STATEMENT OF POLICY
2019-2022

PATIENT ORGANISATION

CMTC-OVM

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COLOFON

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Chairman and Author
Lex van der Heijden

Owned by
CMTC-OVM Board of Directors

Treasurer
Jacob Schipper

Secretary
Anja Fluijt

Graphic design
Rick Schurink, Design Delicious

@CMTC

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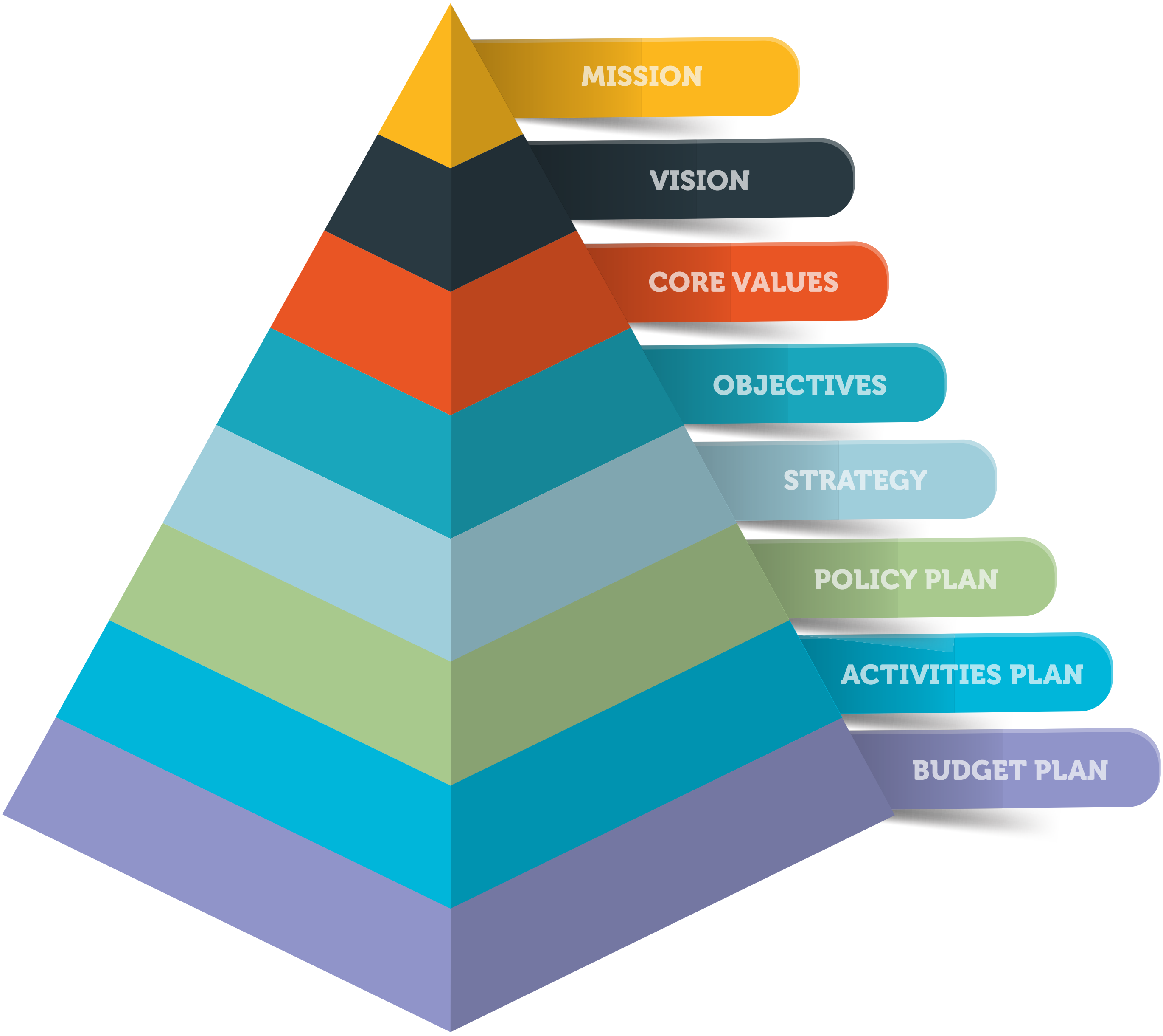
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DIS in brief
26
70
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1997
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500
440
100
+340
40+

MISSION

1 Promotion of the well-being of people suffering from vascular malformations such as CMTC ("Van Lohuizen syndrome") and in particular its own members, and the promotion and development of activities that can support and promote this well-being.

2. 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.

