



ANNUAL REPORT 2017

PATIENT ASSOCIATION
CMTC-OVM
WWW.CMTC.NL



cmtovm

COLOFON

This is a CMTC-OVM publication
All rights reserved

Chairman and author

Lex van der Heijden

Owner

CMTC-OVM Board

Treasurer

Jacob Schipper

Secretary

Anja Fluijt

Graphic design

Rick Schurink, Design Delicious

 @CMTC

 facebook.com/cmtc

 linkedin.com/cmtc

www.cmtc.nl

TABLE OF CONTENTS

1	Introduction	5
1.1	Document Purpose	5
1.2	Introduction	5
1.3	The Board	5
1.4	Medical Advisors	5
1.5	Ambassadors	5
1.6	Volunteers	5
2	Activities 2017	7
2.1	Family Day	7
2.2	General Meeting Netherlands	7
2.3	General Meeting Canada	8
2.4	Medical Advice	8
2.5	Social Media	8
2.6	Conferences	8
2.7	Website	9
2.8	Information Folders	9
2.9	Genetic Research Canada	9
2.10	Newsletter	9
2.11	Rare Connect Project	9
2.12	Cooperation with other Organizations	10
2.13	Financial Information	10
2.14	CBF Certification	11
2.15	Marketing	11
3	Financial Information	13
3.1	Introduction	13
3.2	Expenditure	13
3.3	Income	14
3.4	Notes	15
4	Looking Ahead	16
5	People and Resources	19
6	CMTC-OVM and the Environment	23
A.	Appendix – Terms and Abbreviations	25



**The patient
association
was formally
established on
January 22, 1997**

**Further details
relating to our
ambassadors can
be found on our
website.**

**Further details
relating to our
medical advisors
can be found on
our website.**

1 INTRODUCTION

1.1 Document Purpose

This document is the CMTC-OVM Association Annual Report for 2017. The primary purpose of this document is to provide an overview of the activities carried out by the patient organization during the year.

1.2 Introduction

The CMTC-OVM Association was formally established on January 22, 1997 by notary Van Helden in Amsterdam and 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") and in particular its own members, and the promotion and development of activities that enhance their 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:



1.2 The Board

The Board comprised the following members on 31st December 2017:

Mr. A.F.R. van der Heijden, Chairman.

Mrs. A. Fluijt, Secretary.

Mr. J. Schipper, Treasurer.

1.4 Medical Advisors

Our current specialist medical advisors are:

Prof. Dr. C.M.A.M. van der Horst, Dr. P. de Laat

Prof. Dr. S. Pasmans, Dr. M. Patel, Prof. Dr. M. van Steensel,
Dr. W.W. van der Schaar, Prof. Dr. P. Steijlen, Dr. C. Odubèr
and Dr. M. Vreeburg.

Our website provides further details about the medical advisors.

1.5 Ambassadors

At the end of 2017 we also count three 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 about these ambassadors.

1.6 Volunteers

In practice the Association is exclusively staffed by volunteers including the Board. In addition to Board membership our volunteers are engaged in several activities such as translation work or social media. As of 31st December 2017, in addition to the Board members we have around 30 volunteers active in many areas including translation, member and donor recruitment, fundraising, the audit committee, the complaints committee and helping during meetings. Our medical advisors and ambassadors are also included in this total.



2 ACTIVITIES 2017

With the help of a grant from Fonds PGO in particular, we were able to carry out a wide variety of activities in 2017, the most important of which 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 a General Meeting for CMTC-OVM Canada.**
- 4. Offering medical advice.**
- 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. Publishing a newsletter.**
- 11. Taking part in the Eurordis RareConnect project.**
- 12. Cooperation with other organizations.**
- 13. Reorganization and professionalization of our financial administration.**
- 14. Marketing activities**

2.1 Family Day

In 2017, we organized another Family Day for patients and their direct families. The Efteling was chosen as location and a total of around 80 people from 4 countries attended the event.

