Patient Association
CMTC-OVM
www.cmtc.nl

Annual Report 2015

Date: *14th March 2016*
Version: 1.0
Status: Final

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Owner: Board CMTC-OVM

Document History

Document location

The source document is stored on the computer of the Association Chairman. A copy is available in the activities area of the CMTC-OVM website and can also be obtained through other Association board members.

Version control

Version #	Date	Summary of changes	Changes marked
1.0	14 March 2016	First version	Not applicable

Approvals

Name	Role
J. Schipper	Treasurer
M. de Vries	Secretary

Distribution

This is a public document.

Sources

Not applicable.

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1 Introduction

1.1 Document Purpose

This document is the CMTC-OVM Association Annual Report for 2015. The primary purpose of this document is to provide an overview of the activities carried out by the patient organisation 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 December 31st 2015 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. A.P. Oranje, Prof. Dr. S. Pasmans, Prof. Dr. M. van Steensel, Dr. W.W. van der Schaar, Drs. L. Siderius and Dr. C. Odubèr.

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 Ambassdors

At the end of 2015 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 December 31st 2015 in addition to the Board members, around 30 volunteers are active in the areas of translations, membership recruitment and fundraising, the auditing committee, the complaints committee and providing assistance during meetings. Our medical advisors and ambassadors are also included in this count.

2 Activities in 2015

With the particular help of a grant from FondsPGO we were able to carry out a large number of activities in 2015. The most important of the activities during the year included:

1. Organizing a Family Day for patients and immediate family in The Netherlands.
2. Organizing a General Meeting in The Netherlands.
3. Participating in the General Meeting for the USA organisation.
4. Offering a medical diagnosis.
5. Communication about our Association through social media.
6. Participation in conferences.
7. Expanding the website.
8. Translation of the information folder.
9. Genetic research in Canada.
10. Setting up CMTC-OVM in Canada.
11. Taking part in the Eurordis RareConnect project.
12. Running the project Education for Young People on Rare Diseases (JEZZ).
13. Reorganisation and professionalisation of our financial administration.
14. Knowledge development for volunteers.

2.1 Family Day

In 2015 we organised another Family Day for patients and their direct families. Once again we chose the Efteling amusement park as the location because this has repeatedly proven to be the most popular as is indicated by the number of participants. This year a total of around 80 people attended.

The weather turned out to be perfect and 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 14th of November 2015 in Leusden, The Netherlands. On the Friday evening before the event we held a drinks and snacks reception for our guests from abroad to break the ice for the next day.

In total there were 126 people present from Belgium, Bélize (in Central America), Germany, England, France, Italy, Netherlands, Norway, Austria en Sweden. This is a new record attendance for us!

We had also invited representatives from PGOSupport and from other patient organizations.

Participants could choose again this year from 6 parallel sessions and we could offer the patients in particular a professional massage service tailored to their needs.

Patients were also of course able to obtain a medical diagnosis for their condition or a checkup on their situation and this year around 20 people made use of this facility.

Reports with photos and videos from a number of these sessions are available via our website.

2.3 General Meeting USA

The American CMTC-OVM organisation held their 2015 General Meeting in Atlanta, Georgia and this was attended by around 60 people.

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

Dr Millan Patel (Canada) and Dr. Joan Tamburro were also present this year. Not only were they able to give informative presentations but were also jointly able to provide a medical diagnosis for patients. A number of patients received another diagnosis than expected which had a significant impact, particularly on the parents or carers. Brandy James was also available to provide psychological support.

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

2.4 Medical Diagnosis

Prof. Dr. Maurice van Steensel has been able to provide us with a diagnosis for many years now but due to a change in his sphere of work this is no longer possible.

The Workgroup for Vascular Abnormalities Rotterdam (WEVAR) is based at the Erasmus Medical Centre Rotterdam. This team consists of about 25 medical specialists, including one of our advisors Prof. Dr. Suzanne Pasmans with whom we have made agreements about being able to obtain a medical diagnosis. Members from Chile have already made first use of this facility in April 2015. We will work very closely with this group so that we can support each other together in creating a situation whereby the patient comes first.

2.5 Social Media

The use of social media has effectively 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 the privacy for the 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 our website and Facebook we are able to directly see the effects of any given communication.

We use commercially available software to prepare our communications in advance and then to publish those at pre-defined times via the social media channels listed above.

We have one single person that carries out this activity in principle for all CMTC-OVM organisations although each organisation (CMTC-OVM worldwide plus the USA and also Canada) can also post communications via the social media channels such as an announcement concerning a forthcoming conference.

