ANNUAL REPORT 2021

PATIENT ASSOCIATION
CMTC-OVM
WWW.CMTC.NL/EN/EN

COLOPHON

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The patient association was
formally established on 22 January, 1997

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You can find more details about our (medical) advisors on our website.

The patient association was formally established on January 22, 1997

You can find more details about our ambassadors on our website.

1 INTRODUCTION

1.1 Purpose of this Document

This document contains the 2021 annual report of the patient association CMTC-OVM. The purpose of this document is primarily to provide an overview of the activities performed in 2021.

1.2 Introduction

The patients' organisation was formally established on 22 January, 1997 by notary "Van Helden" in Amsterdam and subsequently registered with 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 mission is:

Promoting the well-being of people suffering from vascular malformations such as CMTC ("Van Lohuizen syndrome"), in particular its own members, and promoting and developing activities that can promote this well-being. The promotion of scientific research with regard to vascular malformations such as CMTC, the causes and treatment thereof, and everything related to it in the broadest sense of the word.

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

The logo is:

cmtc ovm

1.3 Administration

As of 31 December, the board is composed as follows:
Mr. A.F.R. van der Heijden, Chairman;
Mrs. A. Fluijt, Secretary;
Mr. J. Schipper, Treasurer.

1.4 Advisors

Our advisors in 2021 are:
Mrs. Prof. Dr. Laurence Boon (Belgium)
Mr. Dr. Andrea Diociaiuti (Italy)
Mrs. Prof. Chantal van der Horst.
Mr. Dr. Patrick Kemperman.
Mr. Dr. Peter de Laat.
Mrs. Dr. Margaret Lee (USA).
Mrs. Dr. Christianne van Nieuwenhoven.
Mrs. Dr. Charlène Oduber (Aruba).
Mrs. Prof. Dr. Suzanne Pasmans.
Mr. Dr. Millan Patel (Canada).
Mr. Prof. Dr. Maurice van Steensel.
Mr. Prof. Dr. Peter Steijlen.
Mr. Prof. Dr. Miikka Vikkula (Belgium).
Mrs. Dr. Maaike Vreeburg.

More information about our medical advisors can be found on our website.