During the meet-up session and at lunch new members were able to get to know each other and 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 4th of November 2017 in Leusden, The Netherlands. On Friday during the day, patients were able to obtain a comprehensive personal medical advice at the Erasmus Medical Center in Rotterdam, with various members from different countries have made use of this option. On the Friday evening before the event we held a drinks reception with snacks for our guests from abroad, to break the ice for the next day.

This year was a special conference for us being the 20th anniversary year for our organization. To mark this occasion, we offered a dinner to those present. We also chose a new meeting location this year which proved to be excellent for our needs and will remain as our new conference location for future events.

In total there were around 115 attendees from Austria, Belgium, Denmark, England, Germany, Sweden and The Netherlands.

Patients were also of course able to obtain medical advice for their condition and/or a check on their situation. This year we could offer both a simple medical advice option during our meeting or more extensive advice in Rotterdam on the day before our meeting. In total 13 people were able to make use of this facility! This year we also again offered a massage service. The number of massages given came totaled 8, with the long-term neck pain suffered by one patient having disappeared.

Reports with photos and videos from a number of these sessions are available via our website. (For Association members and Doctors only).



2.3 General Meeting Canada

In 2017 CMTC-OVM Canada organized their second General Meeting in Toronto with a total number of attendees of around 40 people

As at the CMTC-OVM meetings in The Netherlands and in the USA, medical advice could also be obtained. This year, Dr. Millan Patel provided this service.

A separate room was provided with guided activities for children so that parents could attend the conference and the children could be entertained. From the Netherlands Isa Veldhuizen and Lex van der Heijden participated in this conference. Lex gave several presentations and led a workshop with the theme 'share your story'. Several patients and patients' parents shared their personal stories often leading to recognition and an emotional response in others as a result.

A report for this conference can be found on our website together with photos and video material from the event.

2.4 Medical Advice

We have already been able to offer a medical advice facility for many years during our worldwide General Meeting in The Netherlands. Several of our medical advisors, generally specialist professors, are available during the day to provide free advice.

In the last few years the number of advice sessions held on the meeting day has significantly increased. In addition to medical advice provided during our worldwide conference, there is now also the option to obtain more extensive medical advice from the WEVAR multidisciplinary team at the Erasmus Medical Center in Rotterdam on the Friday preceding the Leusden conference.

2.5 Social Media

The use of social media has become an indispensable part of our society today. As at the end of 2017, we now make use of the following social media channels:

1. **Facebook group (closed) for adults. to maintain privacy for members of the group and to help prevent misuse of the group for commercial purposes, the sale of sunglasses and shoes for example!**
2. **Facebook group (closed) for young adults (age group 15 – 25 years).**
3. **Facebook group (closed) for children (age group 8 – 14 years).**
4. **Facebook page for general topics (scope worldwide).**
5. **Facebook page for member/donor recruitment (scope The Netherlands).**
6. **Twitter.**
7. **LinkedIn.**
8. **YouTube.**
9. **Instagram.**

Thanks to the statistics provided by our website and Facebook we are directly able to see the effects of our communication actions.

2.6 Conferences

Participation in conferences has several important aims 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 themes.

We attend international conferences of large organizations such as Eurordis and NORD. Important contacts with other patient organizations are made here with a view to developing ongoing cooperation.

The last day of February is the worldwide Rare Disease Day. This year the Dutch Rare Disease Day was organized at the NBC Conference Center in Nieuwegein.



There were about 130 participants from many different organizations. The theme of the Rare Disease Day this year was 'Research on the agenda!'

The American Genetic Alliance had been established for 30 years in 2017 and organized a special conference in March in the USA (Washington DC). The great driving force behind this organization is Sharon Terry. Dr. Francis Collins, director of the National Institute of Health) was also present again. We have known Sharon and her organization since 2005 and thanks to the Genetic Alliance we have visited the US Senate several times with the aim of getting rare diseases on the agenda. In May we participated in the annual Eurordis conference that was organized this year in Hungary (Budapest). This year it was only a members' meeting, which meant that the number of participants was around 300 people. In 2018, this conference will be organized for a wider audience with around 700 participants expected.

