Patient Association
CMTC-OVM
www.cmtc.nl

Annual Report 2014

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Approvals

Name	Role
J. Schipper	Treasurer
A. Eveleens	Secretary

Distribution

This is a public document.

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Not applicable.

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1 Introduction

1.1 Document purpose

This document is the 2014 Annual Report for the patient organisation CMTC-OVM Association, formerly the Association for people with Van Lohuizen Syndrome. The primary purpose of this document is to provide an overview of the activities carried out in 2014.

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

The Association mission is as follows:

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 as follows:

1.3 Board

The Board is comprised of the following members as of December 31st 2014:

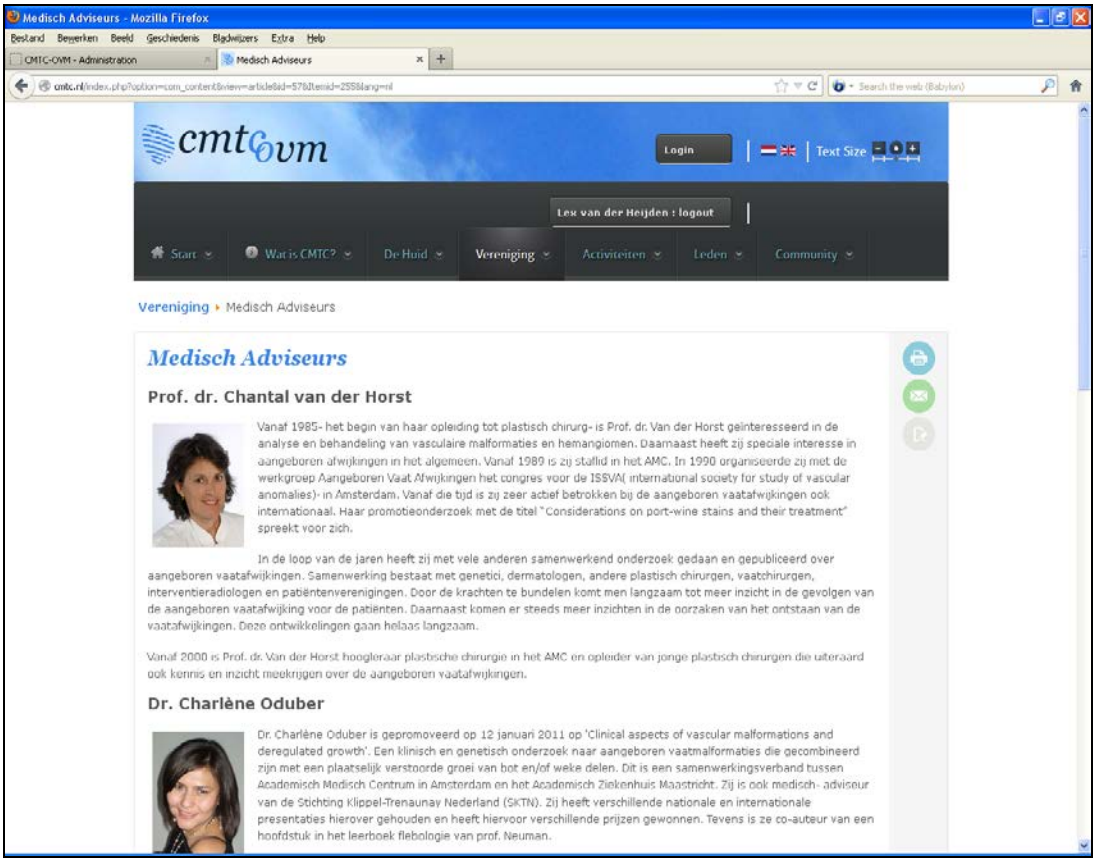
Mr. A.F.R. van der Heijden	Chairman
Mrs. A. Eveleens	Secretary
Mr. J. Schipper	Treasurer

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. 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.



Medisch Adviseurs

Prof. dr. Chantal van der Horst

Vanaf 1985- het begin van haar opleiding tot plastisch chirurg- is Prof. dr. Van der Horst geïnteresseerd in de analyse en behandeling van vasculaire malformaties en hemangiomen. Daarnaast heeft zij speciale interesse in aangeboren afwijkingen in het algemeen. Vanaf 1989 is zij staflid in het AMC. In 1990 organiseerde zij met de werkgroep Aangeboren Vaat Afwijkingen het congres voor de ISSVA(international society for study of vascular anomalies)- in Amsterdam. Vanaf die tijd is zij zeer actief betrokken bij de aangeboren vaatafwijkingen ook internationaal. Haar promotieonderzoek met de titel "Considerations on port-wine stains and their treatment" spreekt voor zich.