1.5 Ambassadors

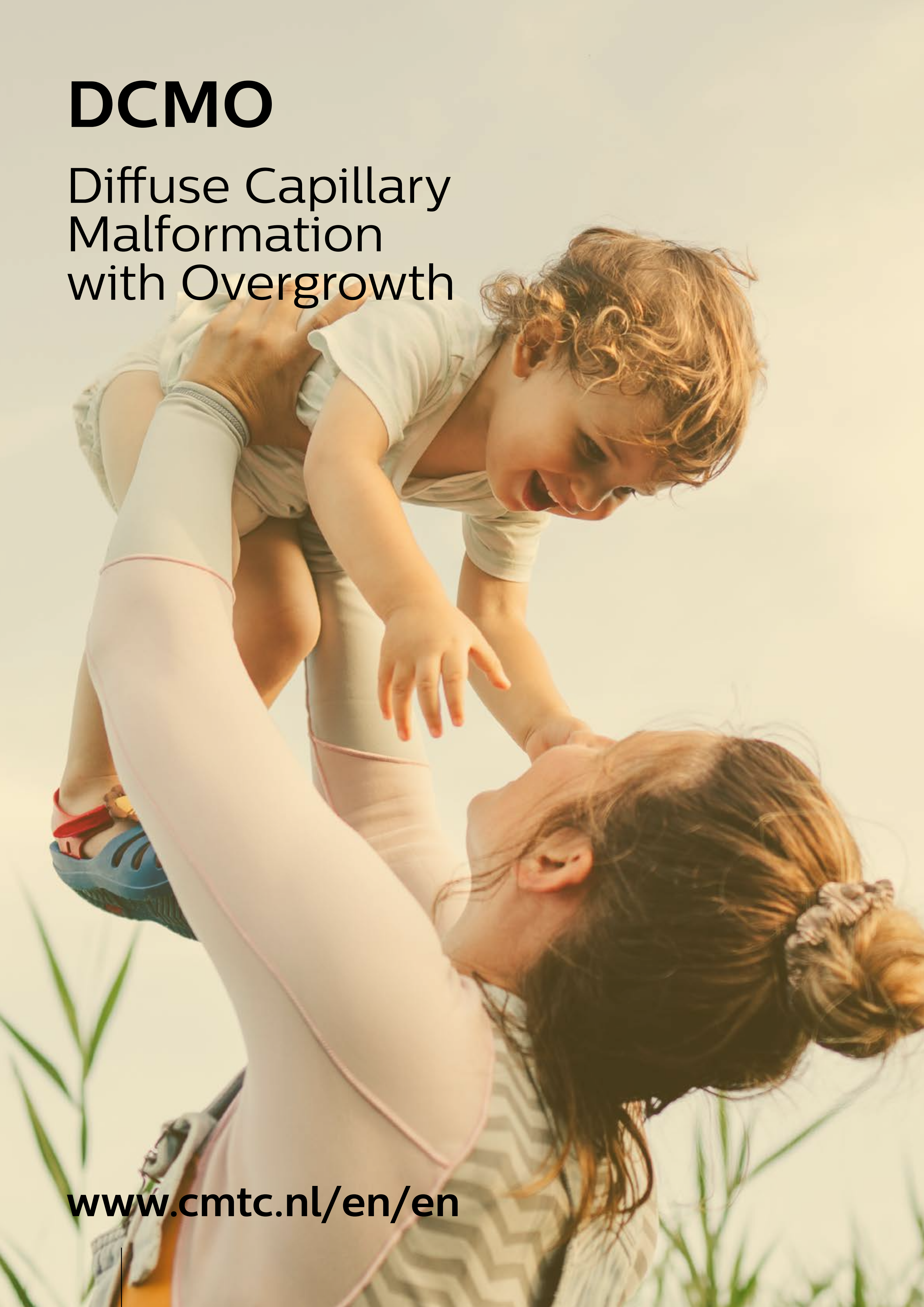
At the end of 2021, we have three ambassadors who represent our organisation. These are Prof. Dr. Jan Peter Balkenende (former prime minister of the Netherlands), Dr. Steve Groft (former director of rare diseases within the American National Institute of Health) and Eden Quine-Taylor (United Kingdom).
More information about our ambassadors can be found on our website.

1.6 Volunteers

The association is supported solely by voluntary staff, including the board. In addition to the board, various volunteers run different activities, such as translation and social media. In addition to the board, there were around 50 active volunteers worldwide as of 31 December 2021, particularly in the field of translation, recruiting members / donors, the audit committee, the complaints committee and during the members' meeting. Our medical advisers and ambassadors are also included in this volunteer count.

DCMO

Diffuse Capillary Malformation with Overgrowth



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2 ACTIVITIES 2021

Thanks to the subsidy from the Ministry of Health, Welfare and Sport, we were able to carry out a large number of (additional) activities in 2021.

Because of COVID-19, we were forced to cancel certain activities or organise them in a different way. In particular, our Family day, member conference and participation in all sorts of conferences.
By mutual agreement with the Dutch Ministry of Health, Welfare and Sport, the reserved budgets were assigned to other activities.

The most important activities we organised in 2021, are:

1. **Online member conference.**
2. **Brochure 'after the diagnosis'.**
3. **Brochure parents support guide.**
4. **Series of new folders.**
5. **ERNs & ePAGs.**
6. **Website young adults.**
7. **External (online) conferences.**
8. **Genetic research.**
9. **Partnerships with (nonprofit patient) organisations.**
10. **Project 'patient advocates'.**
11. **Newsletter.**
12. **Eurordis RareConnect project.**
13. **Fundraising.**
14. **CEO Council.**
15. **Organisation professionalisation.**
16. **Certifications.**
17. **Marketing.**

2.1 Online member conference

Our global member conference was held 'online' this year on 24 October 2021.

More than 30 people participated in our conference. Participants joined from Belgium, Canada, England, Georgia, Kenya, the Netherlands, Austria, Poland and the United States. The greatest challenge was finding a time slot that would suit everyone in the world so they could participate.