In 2016 we will continue with the professionalization of our social media to include an extension of our Social Media Strategy Plan and the implementation of this plan.

2.6 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. Networking, brand awareness and learning from each other are also important keywords.

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

Our experience has been that the time needed to harvest the benefits from these initial contacts is measured in years and that you do also need to keep seeding the ground continually.

In 2015 we took part in the annual NORD conference held at Washington in the USA and we did make a number of new contacts including the President of the Indian organisation for rare diseases. There are estimated to be around 100 million people in India who have a rare condition. Through this contact we are now receiving help with translation work and establishing contacts in India.

For a report from this conference please refer to our website.

2.7 Website

The website is the main communication medium through which we share information. Reports from practically all the conferences that we have attended can be found there for example.

A website is a dynamic entity and in fact is permanently in a state of change. Our website is provided in both Dutch and English language and new articles are added on a regular basis. A significant amount of information has been added over the last few years.

In 2015 we also developed a special website for children via the JEZZ project. See Section 2.12 for more details.

2.8 Information Folders

In 2015 we have translated our information folders into even more languages with the aim of being able to reach as many people as possible. As of the end of 2015 the folder is currently available in 12 languages and this total will be increased in the course of 2016.

Please see our website for more information.

2.9 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.

The research costs are not being charged to our organization which is quite a unique situation! The costs involved, in the region of € 35,000 to € 50,000, could not normally be borne by a relatively small organisation such as ours.

In 2012 a number of patients that met certain criteria had given biopsies (pieces of skin tissue) which were to be examined in Canada. Unfortunately the research was not able to start in 2014 as had been expected because the transfer of human tissue to Canada does require a significant administrative overhead. This is mainly due to legal restrictions concerning medical ethics. We do expect that in 2016 the biopsies will all be able to be sent to Canada and that the research can finally start.

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

2.10 CMTC-OVM Canada

We had received a request to set up an organisation in Canada and naturally we are very pleased to be able to help and support as much as we are able to. Ultimately this is all for the welfare and benefit of the patients.

The organisation in Canada will have their own website and they will also have their own logo. The first General Meeting for CMTC-OVM Canada will be held in 2016.

2.11 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.

2.12 JEZZ Project

Children with rare conditions not only have medical problems but can also often have psychological issues. This can be the case not only at home but at school for example. In The Netherlands around 1 person in 17 has a rare condition and this is illustrated in The Netherlands logo for rare diseases. This implies for example, that in a school with 350 pupils in total, on average around 20 children will have a rare condition of one sort or another.

The age of our target group in this context is from 8 to 15 years old in the upper years of primary or junior school and in the lower years of secondary or senior school. Children in this age group are aware of their physical make up and thus also of any abnormalities. The number of schools in The Netherlands is close to 11.000 with a total of around 200.000 pupils in each school year. With our approach we can reach more than 800.000 pupils and about 1.500.000 parents!

The project has the following main educational aims:

1. Improve understanding of the situation for children with a rare disease

2. Offer information on rare conditions to teachers and pupils with the aim of increasing understanding of the medical and psychological aspects of life with such a condition

As a patient organisation we would like to be able to offer educational material about rare diseases to children in their own language and to use a graphical design that is appropriate for them based on CMTC as a specific example.

In July 2015 the first version of this special children's website went live and this was developed further during the remainder of the year. The site will be available in 5 languages for 2016: Dutch, English, German, French and Spanish.

Several schools have also worked together on the JEZZ project. The children are not only able to download information from the website but they can also share material with other children, a class talk on a chosen subject for example.

2.13 Financal Administration

Under the theme of ongoing professionalization of the organisation, in financial administration we have completed a number of steps to round off the process overall. We now have a monthly report of actual operational cost items compared against their budgeted funds. We also have a dashboard for all payment method alternatives together with status details for each payable invoice. We have also started with our own electronic billing for our own subscriptions and donations. At the beginning of 2016 all members and donors will receive an electronic invoice for easy and straightforward electronic payment.

2.14 Skills Development

Amongst other activities we have been able to trained 2 people via PGOSupport in the area of membership recruitment. Aside from this we have also taken part in meeting events concerning the data protection of personal information for example.

3 Financial Information

3.1 Introduction

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

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

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

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

3.2 Expenditure

Activity	**Expenditure 2015 (€)**	**Expenditure 2014 (€)**
Patient contact	22.205	18.363
Information provision	12.833	17.362
Enablement activities	2.916	4.869
Total	**37.954**	**40.594**

3.3 Income

Source	**Income 2015 (€)**	**Income 2014 (€)**
FondsPGO grant	35.000	35.000
Membership Fees	1.911	1.325
Donation/gift/miscellaneous	4.494	2.119
Total	**41.405**	**38.444**

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 taking into account their varying age groups.