In de loop van de jaren heeft zij met vele anderen samenwerkend onderzoek gedaan en gepubliceerd over aangeboren vaatafwijkingen. Samenwerking bestaat met genetici, dermatologen, andere plastisch chirurgen, vaatchirurgen, interventieradiologen en patiëntenverenigingen. Door de krachten te bundelen komt men langzaam tot meer inzicht in de gevolgen van de aangeboren vaatafwijking voor de patiënten. Daarnaast komen er steeds meer inzichten in de oorzaken van het ontstaan van de vaatafwijkingen. Deze ontwikkelingen gaan helaas langzaam.

Vanaf 2000 is Prof. dr. Van der Horst hoogleraar plastische chirurgie in het AMC en opleider van jonge plastisch chirurgen die uiteraard ook kennis en inzicht meekrijgen over de aangeboren vaatafwijkingen.

Dr. Charlène Oduber

Dr. Charlène Oduber is gepromoveerd op 12 januari 2011 op 'Clinical aspects of vascular malformations and deregulated growth'. Een klinisch en genetisch onderzoek naar aangeboren vaatmalformaties die gecombineerd zijn met een plaatselijk verstoorde groei van bot en/of weke delen. Dit is een samenwerkingsverband tussen Academisch Medisch Centrum in Amsterdam en het Academisch Ziekenhuis Maastricht. Zij is ook medisch- adviseur van de Stichting Klippel-Trenaunay Nederland (SKTN). Zij heeft verschillende nationale en internationale presentaties hierover gehouden en heeft hiervoor verschillende prijzen gewonnen. Tevens is ze co-auteur van een hoofdstuk in het leerboek flebologie van prof. Neuman.

1.5 Volunteers

The Association is exclusively staffed by volunteers, including the Board. In addition to the Board members, volunteers are engaged in a number of activities such as translation work for example. In addition to the Board, as of December 31st 2014, 12 volunteers are active in the areas of translation support, the auditing committee, the complaints committee and providing assistance during meetings

2 Activities 2014

2.1 Introduction

With the help of a grant from FondsPGO in particular, we were able to carry out a large number of additional activities in 2014.

The main activities carried out in 2014 were:

1. Organizing a Family Day for patients and immediate family in The Netherlands.
2. Organizing a General Meeting for The Netherlands.
3. Participating in the General Meeting for the USA.
4. Offering free medical examinations.
5. Communication about our Association through social media.
6. Participate in conferences.
7. Expanding the website.
8. Genetic research in Canada.
9. Producing a series of films.
10. Taking part in RTL4/5 television *LifeStyleXperience*.
11. Setting up CMTC-OVM in Canada.
12. Taking part in the Eurordis *RareConnect* project.
13. Performing research by VU University, Amsterdam.
14. Taking part in the *Expertise Mapping* project.
15. Running the project Education for Young People on Rare Diseases (JEZZ).
16. Reorganisation and professionalisation of our financial administration.

2.2 Family Day

In 2014 we again organised a Family Day for patients and their direct families.

This year we had offered our members three different alternative events that they could vote for. The animal park in Amersfoort came out as the winning location.

In total around 30 members took part in this great day out for which the weather was perfect.

During the meet-up session and also at a lunch together we were able to get to know other (new) members, and swap experiences.

You can find photographs from the day’s events on our website.

2.3 General Meeting Netherlands

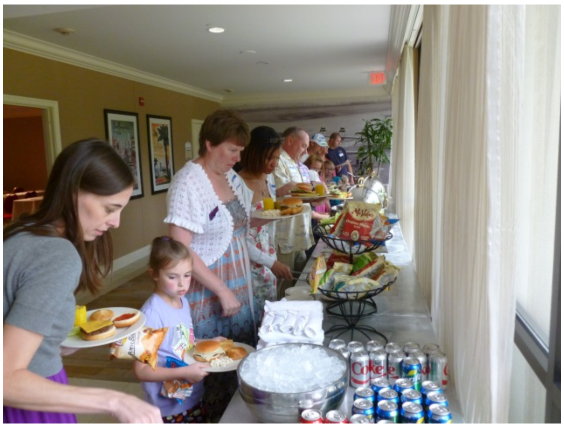
Our worldwide General Meeting was held this year on the 15th of November 2014 in Leusden, The Netherlands.