Presentations were given by Prof. Dr. Miikka Vikkula (Belgium), Prof. Dr. Laurence Boon (Belgium), Dr. Margaret Lee (USA) and Lex van der Heijden.

Reports and videos of the sessions can be found on our website.

if your brother or sister is ill

www.cmtc.nl/en/en

2.2 Brochure 'after the diagnosis'

The practical and disease-independent information brochure 'after the diagnosis' turns out to be a hit. This brochure is now available in 6 languages and we have already sent it around the world many times on request to, among others, doctors in hospitals.
It is also possible to 'download' the brochure from our website.

2.3 Brochure parents support guide

In cooperation with the organisation Naevus Global, we have developed a series of disease-independent brochures to support parents with children in different age groups (0-4 years old, 5-11 years old and 12-17 years old).
These brochures are also available in multiple languages and can be downloaded from our website.

2.4 Series of new folders

It was time to renew our CMTC folders and, besides that, we have also developed new folders on the Klippel-Trenaunay syndrome, arteriovenous malformation and Diffuse Capillary Malformation with Overgrowth.
These folders are also available in multiple languages and can be downloaded from our website.

2.5 ERNs & ePAGs

We actively participate in the European Reference Networks and the European Patient Advocacy Groups SKIN and VASCERN.

2.6 Website young adults

In 2021, we started developing a special website for young adults (approx. 15-30 years old). The goal is to offer information about vascular malformations in language and style that is understandable for young adults. Besides that, we can contact each other in a protected and private online environment.

2.7 External (online) conferences

Because of COVID-19, almost all conferences were organised as online conferences.
For example, we participated in a number of international conferences.

2.8 Genetic research

The genetic research into CMTC, which is mainly being executed in Belgium, progresses slowly because we still cannot find enough patients with 'classic' CMTC who are willing to have a biopsy (taking a little piece of skin).

2.9 Partnerships with (nonprofit patient) organisations

In 2021, we established new partnerships with a number of umbrella organisations in different countries that are specialised in rare diseases in their respective countries.

In 2022, we will establish even more partnerships.
Our website includes, among other things, a complete and current list of organisations we work with.

2.10 Project 'patient advocates'

The biggest problem patients and parents (our target groups) have to deal with, is getting the correct medical diagnosis. In fact, this is the case for all rare diseases. Our idea is to start using 'Patient Advocates' (PAs) in countries where patients with CMTC and Other Vascular Malformations (OVM) live. A PA is an expert by experience, such as a patient or an immediate family member, who knows the language and culture in a certain country, who knows which doctors have knowledge/experience with vascular malformations for a correct medical diagnosis, who can make and maintain contact with fellow patients, who knows local health services, who spreads information, who uses local social media platforms, etc. The goal of this project is to bring PAs from different countries to the Netherlands at our expense and to educate them with a workshop in the Netherlands. This workshop connects to our global conference in the Netherlands.
We have been granted a subsidy by the Dutch government for this project and we started it in July 2020.

Because of COVID-19, the final date has been moved to December 2022 so the project could be connected to our conference in the Netherlands in 2022.

2.11 Newsletter

Our newsletter has been published three times in 2021 in both Dutch and English. You can find our newsletters archive on our website.

2.12 Eurordis RareConnect project

We participate in the Eurordis Rare Connect Project in which we have our own group and fulfill the function of moderator.

2.13 Fundraising

In 2021, we successfully organised our own fundraising. In addition to subsidy we received from the Ministry of Health, Welfare and Sport, we also received a project subsidy for our 'teacher brochure' from Novartis.

2.14 CEO Council

We, as a nonprofit patient organisation, participate in the CEO Council of the Ministry of Health, Welfare and Sport (VWS), among others.
In this context, CEO Council stands for 'Chief Experience Officers' Council, or experts by experience in healthcare. You are an expert by experience when you regularly need healthcare (or needed it in the past), because you have a disability or are an informal carer yourself. The CEOs offer a refreshing and patient-oriented look on the policy of VWS and put issues on the agenda that are very important to them and us. The goal is to bring systems and living environment together.