In October we also participated in the annual NORD conference in the USA (Washington DC). One topic on the agenda was the cost of medicines which are even higher in the USA than in the Netherlands. Several people from the US Food & Drug Administration attended, gave presentations and participated in panel discussions. One of our ambassadors, Dr. Steve Groft, was also present again so that we could personally bring each other up to date.

For reports from these conferences please do refer to our website.

2.7 Website

Our website is the main communication medium through which we share information. We can also link our social media to the website and through statistical analysis we can see how many people visit the site and from which countries following a specific message posting via these social media channels.

The current website is available in both Dutch and English and as of the end of 2017 contains around 2000 photos, 50 videos and a very large number of articles. We publish reports from nearly all the conferences that we have attended for example.

Please do visit our website for more information.

2.8 Information Folders

In 2017 we translated our CMTC information folders into more languages with the aim of being able to reach as wide a public as possible, including patients, parents of patients and care givers.

As of the end of 2017 the folder is currently available in 16 different languages. The folders can be downloaded from our website.

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. In 2012, several patients that met certain criteria had given biopsies, or pieces of skin tissue, which are being examined in Canada.

The process of obtaining biopsy samples has been on hold for a long time now and in the second half of 2016 we submitted a new request to the Medical Ethics Committee to be able to obtain biopsies again for genetic research. The progressing of this application is proving to be extremely slow, which means that we are experiencing a considerable delay. We do expect that we will be able to obtain sufficient biopsies in 2018 so that the research can finally begin.

2.10 Newsletter

In 2016, we started with the production of a new style newsletter. For this work we have been able to find a dedicated volunteer with a background in scientific journalism. In 2017 the newsletter has been published four times in both Dutch and English language versions. The website has a special archive section for these newsletters.

2.11 Rare Connect Project

We are participating in the Eurordis Rare Connect project for which we have our own online group and carry out a moderator role for the community.

2.12 Cooperation with Other Organizations

We work together with the following organizations, among others:

1. **The WEVAR (Workgroup on Vascular Abnormalities Rotterdam) team at the University Medical Centre Rotterdam, Sophia Children's Hospital. A variety of specialists work together within the Pediatric Surgery Group. Joining forces ensures optimal cooperation on treatment and maximizes use of the available capacity. The specialisms that belong to the Pediatric Surgery Group are: Pediatric Anesthesia, Dermatology, Dental Surgery, Pediatric Surgery, ENT, Neurosurgery, Neurology, Ophthalmology, Orthopedics, Plastic Surgery, Thoracic Surgery and Urology. Adult patients can also now be treated by this team.**
2. **The Department of Dermatology at the Maastricht University Medical Centre (MUMC). The Department of Dermatology is recognized as a center of expertise on Genodermatoses or inherited genetic skin conditions and is led by Prof. Dr. Peter Steijlen.**
3. **The Hecovan Workgroup, an expertise center for hemangiomas and congenital vascular malformations. This is a multidisciplinary team at the Radboud University Medical Centre in Nijmegen, Netherlands.**
4. **LGDA-E. This organization is focused on people in Europe with Lymphangiomatosis and Gorham's Disease.**
5. **During the October 2016 NORD conference in Washington we contacted 'The Mighty' from which an agreement to work together arose.**

The Mighty is an American website with a large world-wide readership and on which there are all sorts of personal stories from people with a disease, (mental health) condition, or disability. For example, there are personal stories from people with diabetes, autism or hemangioma. Our cooperation means that a CMTC-OVM home page will be created on their website.

Many people in the world suffer from one form of (serious) medical problem or another. These individuals not only seek information about their condition but are also looking to be inspired. This could mean reading stories from people that have the same medical problems and who describe how they have learned to live with them for example, or what they experience because of having their condition. The Mighty presents 'real stories from real people that have real challenges' as they say themselves.

Because there is now a home page on The Mighty for CMTC-OVM we hope to be able to help more people as we will have a much wider reach.

2.13 Financial Administration

In the year 2017 we have taken another major step in the simplification and streamlining of our financial administration. In 2016, we used various suppliers for invoicing, sending invoices and monitoring the payment process for example. In 2018 we will start with a single new supplier where these systems are integrated into one system.