On the Friday evening before the event we held a drink with snacks reception for our guests from abroad to break the ice for the next day. In total there were around 80 people present from Germany, England, The Netherlands, Norway, Austria, Slovakia, the USA and Sweden. Unfortunately several more were not able to attend due to illness, otherwise we would have had around 90 attendees at the meeting.

Again this year, participants could choose from a series of parallel sessions. One of these sessions was a presentation and demonstration on the principles of remote care. This concept has already been implemented in The Netherlands.

Meeting reports with photos are available via our website.

2.4 General Meeting USA



The CMTC-OVM organisation in the USA became more independent during 2014 and this was also true from a financial perspective. The General Meeting was organised completely out of the USA this year. The location for the event was as for last year in St. Louis but at another venue in the city then last time.

Prof. Dr. Suzanne Pasmans had flown over to give a presentation to the meeting and also to be able to give a medical diagnosis for patients.

The day before the meeting a Family Day was also organised at a fun park in St. Louis.

The Netherlands organisation has further reduced our planned financial contribution for this conference in 2015 as a result of the USA organisation being increasing able to draw on their own financial resources for this event.

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. To date, 40 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

During 2015 the organisation for this service will change. More details will be published on our website in due course.

2.6 Social Media

Use of social media today has effectively become an indispensable part of our society. Starting in 2014 we made use of the following social media:

1. Facebook group (closed). To maintain the privacy for the members of the group and to prevent as far as possible misuse of the group for commercial purposes.
2. Facebook page.
3. Twitter.
4. LinkedIn.
5. YouTube.

From statistics provided by our website and Facebook we are able to see directly the effects of a communication message.

We use commercial software to prepare the notices in advance and to subsequently publish them at chosen times and via the social media channels already mentioned.

We have one person that carries out this activity in principle for all CMTC-OVM organisations. In 2015 we intend to continue with the professionalization of our social media including advancing our social media strategy plan and the implementation thereof.

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.

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

Our experience has been that the time between planting and harvesting from these contacts is measured in years and that you have to keep seeding continually.

In 2014 we took part in the annual Eurordis conference which this year was held in Berlin. We did not attend the NORD conference in the USA this year due to financial constraints.

For specific conference reports please refer to our website.

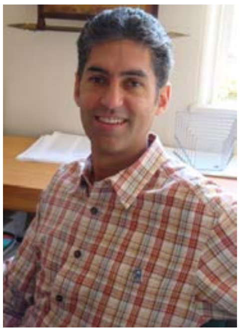
2.8 Website

The website is our main medium through which to share information.

Reports from practically all the conferences that we have attended can be found there. Separate pages have been created for donors, volunteers and for sponsors. The homepage has been changed in the course of the year and the use of Social Media has been integrated into our site.

The website has been extended with the category Other Vascular Malformations (OVM) for information concerning vascular anomalies in the form of text and photographic material.

2.9 Genetic Research Canada



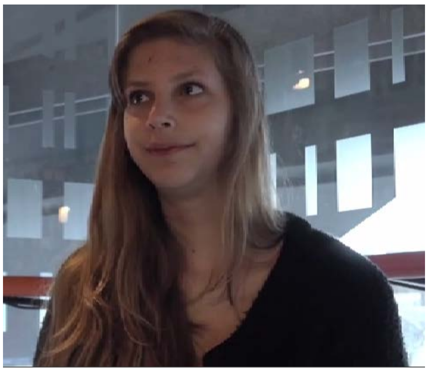
Thanks to many years of international networking we have succeeded in starting a genetic research program into the causes of CMTC.

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 charged to our organization which is quite a unique situation! These kind of costs (Around € 35,000 - € 50,000) could not normally be borne by a small organisation like 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 as had been expected in 2014 because the transfer of human tissue to Canada requires a significant administrative overhead, in the main part due to legal restrictions concerning ethics. We do expect that in 2015 the biopsies will be able to reach Canada and that the research can finally commence.

