

Patients Association CMTC-OVM
www.cmtc.nl

ANNUAL REPORT 2009



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Approval

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

Distribution

This is a public document.

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1 Introduction

1.1 Goal of Document

This document contains the annual report of the patient association CMTC-OVM, formerly Association for People with the 'Van Lohuizen Syndrome'. The purpose of this document is to give an overview of the activities performed in 2009.

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.

In 2009, the name, mission, logo and the statutes of our organization have been adapted.

Previous mission statement:

"Improving the well-being of people suffering from the 'Van Lohuizen syndrome' (CMTC), specifically for her 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."

Current mission statement:

Promoting the welfare of people who suffer from vascular malformations of CMTC ("Van Lohuizen syndrome), particularly serving its own members and to promote and develop activities that promote well-being, the promotion of (scientific) research regarding vascular malformations such as CMTC, its causes and its treatment, and all that is related.

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

The logo is now:



1.3 Board

As of December 31, 2009, the board consists of:

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

Medical advisors are: Professor Dr. A. P. Oranje, Dr. M. van Steensel, Dr. W.W. van der Schaar and Ms. Drs. C. Oduber.

We also work closely with many other doctors from various countries.

1.4 Volunteers

The association is completely run by volunteers, including the board. Exclusive the board, several volunteers are active in various activities; such as translation. As of December 31, 2009, six volunteers are active in the field of translation.

1.5 Website

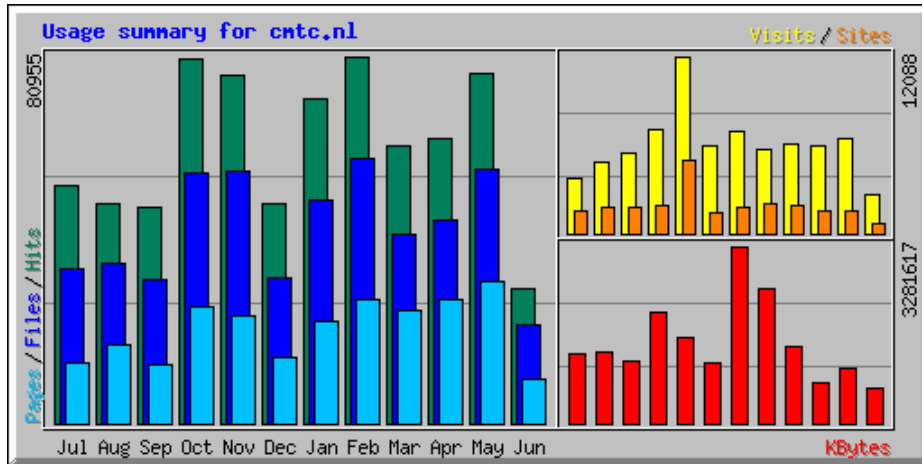
Our website is our primary medium for sharing information. In 2009 we started the design and construction of a new website which not only included a different "face", but also new functionalities. The most important new feature is the "context sensitive search", allowing users, depending on what kind of access they are granted, to search files in their authorized website environment. It can also be used by non-members, but they will only be allowed to view what is accessible to the open public. The newsletters and presentations are now numbering in the hundreds, so it has become impossible to search manually. This search solution should relieve this problem.

In early 2010, the new web service is active after thorough testing.

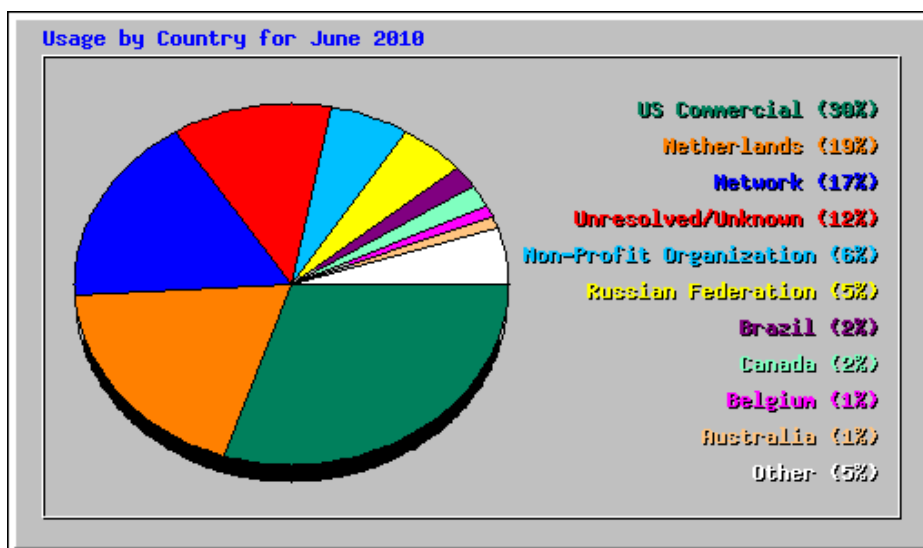
The website security is expanded in 2009 to further protect the privacy of our members.



