members increases. Internet technology will strengthen our global network and be a key item in the contact between mutual doctors and between patients and doctors.

We expect our contacts within Eurordis, NORD and Genetic Alliance will become increasingly important and provide us with entrances and opportunities, which would otherwise be impossible for a small organization like ours. Working together and sharing knowledge and experiences is also crucial to reach our primary goal of improving the lives of patients.

In 2012 we would like to develop the following activities:

1. Publish a quarterly newsletter meant for our members. A special, anonymous version of the newsletter will go to a number of doctors in different disciplines and in various (academic) hospitals. All newsletters will be translated in English. Especially the personal experiences of patients have a special appeal to other members.

2. Maintain and expand contacts and cooperation between patients as well as with patient associations, within and outside the country.

3. Establish an independent CMTC-OVM organization in the USA.

4. Maintain and expand contact with medical specialists, like dermatologists, within and outside the country.

5. Research into vascular malformations like CMTC. Especially in the field of genetic research of DNA material of patients.

   In September 2010 we were asked to participate in a genetic research project in Canada. After consulting our medical consultants, we decided to continue this project in 2011 by gathering genetic material (mainly blood) of patients that met specific criteria. We ‘provide’ the people who want to take part in this study and communicate about this project with members as well as doctors.

6. Organize meetings for personal contact and data exchange in the form of meetings as well in the Netherlands as in the USA.

7. Organize a family day (previously patient’s day) in the Netherlands in an informal setting, with attention on joint activities between patients and their immediate family.
   This enables people to meet fellow-sufferers and to exchange knowledge and experiences.

8. Create and expand our website with, for example, a list of questions and answers which we have collected over the years and provide the possibility to create your own profile and determine which information you want to share.

9. Attend (international) congresses in the field of rare diseases. Mainly congresses of ICord, Eurordis, NORD and Genetic Alliance.

10. Attend (international) medical congresses with, for example, a stand with promotional material.

11. Raise new funds to enlarge our financial basis and to spread our risks. Total dependency on one sponsor can be a risk to the continuation of our organization.

12. Recruit new members and donors and obtain grants to increase the awareness with the main purpose to support more people and to gather more information about the condition.

13. Design Patient Information leaflets for Other Vascular Malformations and publish these in different languages. Currently, the CMTC leaflet is available in 6 languages (Dutch, German, English, French, Russian and Spanish).

14. Further expand the use of the Internet. Using this can create a significant time and cost saving in an environment where both time and financial resources are limited. By providing information, such as patient information leaflets, electronically, the load on the organization can be substantially reduced because people can retrieve the information directly, without use of the organization. Another major (financial) benefit of electronic provision of information is the fact that changes can be done free of costs.

15. Maintain protection against dangers of use of the internet. Main dangers being viruses and breaking into computers used by the board members during connecting to the internet. Not many people realize the risks they take when connecting to the internet. As our computers contain all (medical) data of our members, this is a very important issue.

16. Further implementation of the marketing plan.

5 Available resources

The number of available human resources is very limited in a small association as ours. The amount of work, however, is not proportional to the size of an association which means that there is still a considerable amount of work per person to be done. During 2011, the board consisted of four persons. By recruiting additional volunteers for, for example, translations and other activities, a lot could be accomplished.

Through a new subsidy structure we now have a substantial subsidy available that allows us, first, to continue to improve the quality of life of CMTC patients and their families. Secondly we were able to professionalize our organization a bit more.

6 CMTC-OVM and the environment

Like all organizations our activities can have a negative environmental impact. We have taken the following precautions to limit these negative environmental impacts:

1. Newsletters etc are distributed through the website and only printed and posted in exceptional cases.

2. Printing is done on double-sided paper as much as possible.

3. When traveling by car we try to car-pool with other people.

4. Computers are only switched on when actually used.

5. When possible tele-conferencing is used (for example through Skype).

6. E-mail is preferred above printed mail.

7. Empty inkjet cartridges are collected and handed in to the known collection points. In return we receive € 1 discount on our next Hewlett Packard cartridge.

8. Paper, plastic and chemical waste are kept apart from the other waste and separately disposed.

9. Materials are recycled as much as possible.

A. Appendix – Terms and Abbreviations

Term/Abbreviation	Explanation
ANBI	Algemeen Nut Beoogende Instelling.
CMTC-OVM	Our organization.
Eurordis	European organization for rare diseases.
PGO Fund	Grant runner from Dutch Government (Patients, Disabled and Elderly).
NORD	National Organization for Rare Disorders (USA).
VSOP	United Parents and Patients Cooperating Organizations.