2.10 Films

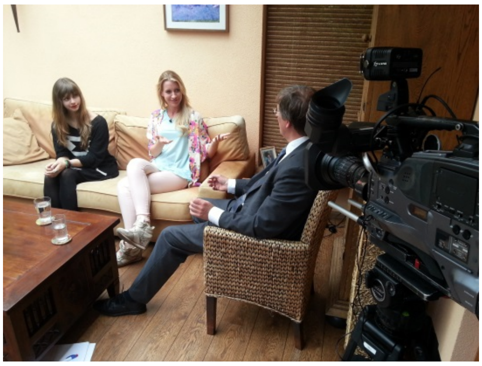


The *Filmproject* Foundation has made a series of four short documentaries for us (under their own sources of funding), with aims of providing information about and raising the level of understanding on people with CMTC. The films are aimed at the general public, patients, doctors and schools.

In the films, amongst other aspects psychological issues affecting both patients and their parents are also considered. These films can be viewed on YouTube or via our website.

Currently the films are mainly in the Dutch language although we are looking for ways to be able to add English subtitles so that we can reach a wider audience.

2.11 RTL4/5 LifeStyleXperience



With the aim of increasing awareness of our organisation and so to be able to reach more patients, their families, doctors and the general public we took part in two separate editions of the television program *LifeStyleXperience*.

These were both broadcast on television in June 2014 and we do have the filmed material in our possession and available for our own use.

2.12 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 Canda will have their own website and will also have their own logo.

2.13 Eurordis RareConnect Project

The European Organisation for Rare Diseases, *Eurordis* together with the American National Organisation for Rare Diseases, NORD started a joint project some time ago to connect and bring people together on these rare conditions.

Via the Eurordis website people can share their knowledge and experience with others around the globe. CMTC-OVM has also been set up as organisation with our own online community on the Eurordis website: http://bit.ly/1C1nslq

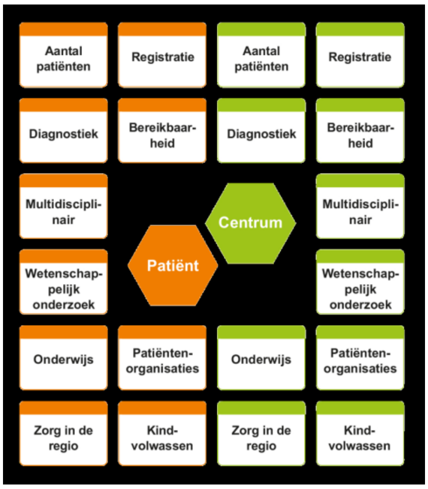
2.14 Research VU University Amsterdam

Kirsten de Wit, a neurobiology student with special focus on society at the VU University Amsterdam, is carrying out a research study for our organisation CMTC-OVM for her Masters degree.

Kirsten will consider how we as an organisation can best reach and support more patients and medical specialists. Using literature study and interviews with patients and doctors she will prepare an advisory report.

Guidance will be provided from the VU University by Dr. Theo Groen and from CMTC-OVM by Lex van der Heijden.

2.15 Expertise Mapping



The Netherlands patient organisation for adults and children with metabolic diseases (VKS) is running a joint *Expertise Mapping* project together with the Vasculitis Foundation, the Pulmonary Hypertension Association Netherlands, the Lung Fibrosis Patients Association, Nevus Network Netherlands, and Histiocytosis Netherlands. The project is looking at the current state of care for rare conditions.

As Netherlands CMTC-OVM organisation we have also been asked to approach our members with a view to supporting this project. The project is constructing a knowledge map through which patients and carers can see which resources are available and where these can be found. A knowledge map is created in three basic stages:

1. An online questionnaire to determine the patients perspective
2. Discussions with experts on the specific disease or condition.
3. Development of the knowledge map.

2.16 JEZZ Project

Children with rare conditions not only have medical problems but often can also 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, around 20 children on average will have a rare condition of one sort or another.

The age of our target group in this context is from 10 to 15 years old (upper years of primary or junior school and 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 primary 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 use a graphical design that is appropriate for them based on CMTC as one specific example. We would like to offer this information to schools in the form of an education package about rare conditions and to also make this information available via a special website built to function as part of our existing site.

2.17 Financial Administration

Under the theme of ongoing professionalisation we have made a significant step forward in the area of our financial administration which we outsourced to an external party in the fourth quarter of 2014. This will save us considerable time and effort and provide us with a much better overview of our actual operational costs when compared against budgeted funds (improved control) and with the added benefit of being able to produce annual reports in a shorter timeframe.