The statistics which we use in order to determine the impact of certain activities and actions that we take as an organisation is an important tool in our marketing.



Summary by Month										
Month	Daily Avg					Monthly Totals				
	Hits	Files	Pages	Visits	Sites	KBytes	Visits	Pages	Files	Hits
Jun 2010	1976	1437	641	174	724	641876	2624	9627	21559	29650
May 2010	2488	1805	1014	208	1533	1025793	6471	31464	55955	77153
Apr 2010	2098	1496	909	199	1547	747893	5981	27276	44902	62952
Mar 2010	1977	1349	801	197	1888	1435088	6111	24850	41848	61297
Feb 2010	2891	2089	982	203	1980	2491554	5704	27513	58519	80955
Jan 2010	2313	1583	733	225	1751	3281617	6993	22727	49079	71720
Dec 2009	1565	1041	470	193	1467	1134061	6005	14574	32283	48544
Nov 2009	2553	1860	795	402	4966	1601103	12088	23862	55820	76590
Oct 2009	2591	1781	829	227	1958	2065867	7054	25699	55230	80333
Sep 2009	1593	1058	437	182	1819	1152339	5472	13139	31751	47804
Aug 2009	1558	1143	556	157	1787	1323481	4875	17247	35459	48302
Jul 2009	1693	1106	431	121	1568	1279445	3779	13367	34294	52510
Totals						18180117	73157	251345	516699	737810



2 Activiteites 2009

2.1 Introduction

Thanks to the FondsPGO grant, we were able to have additional activities in 2009. Especially in the areas of professionalism, we were able to take big steps.

The most important activities which we conducted in 2009 were:

1. Organising a patient's day for the patient and his/her immediate family.
2. Organizing member's meetings.
3. Offering free medical examinations.
4. Professionalize member and financial administration.
5. Active promotion of our organization through marketing.
6. Set-up a procedure manual.
7. Set-up a volunteer policy.
8. Participate in conferences.
9. Complete the newsletter.
10. Design and build the new website.

2.2 Patient's Day

In 2009, for the first time we enjoyed a patient's day organized for patients and their immediate family. This was a great success thanks to the wonderful weather! Approximately 50 people visited the Efteling amusement park and received VIP passes allowing them to go directly to the front of the line for the rides.



2.3 Membership Meeting

In 2009 we held two membership meetings. In July, we met in Washington DC, where Dr. Maurice van Steensel offered free diagnosis and diverse medical questions were answered. Members from both the USA and Canada took full advantage of this opportunity.



In October, the membership meeting was held in the Netherlands. Members were present from the Netherlands, Belgium and Germany. This year we had a medical forum which was put on video and could be viewed later through the Internet (for members only). People who could not attend could still see and hear what medical questions were asked and what answers were given.

The meeting was also broadcasted live on the internet. Members who could not attend had the option of attending via the live broadcast and participants could ask questions using audio/video conferencing.

2.4 Free Medical Examination

There is currently research being done at the Maastricht Academic Hospital concerning vascular abnormalities and diseases. For this research, we 'supply' patients to one of our medical advisors, Dr. Maurice van Steensel, for research. This helps in two ways: the patients can ask medical questions and get direct answers and Dr. Maurice van Steensel has the patient 'material' he needs for his research. We have approx. 20 patients from around the world (Australia, USA, Canada, Italy, Greece, Denmark, England, etc.) that have been in Maastricht for this free research.

2.5 Member & Financial Administration

For many years, our member and accounting administration has been mostly done using MS Excel which takes time especially when the yearly financial report needs to be completed.

We have decided to purchase a software package that will make things easier and faster. We chose for Davilex Club. In 2010, we purchased licenses and in 2010 this package will be fully configured to our specifications so that our member and financial administration can be further improved and professionalized.

2.6 Marketing

For quite some time, we have been looking into how we can enhance our reputation and reach more patients. We have decided to create a marketing plan that should provide ways to do this by using modern internet technology.

This marketing plan will be converted in to concrete actions, to be carried out in 2010 and 2011.

2.7 Procedure Handbook

The preparation of a procedure handbook was necessary not only from a professional point of view but also from a organisational vulnerability perspective. If for some reason the chairman should leave the organisation, this could put the strength of the organization in to jeopardy. All the procedures that the chairman and the board have built up over the years are now anchored in the procedure handbook. The handbook is a dynamic document that should be regularly updated.