In 2015 we again organised a Family Day with the aim of not only bringing patients but also their direct family together in one environment and to have an enjoyable time, to get to know each other and to share experiences.

	2015	**2014**
Utilisation Rate Expenditure (%)	92,31	88,00
Utilisation Rate Income (%)	84,62	92,93

4 Looking Ahead

Experience shows that it takes many years for a patient organization to gain visibility. For a rare condition organization this is an even harder challenge, which requires a lot of 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 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 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 the year 2016, we want to be able to develop the following activities:

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

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

3. Research into vascular malformations such as CMTC. In particular towards genetic research into the DNA material of patients.

4. Further development and implementation of a Social Media strategy taking into account the changes in strategy of seach engines such as Google and of Facebook.

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

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

7. 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.

8. Provide support for the Canadian CMTC-OVM organisation in getting up and running. We will not be providing a financial contribution to this organisation.

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

10. Building on and expanding the website including:
    a. A new navigation and menu structure.
    b. Development of a special website for children to learn about rare diseases (The JEZZ project). This could include provision in a number of languages but also material such as special subject talks and project reports.

    Separate projects will be defined for these various changes and for which financial support will be requested from a number of organisations.

11. Publish a newsletter. One of our volunteers is a professional scientific journalist and the the aim would be to 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. In particular conferences such as Eurordis and NORD for example.

13. Working with the EPPOSI organisation, a European think-tank for industry, science and patient organisations (www.epposi.org).

14. Recruiting new members and donors and obtaining additional 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 medical conditions. We do now have a dedicated volunteer assigned to this role.

15. Extend the number of languages for the CMTC folder that is currently available in 12 languages.

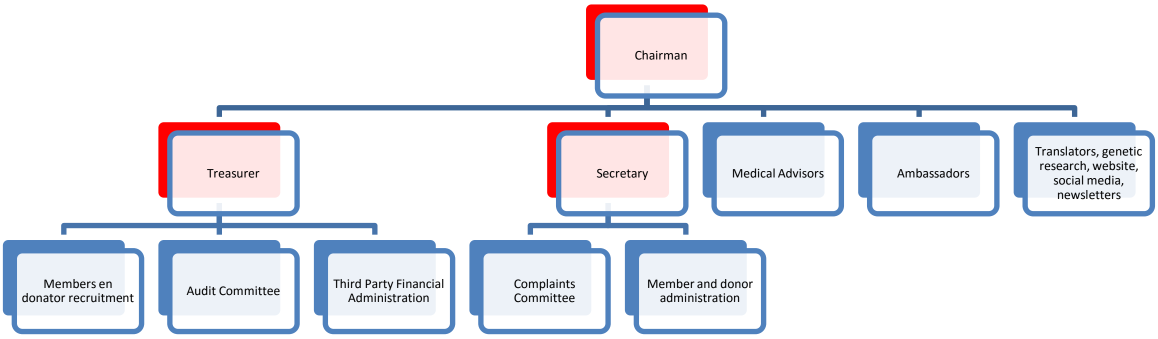
16. Ongoing professionalization of our organisation such as through development and implementation of the fund raising strategy.

17. Provide local representation for our organization in other countries through a liaison construction (so not via a separate new local CMTC-OVM organization). The first example of this setup is now 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 organisation which means that there is still quite a considerable quantity of work to be done. During most of 2015 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 additional volunteers for translation work and various other activities a lot of additional work could also be carried out.

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

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

In terms of financing we need around € 40.000 on an annual basis for what can be described as the standard activities. Extra activities on top of this are carried out on an individual project basis and these are funded separately.
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6 CMTC-OVM and the Environment

Just as in the case of any commercial organisation 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 organisation from the Dutch Tax Authority which implies that donations are tax deductible.
CMTC-OVM	Our organization.
EPPOSI	European Platform for Patients' Organisations, Science and Industry
Eurordis	European Organisation for Rare Diseases.
Fonds PGO	Arranges subsidy from the Dutch Government for national disabled people and patient organisations.
JEZZ	Education for Young People on Rare Diseases, project
NORD	National Organization for Rare Disorders (USA).
PGOSupport	An independent network for and by patient and disability organisations
VSOP	The Dutch Genetic Alliance, an umbrella organisation of about sixty national, disease-linked, parent and patient organisations (NL)