2.15 Organisation professionalisation

In 2021, thanks to our new website, we were able to take a few steps forward in the field of professionalisation.

The largest part of this professionalisation is not immediately visible to our members and donors.

2.16 Certifications

We have different certifications:

1. **ANBI (Dutch Tax and Customs Administration).**
2. **CBF (The Netherlands Fundraising Regulator)**
3. **NORD (USA, Platinum status).**

2.17 Marketing

In this context, we see marketing as a way to make our organisation and information visible in order to reach patients with CMTC-OVM, their families, carers and donors/sponsors.
Furthermore, we want to improve comprehension among the general public of what people with CMTC-OVM can face in both their daily and long-term life.
We use different social media platforms such as Facebook, Instagram, Twitter, LinkedIn and YouTube.
In addition, we campaign on social media platforms such as Google AdGrants and Facebook.

1.
Fellow Patients

2.
Provision of Information

3.
Enabling Activities

4.
Patient Advocacy

5.
Backoffice

3 FINANCIAL OVERVIEW

3.1 Introduction

Once again, we have been able to develop many activities in diverse areas and we have further strengthened our position. An overview of the various main items (expenditures and receipts) can be found below.

The main items largely correspond to the structure which the Ministry of Health, Wellness and Sport uses, namely:

1. Contact with fellow patients;
2. Information provision;
3. Advocacy;
4. Backoffice.

The goal of the activity Backoffice is to execute tasks that are not part of our core tasks (point 1 to 3), such as hosting our website, setting up and managing social media campaigns, drawing up our annual account and making graphic designs.

We have to pay for the 'enabling activities' ourselves and this consists of, for example, travel expenses of the council, banking costs and training for volunteers.

3.2 Overview of Expenditures

ACTIVITY	EXPENDITURE 2021 (€)	EXPENDITURE 2020 (€)
1. CONTACT WITH FELLOW PATIENTS	12.600	5.873
2. PROVISION OF INFORMATION	26.736	31.428
3. ENABLING ACTIVITIES	1.559	2.736
4. ADVOCACY	8.035	9.815
5. PROJECTS	5.560	3.847
TOTAL	64.990	62.253

3.3 Receipts

SOURCE	RECEIPTS 2021 (€)	RECEIPTS 2020(€)
MINISTRY OF HEALTH, WELFARE & SPORT	64.506	43.604
CONTRIBUTIONS	3.512	3.375
DONATIONS/SUNDRIES	1.904	1.800
PROJECTS	0	3.850
TOTAL	69.922	62.825

3.4 Utilisation

	2021	2020
UTILISATION RATE OF LIABILITIES (%)	81,44	81,86
UTILISATION RATE OF ASSETS (%)	75,70	81,12

4 A LOOK INTO THE FUTURE

The world is changing at a fast pace, in which COVID-19 has been a catalyst.
In the past, it was very rare for patients and doctors to speak to each other via video calls. The patient always had to travel to see the doctor. In a very short time and from sheer necessity, distance health care became a real thing.
We expect this trend to continue rising in the future.

We have also seen and experienced that online conferences will be organised more often. In 2020, this trend arose and suddenly an avalanche of online conferences approached us.
It is obvious that online conferences have a lot of advantages, for example, there are no travel costs, no time lost to travelling, it is easier to organise and the costs are lower.
But human contact, being able to look each other in the eye, is something we do miss.
In case of international conferences, time zones can be a complicating factor, for example, when you want to attend a conference in Asia or the United States from Europe.

To us, there are different possibilities, such as a hybrid conference (both physical and online) or organising both a physical conference and an online conference once a year (spread throughout the year).

The trend of people not wanting to become members of an organisation quickly, is a trend we do not see changing. Through social media, especially Facebook groups, people can get into touch with other patients and family.

Since 2019, the Ministry of Health, Welfare and Sport has been trying to change the criteria to be eligible for a subsidy from the number of members/donors to the impact and range an organisation has. The concept of this new policy framework was the subject of discussion near the end of 2020, which we also contributed to.
This new policy framework will be established in 2024.