2.8 Volunteer Policy

Mapping how we as an organization handle volunteers, and what are our expectations of volunteers, is an important issue to define. At the end of 2009 we have attempted to establish ground rules and our first version of the document is planned to be launched in 2010.

2.9 Conferences

Participating in conferences is a key activity, particularly for organizations active in the field of rare diseases. Cooperation is the key word in this context. Also important are networking, awareness and learning from each other.

We mainly visit large international conferences from well known organizations such as Genetic Alliance and Eurordis. During these conferences, we establish important connections with people who can make a difference for our organisation.

2.10 Newsletter

The CMTC OVM-newsletter appears four times a year in both Dutch and English. This newsletter is also available to physicians and others interested parties but the information is always anonymised to protect the privacy of our members. The newsletter includes medical articles, personal stories, as well as reports of conferences attended.

2.11 Website

Maintaining the website requires a substantial time investment. At this stage, the graphic designer who has designed and built the website, also performs all changes and enhancements. To help with this, we have purchased an internet software package.

The website will be expanded considerably in 2010, including a separate section for 'other vascular malformations'. The bulk of the site is unaccessable to the public and is intended for members. In 2010 we want to also add a local forum to the website where users can decide for themselves what information they want to share and with whom.

3 Financial

3.1 Introduction

The year 2009 was a good year financially. We were able to be deploy many activities in various fields and further strengthen our position as an organisation.

Below is an overview of the key items (income and expenditures) and the balance sheet.

The main items are very similar to the structure which FondsPGO adheres to, namely:

1. Member contact.
2. Education.
3. Promotion.
4. Activities.
5. Professionalization.

3.2 Expenditure Member Contact

Activity	Budget (€)	Actual Spent (€)
Members meetings	5500	5699
Patient's day-out	2000	2102
Heart and soul small gift fund	1100	1139
Office and computer products	2000	2436
Total	10600	11376

3.3 Expenditure Education

Activity	Budget (€)	Actual Spent (€)
Website	700	714
Information brochure (included in last paragraph)	0	0
Marketing & public relations	100	98
Office and computer products	2500	2234
Total	2600	3045

3.4 Expenditure Promotion

Activity	Budget (€)	Actual Spent (€)
Collaboration	6000	6239
Expense allowance for medical advisors	1300	1290
Travel costs for medical advisors	300	274
Travel management	800	723
Supporting research	5000	5000
Board expenses	1500	1650
Total	14900	15176

3.5 Expenditure Activities

Activity	Budget (€)	Actual Spent (€)
Training / courses	100	59
Board expenses	1500	1440
Volunteer expenses	500	500
Miscellaneous fees	100	99
Chamber of Commerce	50	29
ADSL, telephone, etc.	1000	960
Total	3250	3087

3.6 Expenditure Professionalization

Activity	Budget (€)	Actual Spent (€)
Member and fin. software package	1000	618
Notary (for name change, etc.)	1000	928
New website	5000	5801
Accountant	1000	723
Total	8000	8070

3.7 Expenditure Summary

Activity	Budget (€)	Actual Spent (€)
Member contact	11376	5307
Education	3045	1394
Promotion	15176	4600
Activities	3087	2264
Professionalization	8070	0
Total	40754	13565

3.8 Income

Source	Income 2009 (€)	Income 2008 (€)
FondsPGO grant	40600	8040
Contribution	1475	1651
Donation	2222	1062
Gifts	2050	1000
Miscellaneous	403	0
Total	46750	11753

3.9 Balance

	Annual Income (€)	Expenses (€)
Expenses according to financial statement		40754
Annual income according to financial statement	46750	
Less: contribution FondsPGO	40600	
Yearly Account		
Adjusted income	6150	
Deficit for calculating grant		34605
Contribution to operating expenses		28455

3.10 Explanation of Costs

The year 2009 was the first year in our history that we did not have to worry about our financial position and our survival. This is mainly due to the FondsPGO grant.

The major costs in the category 'Member contact' are the two member's meetings. During the general meeting in the Netherlands there was also a separate children's entertainment room organized so that parents can attend the meeting and the children are kept busy with fun activities.

In 2009 we also organized the first patient's day with the aim to get patients together and also their families in a fun environment, to get acquainted with each other and share experiences.

The major costs in the category 'Education' were office and computer related costs.

The major costs in the category 'Promotions' are mainly by participating in conferences and the contribution to a project that we are involved in. This project is the "Aardbeesie" project and focuses on the psychosocial aspects of people with skin conditions. Several members of our organization have embarrassing or insulting comments made to them from people in public, some are victims of child abuse and children with CMTC are often bullied at school.

The major cost in the category of 'Activities' is the expenses of the board. These expenses meet both the ANBI and tax laws, in close consultation with an accountant.

The major cost in the category of 'professionalisation' is our new website which after approx. 10 years had to be urgently renewed.