For example, we also want a monthly overview of the budgets by item and the actual costs so that we can quickly see our overall financial status.

In 2016 we had already started with the use of electronic invoices, primarily for contributions and donations. These invoices can be paid electronically in several different ways.





2.14 CBF Certification

On the 1st of July in 2016 we obtained CBF recognition. The Central Bureau on Fundraising (CBF) has provided recognition for fund raising institutions since 1996. A CBF logo shows that the organization conforms to applicable rules of the independent Central Bureau on Fundraising. Recognition for good causes, that can demonstrate clear goals, have established organizational controls and are able to explain their processes in an open and understandable manner. The CBF will revalidate an organization at least every three years and interim assessments can also take place.

2.15 Marketing

During 2016 a start was made with the making of our marketing, fundraising, member and donor recruitment functions more professional. To this end, we had contacted a professional fundraiser, but results were disappointing unfortunately.

At the end of 2017 we signed a contract with a new fundraiser and we very much hope that he will be successful.

**1.
Patient
contact**

**3.
Advocacy**

**2.
Information
provision**



3 FINANCIAL INFORMATION

3.1 Introduction

This year we have again been able to move forward and strengthen our position in several different areas. The following sections provide an overview of various items concerning income and expenditure.

The main activity items largely correspond to the structure provided by the government organization Fonds PGO, as follows:

1. Patient contact.
2. Information provision.
3. Advocacy.

3.2 Expenditure

ACTIVITY	EXPENDITURE 2017 (€)	EXPENDITURE 2016 (€)
PATIENT CONTACT	21.436	18.171
INFORMATION PROVISION	23.535	12.908
ENABLING ACTIVITIES	1.852	2.671
ADVOCACY	10.777	5.195
TOTAL	57.600	38.945

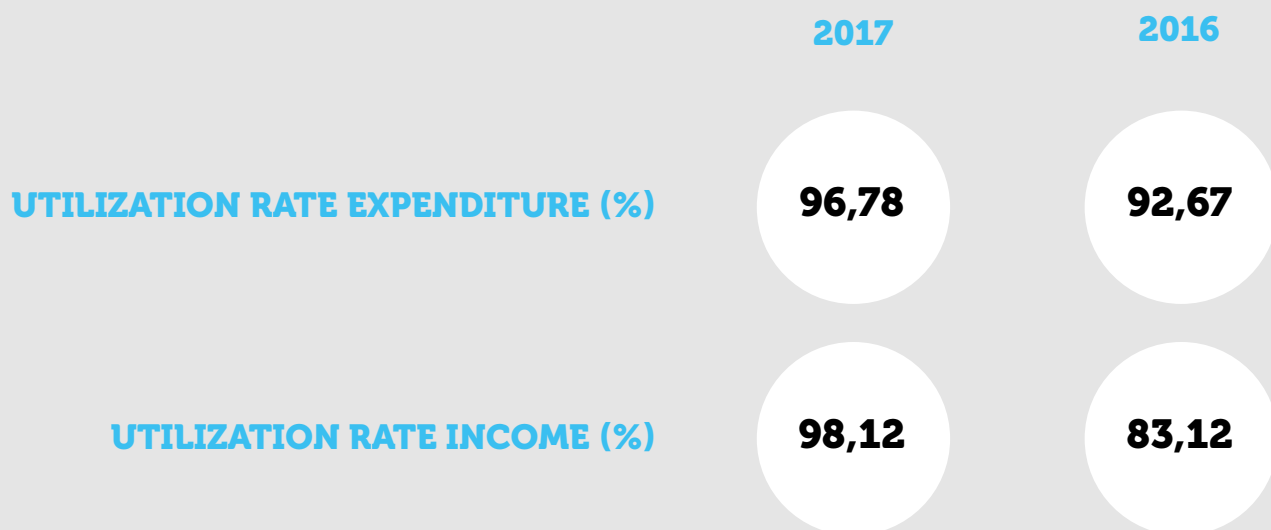
3.3 Income

SOURCE	INCOME 2017 (€)	INCOME 2016 (€)
FONDSPGO GRANT	45.000	35.000
MEMBERSHIP FEES	2.380	4.554
DONATION/GIFT/MISCELLANEOUS	4.437	4.077
PROJECT DONATION	5.000	0
TOTAL	56.817	43.631

3.4 Notes

During the members' meeting in the Netherlands, children's entertainment is organized in a separate room so that the parents can attend the meeting and the children are kept busy in various ways, according to the age groups of the children.