In 2022, our organisation will be 25 years old and we want to develop more activities as listed below (also dependent on the consequences of COVID-19):

1. **Organise a hybrid international member conference (both online and physical in The Netherlands). We will combine this with the Patient Advocate Training (2022).**

2. **Organise an international family day in the Netherlands in an informal environment, so the activity will be approachable for everyone. The focus will be on taking action with patients and their family.**
   This family day will offer an opportunity to get to know other people and to exchange knowledge and experience.

3. **Reach the target audience with the age of approx. 15-25, in cooperation with, for example, JongPIT!**

4. **Organise public webinars.**

5. **Expand our new website both functionally and content-wise.**

6. **Maintain and expand our contacts and cooperate with other patient organisations, both nationally and internationally.**

7. **Maintain and expand contacts with medical experts such as dermatologists, both nationally and internationally.**

8. **Conduct research into vascular malformations such as CMTC. We are particularly thinking about genetic research of DNA samples of patients. But it turns out to be very difficult to find enough candidates who want**

In the Netherlands, the use of experts by experience is seen as valuable and required by different committees (nothing about us without us). Consequently, this means that experts by experience are increasingly being more valued financially.

Reaching patients between approx. 15-25 years old has turned out to be difficult. We would like to know what is going on in their lives and what their needs are.

International contacts will also continue to increase, as well as the number of international members.

By using internet technology, we want to strengthen our global network and be the key figure between patients and doctors and between doctors themselves.

Contacts through international umbrella organisations such as Eurordis, NORD and Genetic Alliance are still very important and they offer us entryways and possibilities that would have never been possible for our small organisation if we were to do this all by ourselves.

Cooperation and sharing knowledge and experience is also crucial to our goal to improve the lives of patients and the people close to them.

At this point, around 7000 rare diseases are identified and the number of people with rare diseases is low.
Consequently, it takes many years for a patient organisation to have a certain reputation, but it also means we constantly have to work on this reputation through marketing.
This does not only require additional efforts time-wise, but also financially.

to have biopsy done. In addition, the administrative work is complex and time consuming, especially because of the privacy law.

9. **Expand social media campaigns, taking, among other things, the changing strategies of search engines into account.**