Several other items relating to professionalism are spread across the other categories because it is more logical. Therefore this item is relatively small.

We are considering to organize a vascular malformation conference in 2011 or 2012. If we decide to do this, there will be an activity plan with a budget created. Perhaps we can already reserve € 5000.

4 A Look Ahead

It appears in practice that it takes many years before a patient organization can build up their reputation. When it concerns a rare condition than this requires extra effort in every way including financially.

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

International contacts will increase further as the number of international members increases. Through Internet technology, we want our network to expand globally and to strengthen our pivotal role among physicians, and also between patients and the physicians.

Contacts through Eurordis, NORD, VBF and Genetic Alliance are expected to become increasingly important and it helps open doors for a small organization like ours. Making the right contacts is very difficult without their help. Collaborate, knowledge share and experience is crucial to improving the lives of patients.

In the year 2010 we would like accomplish the following:

1. Issuing a quarterly newsletter for members and also a special anonymous (no patient / member specific information) version of the newsletter will go to several doctors in various disciplines and to different (academic) hospitals. All newsletters will be translated into English. Of special interest will be the personal experiences of patients, this is enormously appreciated and helpful for other members.
2. Maintenance and expansion of our contacts, working together with patients, and other patients organisations world wide.
3. Set-up a daughter CMTC organization in the USA. This is a slow process because many aspects, in particular legal, tax and financial need to be worked through.
4. Maintenance and expansion of our medical specialist contact list, for example dermatologists world wide.
5. Investigation of CMTC as well as other vascular malformations, with a focus on genetic testing of patient DNA material. One of our medical consultants is working on a medical research project in this area in partnership between the university hospitals of Maastricht, Rotterdam and Amsterdam. In addition, genetic centers in Germany and Britain were also involved in the research. We "supply" patients who wish to participate in this study and then we can communicate the results to both the members and physicians. We hope during the member's meeting in 2010 to announce the results of this project.

6. Organizing a meeting enabling people to make contact and to share information in the Netherlands and the USA.
7. Organising a patient's day in the Netherlands in an informal environment where the focus is on the patients and their immediate family. This provides an opportunity for everyone to get acquainted and share knowledge and experiences.
8. Build and expand the website, including a list with questions and answers which the organisation has collected over the years. Also, adding a feature on the website which give the opportunity for members to create their own profile where they can personally determine what information is shared and with whom.
9. Attendance at (international) rare disease conferences. In particular the conferences held by ICord, Eurordis, NORD and Genetic Alliance.
10. Participating in (international) medical conferences with a stand displaying our promotional material. We are invited to participate in the Global Gendermatology Conference in Maastricht. We will have a stand and will have the chance to have our pamphlets included in the conference folders which are distributed to the press, other organisations, and other interested parties.
11. Raise funding in order to strengthen our financial base and to spread the financial risks. Being totally dependent on only one sponsor is a large risk to our organization.
12. Recruiting members and donators, and obtaining grants in order to support more people and gather and share more information about the condition.
13. Publish the new website. Also, to bring the site in line with new security demands and threats.
14. Design and publish new patient information leaflets for both CMTC and other vascular malformations in different languages.
15. Design and publish new posters.
16. Further expanding our use of the Internet. This can help with significant time savings, which is important in an environment where both time and financial resources is a structural deficit. By offering information such as leaflets in digital form, the work load of the organization can be greatly reduced because people will be able to download the information on-line directly from our website, in place of the information being delivered personally by the organization. Another big (financial) benefit of the sharing of information digitally, is that there is no costs.
17. Maintenance of internet security threats. The main dangers are viruses and hacking into the computers while board members are connected to the Internet. Considering that the medical information of our members is on-line, we find this a very important point to deal with.

18. Complete the procedure handbook.
19. Complete the documentation of the volunteers policy.
20. Begin the implementation of the marketing plan.

5 Available People & Resources

The amount of people available is quite limited in a small organization like ours. The amount of work is not proportional to the size of the association, which means that there is a considerable amount of work to be done. During 2009, the board consisted of four people. Through the deployment of additional volunteers for tasks such translation and other various activities, a large amount of work has been completed and many tasks were accomplished.

Thanks to the new subsidy, we now have substantial finances available that enables us to focus on the quality of CMTC patient's lives and their families and also gives us the opportunity to further professionalise our organization.

A. Appendix – Terms & Abbreviations

Abbreviations	Explanation
ANBI	General Benefits Analysis Institution
CMTC-OVM	Our organization
Eurordis	European Organisation for Rare Diseases
Fonds PGO	Dutch government fund (Patients, Disabled and Elderly)
NORD	National Organization for Rare Disorders (USA)
VBF	Vascular Birthmark Foundation
VSOP	United Parents and Patients Organizations.