In 2016 we also organized a family day with the aim not only to bring patients together but also their immediate family in one single environment and have fun together, to get to know each other and to share experiences



4 LOOKING AHEAD

Experience shows that it takes many years for a patients' organization to gain visibility. When this concerns a rare condition, the challenge can be even harder and is one which requires a significant 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 central point of communication between doctors and their patients.

Contacts via Eurordis, NORD 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 aim of improving the lives of patients.

- 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. Promote research into vascular malformations such as CMTC, especially towards genetic research into the DNA material of patients.**
- 4. Further development and implementation of a Social Media strategy considering any changes in approach of search engines such as Google and Facebook.**
- 5. Further development of special Facebook groups for young adults and children.**
- 6. Fundraising to be able to develop extra activities and become less reliant on funding subsidy from the Dutch Government.**
- 7. Member and donor recruitment via social media.**
- 8. Organize a meeting for personal contacts and exchange of information in the Netherlands. Taking part in the AGM for our sister organizations in the USA and in Canada.**
- 9. Organizing a Family Day in The Netherlands in a casual setting so that people easily feel able to participate and where focus is placed on working together with patients and their immediate family. This also provides the opportunity to gain knowledge and exchange experiences.**
- 10. Provide support for other small patient organizations regarding development and cooperation. We can act as an umbrella organization for vascular malformation and growth related medical conditions. These organizations could piggyback with ours in some areas such as websites or the use of social media for example.**
- 11. Implement the 'Impact' program that consists of several separate projects:**
 - a. Translate the specially developed website for children into more languages such as German, French and Spanish, currently only available in Dutch and English.**



- b. Create subtitles for the available video material.
- c. Prepare new folders and information material.
- d. Create a CMTC booklet that will cover practically all aspects of CMTC in English and Dutch.
- e. Modernize and add new functionality to the current CMTC-OVM website.

This program will be financed separately.

- 12. Publish a newsletter. The aim would be to actively provide news updates and to direct readers to our website for more information.
- 13. Attend national and international conferences in the field of rare diseases. Conferences such as Eurordis and NORD for example.
- 14. Provide local representation for our organization in other countries through a 'patient advocacy' construction (so not via a separate new local CMTC-OVM organization). The first example of this has been established in Germany, starting in 2016. At the end of 2017 we have 'patient advocates' in 9 countries.

Early in 2018 we will communicate more about this initiative via the website and social media channels.