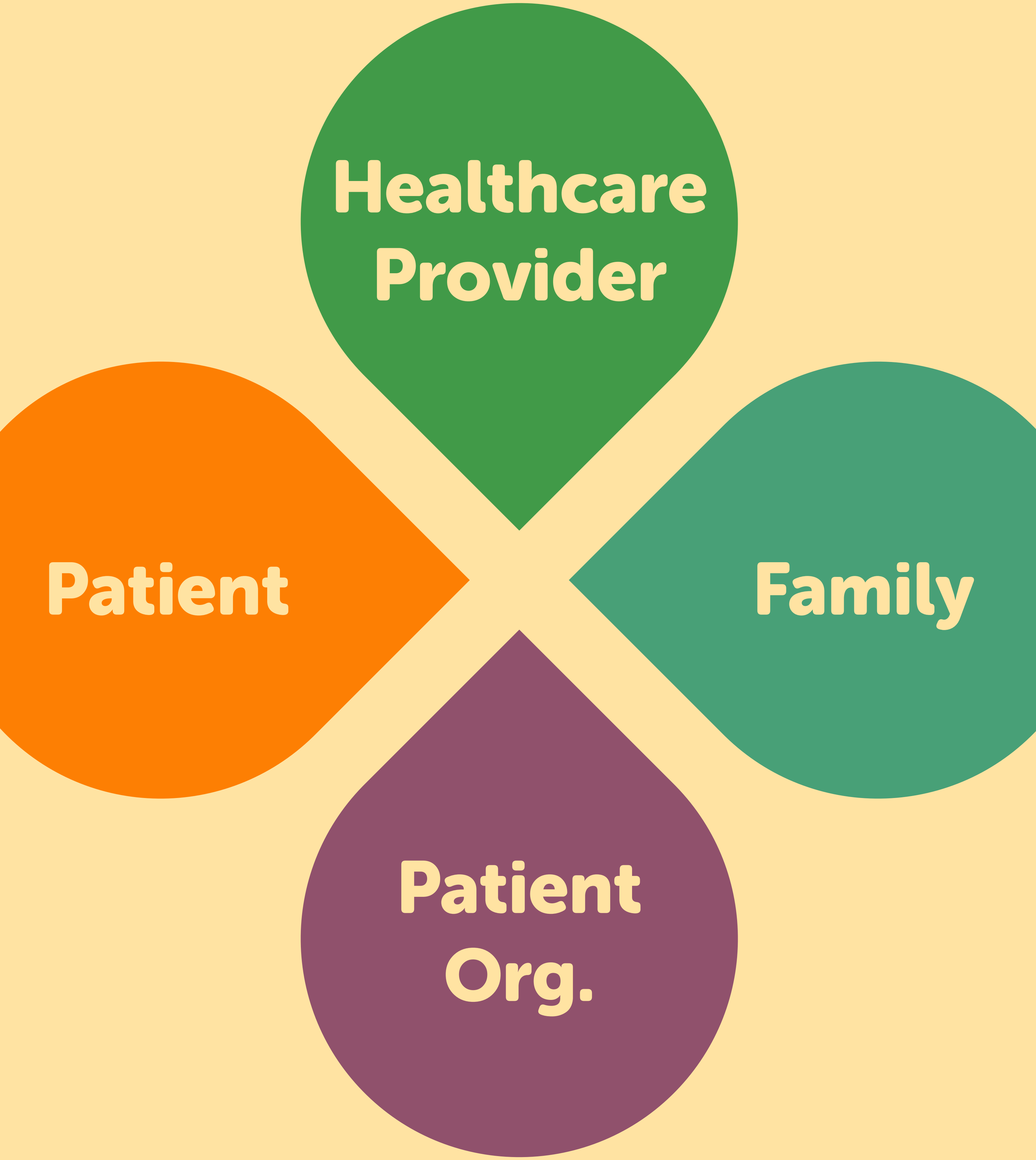
10. **Expand our activity on Facebook, Instagram, YouTube, Twitter and LinkedIn.**

11. **.Fundraising so we can develop additional activities and become less dependent on the Dutch government.**

12. **Attract members and donors through social media. For this goal, we use campaigns on Google AdWords and Facebook.**

13. **Actively participate in the European Expertise Reference Networks (ERNs) and the ePatient Advocacy Groups (ePAGs).**

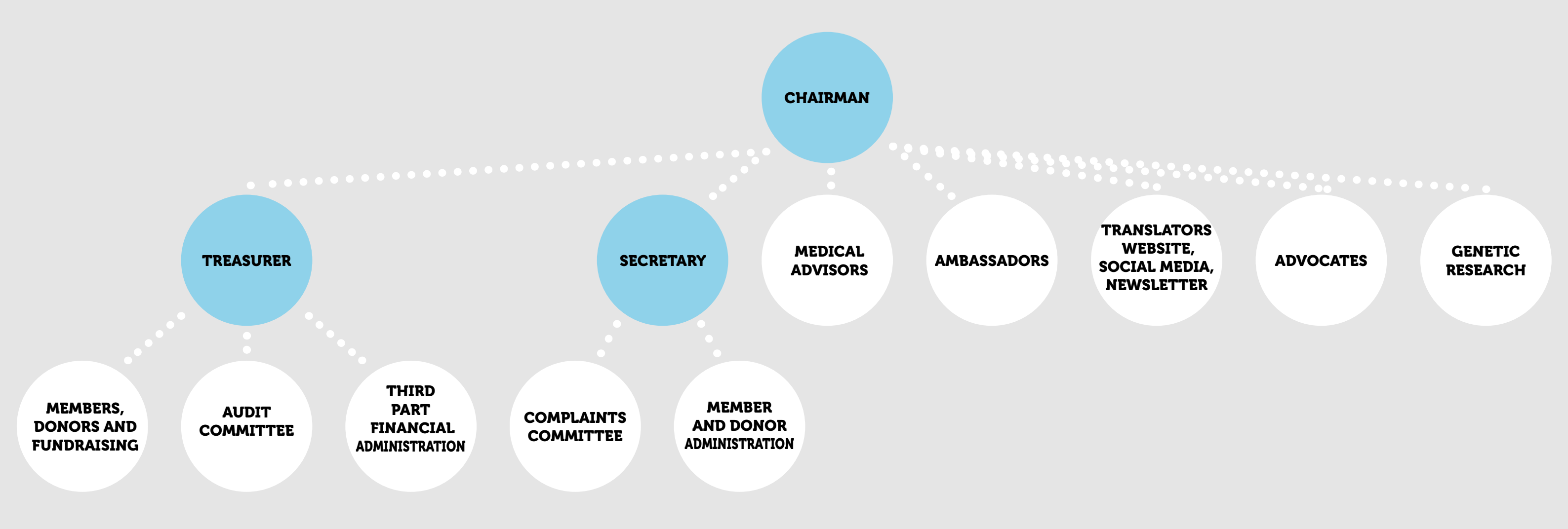
14. **.Publish a newsletter. The goal is to actively bring news and to refer readers to our website for more information.**