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. Contacts.
2. Information.
3. Advocacy.
4. Enablement activities.

3.2 Expenditure

Activity	**Expenditure 2014 (€)**	**Expenditure 2013 (€)**
Contacts	18.363	22.522
Information	17.362	14.600
Advocacy	[*1]	6.215
Enablement activities	4.869	6.958
Total	**40.594**	**50.295**

3.3 Income

Source	**Income 2014 (€)**	**Income 2013 (€)**
FondsPGO Grant	35.000	35.000
Membership Fee	1.325	1.845
Donation/gift/miscellaneous	2.119	7.974
Total	**38.444**	**44.819**

3.4 Notes

During the General Meeting in The Netherlands there are also children's activities and entertainment organized in a separate hall so that parents can attend the meeting and the children can be kept active in all kinds of ways, taking into account the varying ages of the children.

In 2014 we again organised a Family Day with the aim of not only bringing patients together but also their direct family in one environment to have an enjoyable time, get to know each other and to share experiences.

*[*1] From the book year 2014 the item ‘Advocacy’ has been re-allocated to the ‘Contacts’ and ‘Information’ items.*

In 2014 we also invested in the provision of information, for example via work on television programs with the broadcast television channels RTL4 and RTL5.

	2014	**2013**
Utilisation Rate Expenditure (%)	88,00	86.17
Utilisation Rate Income (%)	92,93	96.69

4 Look 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 because it would not be possible to achieve this 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 2015, 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 like dermatologists, both at home and abroad.

3. Research into vascular malformations such as CMTC. We are thinking in particular here towards genetic research into the DNA material of patients.

4. Further development and implementation of a Social Media strategy.

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 both the Netherlands and the USA. Since 2014 in the USA this meeting has been arranged, held and largely funded by the CMTC-OVM US organisation. In 2015 we have minimalized our financial contribution towards this event (covering only our own travel and accommodation costs).

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 started and up-and-running. We will not be providing a financial contribution to this organisation.

9. Building on and expanding the website including:
    a. Adding the ability for the site to recognise with which type of device the user is interacting with the content (smartphone, tablet, PC) and presenting the requested information in the most appropriate way through *Responsive Design*.
    b. Development of a special website for children to learn about rare diseases (The JEZZ project). Starting with the Dutch language.
    c. Restructuring the current website including improved navigation for the user.
    d. Simplification of the registration process for the various types of users.

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

10. Attending national and international conferences in the field of rare diseases. In particular conferences such as Eurordis and NORD for example.

11. Working with the EPPOSI organisation, a European thinktank for industry, science and patient organisations (www.epposi.org).

12. 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 condition.

13. Extend the number of languages for the CMTC folder that is currently available in 6 languages (Dutch, German, English, French, Russian and Spanish). In 2015 this will be available in Polish, Czech and Slovak languages. We are approached on a regular basis by both patients and doctors from Eastern Europe and we expect the level of interest from this region to increase further. This regional development is also clearly noticeable during the Eurordis conferences where we see that the number of delgates from Eastern Europe has increased considerably over the last few years.

14. Ongoing professionalisation of our organisation such as through development and implementation of the fund raising strategy.

15. Formalisation and improvement of the process for medical diagnosis. In the past this was sometimes carried out by a single specialist and sometimes by a number of different specialists. In the future we would like to be able to have a multidisciplinary medical team be able to provide a medical diagnosis. This approach will be defined in cooperation and agreement with CMTC-OVM medical advisor Prof. Dr. Suzanne Pasmans of the University Hospital Rotterdam.

5 Staff and Resource Availability

The number of available people is quite limited in such a small Association. The amount of effort required however, is not proportional to the size of the Association which means that there is still a considerable quantity of work to be done.

During most of 2014 the Board consisted of three people. 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 recruitment of new members and donors, other fundraising activities and attending conferences for example. A number of members had simply volunteered themselves to help out with some of these activities.

In 2014 a new volunteer has made a start on activities in the area of Social Media. This is a relatively economical way to raise our profile and to be able to reach out to and to help more individuals.

In the first quarter of 2015 we aim to complete our marketing strategy and the implementation plan, the work for which will then also be started directly.

6 CMTC-OVM and the Environment

Just as is the case for a 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.

A. Appendix – Terms en 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).
VSOP	The Dutch Genetic Alliance, an umbrella organisation of about sixty national, disease-linked, parent and patient organisations (NL)