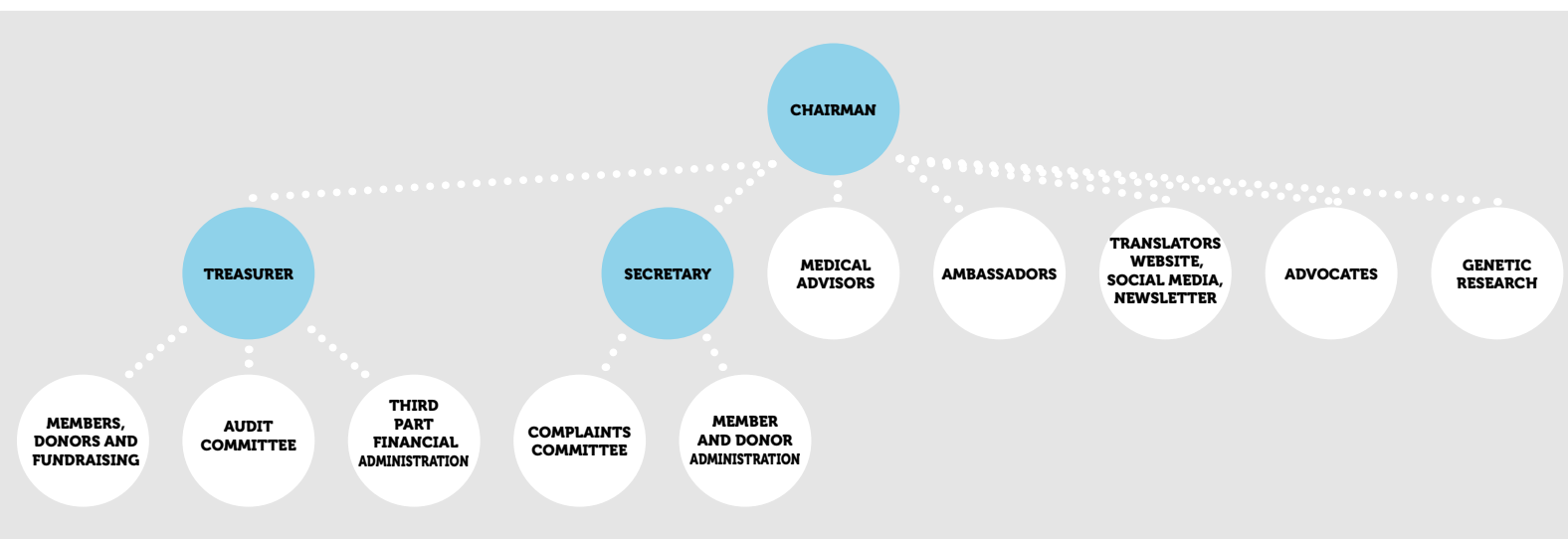
- 15. From 25th May 2018 the new European General Data Protection Regulation (GDPR) will apply and we will need to comply as an organization. We aim to implement GDPR in the first quarter of next year.



5 PEOPLE AND RESOURCES

The number of people available in a small Association such as ours is quite limited. The effort required is not proportional to the size of the organization however, which means that there is still a considerable amount of work to be done. During the year 2017, the Board consisted of three people.

Our organogram is shown here with Board members indicated using a red marking:



Using extra volunteers for translation work and various other activities, a lot of additional work has also been carried out. Several members have themselves generously volunteered to help with some of these activities

The 2018 budget contains the key items Patient Contact, Information Provision, Advocacy and Enabling Activities. This budget amounts to approximately € 53,000. Extra activities on top of this are carried out on an individual project basis and these are funded separately

ACTIVITY (EXPENDITURE)**BUDGETED 2018 (€)****PATIENT CONTACT****22.400****INFORMATION PROVISION****18.500****ADVOCACY****9.760****ENABLING ACTIVITIES****2.550****TOTAL****53.210**

SOURCE (INCOMES)	BUDGETED 2018 (€)
FONDSPGO SUBSIDY	45.000
SUBSCRIPTION (MEMBERS, DONORS, SPONSORS)	8.200
INTEREST	10
TOTAL	53.210

We carry out extra activities on a project basis which are financed separately



6 CMTC-OVM AND THE ENVIRONMENT

Just like any commercial organization 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 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.**



7 A. APPENDIX A - TERMS AND ABBREVIATIONS

Term/Abbreviation, Definition	
ANBI	Formal status of a non-profit organization from the Dutch tax authority which implies that donations are tax deductible.
AVG	General Data Protection Regulation, GDPR.
CBF	Central Bureau on Fundraising.
CMTC-OVM	Cutis Marmorata Telangiectatica Congenita and Other Vascular Malformations, our organization.
Eurordis	European Organization for Rare Diseases.
Fonds PGO	Arranges subsidy from the Dutch government for disabled people and patient organizations.
NORD	National Organization for Rare Disorders, USA.
VSOP	The Dutch Genetic Alliance, a national umbrella organization of about sixty disease-linked parent and patient organizations.

ANNUAL REPORT 2017

PATIENT ASSOCIATION
CMTC-OVM
WWW.CMTC.NL



cmtovm