Healthcare Provider
Patient
Family
Patient Org.

5 AVAILABILITY OF PEOPLE AND RESOURCES

The amount of available people is quite limited in a small association. However, the amount of work is not proportional to the size of an association, which means that a considerable amount of work needs to be done.

During 2021, the board consisted of three people and in total around 50 volunteers.
The organization chart of our organization where the board members are marked separately, can be found below.



A lot of work, for example, has been done through the use of extra volunteers for translation and other diverse activities. Members even sign up spontaneously to perform activities.

The budget for 2022 consists of the main items: contact with fellow patients, provision of information, advocacy, backoffice and related activities. This budget comes to € 61,150 (excluding projects).

ACTIVITIES (EXPENDITURES)	BUDGET 2022 (€)
CONTACT WITH FELLOW PATIENTS	26.500
PROVISION OF INFORMATION	9.800
ADVOCACY	14.100
ENABLING ACTIVITIES	750
BACKOFFICE	10.000
TOTAL	**61.150**

SOURCE (RECEIPTS)	BUDGET 2022 (€)
MINISTRY OF HEALTH, WELFARE & SUBSCRIPTIONS	55.000
(MEMBERS, DONATIONS AND SPONSORS)	5.850
OTHER	300
TOTAL	**61.150**

We carry out extra activities on a project basis, which are funded separately.

The Klippel-Trenaunay Syndrome (KTS)

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6 CMTC-OVM AND THE ENVIRONMENT

Just like companies, our activities can have negative environmental effects. We have taken the following measures to limit any negative environmental impact:

1. **Newsletters etc. are available on the website.**
2. **Double-sided paper printing happens as much possible.**
3. **Travelling by car is shared as much as possible with other people. If possible, public transport is used as much as possible.**
4. **Computers are only switched on if they are actually being used.**
5. **If possible, a meeting is held by telephone (e.g. via Skype). We do this, for example, with our board meetings.**
6. **E-mail is preferred to physical mail.**
7. **Empty inkjet cartridges are collected and returned to the designated collection points.**
8. **Paper, plastic and chemical waste are separated from the other waste and are disposed of separately.**
9. **Materials are as much as possible recycled and reused.**

Arteriovenous malformation (AVM)

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7 APPENDIX A TERMS AND ABBREVIATIONS

Term/abbreviation	**Explanation**
ANBI	**Algemeen Nut Beogende Instelling (Public Benefit Organisation).**
CBF	**Centraal Bureau Fondsenwerving (The Netherlands Fundraising Regulator).**
CMTC-OVM	**Our organisation.**
Eurordis	**Europese organisatie voor zeldzame ziekten (European Organisation for Rare Diseases).**
Fonds PGO	**Subsidie vertrekker vanuit Nederlandse Overheid (Subsidy provider by the Dutch government) for patients, disabled people and elderly.**
GDPR	**General Data Protection Regulation.**
NORD	**National Organization for Rare Disorders (USA).**
VSOP	**Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (Dutch Patient Alliance for Rare and Genetic Diseases).**

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