VISION

Providing medical and psycho-social support to people with vascular malformations and their immediate families so that the quality of their lives improves.

1 We offer patients and their families worldwide support in both medical and the psycho-social areas (offering a holistic approach).

2 We promote and support self-reliance in patients as much as possible, allowing them to be in control of one's own life and being able to participate in society.

3 By conducting genetic research into the causes of CMTC, we hope to ultimately be able to treat the condition.

4 Contact with fellow patients is crucial for patients and their families to exchange knowledge and experience and to help each other.

5 The provision of information is essential. The information must be current and available in multiple languages.

6

Representation of patient interests and cooperation are required, particularly in the rare diseases world.

7

Not having a (correct) medical diagnosis is a stressful psychological burden on the patient and the family.
It is therefore important to not only get a medical diagnosis quickly, but also a correct and accurate diagnosis.

8

A rare condition is almost always chronic, which implies that a patient has this condition throughout life. This often means that the patient may have limitations in areas such as school / study, dealing with friends, leisure activities and in the workplace.

9

Local support for patients and families is of great importance. In countries where we are not present, we use the "patient advocate" concept which is in fact a local representation. The patient advocates receive support from the worldwide Dutch organization.

Wereldwijde leden conferentie Nederland

Programma 2018

CORE VALUES

Our core values are:

1

Representation of interests. We look after the interests of patients and their families.

2

Expert
We have a team of (medical) professionals who are experts in their field.

3

Empathy. We can empathize with the patient and the family based on our own knowledge and experiences

4

Impact and range. We want to have a positive impact on the quality of life of the patient and family. Our reach is worldwide.

5

Innovation. We use modern technology and use a modern approach for support and information distribution.

6

Cooperation. We work together with all kinds of organizations and individuals to achieve our goals.

MAIN GOALS

We have created the the following primary goals for the lifetime of this statement of policy:

1

Our organization is the global expertise center and supports patients, their families and healthcare professionals in both medical and psycho-social areas. We want to impart a positive impact on the lives of people with vascular malformations and create a global reach.

2

Unravel the genetic cause of CMTC and if possible also of other vascular malformations so that the disorders can be treated.

3

Improve medical diagnosis (both speed and accuracy).

4

Bringing together of patients, their families and healthcare professionals through creating contact with fellow sufferers.

5

Collaborate with other organizations from the basis of "you are stronger together" and with the aim of achieving "win-win" situations for all parties involved. It is crucial that these organizations are (fairly) equal in terms of professionalism, ambitions and activities.


IKE

STRATEGY

Our core pillars are: creating contact with fellow sufferers, provision of information and advocacy. All our activities are directly or indirectly focused on these pillars.

Local presence can, in certain countries, lower the ability to get support threshold for people living in a country (think of aspects such as language). We use “patient advocates” for this. A “patient advocate” can, among other things, work on local brand recognition, be a first point of contact in terms of information, members, donors and sponsor recruitment, translations, etc.

As an organization, we want to be seen as the center of expertise for patients and their families in particular when it comes to disorders that are related to vascular malformations. We also want to act as an intermediary for medical care professionals through our work with medical advisors.

Collaboration in the rare diseases world in particular is crucial. We work together with (international) umbrella organizations and other patient organizations. We also attend conferences in this context. Examples are: Eurordis, Genetic Alliance, ICord, Global Skin, NORD and VSOP.

We mainly use technology such as the Internet, websites, social media, etc. to reach, connect and provide patients, parents of patients, care providers, the public, etc. with (requested) information.

STAKEHOLDERS

We recognise the following stakeholders

1. **Patient**
2. **Family of the Patient**
3. **The wider public**
4. **Professional Care providers**
5. **Donors**
6. **Companies providing sponsorship**
7. **Volunteers**

ACTIVITY PLAN

1. Organisation of the annual global family day in the Netherlands.
2. Organisation of the annual global members conference in the Netherlands.
3. The performance of genetic research into CMTC.
4. The maintenance and addition of content to our website.
5. The usage of social media channels incl. Campaigns (Facebook, Twitter, Google AdWords, Instagram, etc.) especially for reaching target groups, information provision, marketing and branding.
6. Project fundraising
7. Participation in international conferences, especially in the context of advocacy.
8. Creation and promotion of the “patient advocates” initiative.
9. Continuing to provide personal medical advice.
10. The development of an international patient register.
11. Collaboration with the pharmaceutical industry.
12. Collaboration with (academic) hospitals and medical expert teams (worldwide).
13. Publication of news, updates etc. in particular via our social media channels.
14. Publication of the CMTC-OVM newsletter.
15. Participation in the National Rare Diseases Day in the Netherlands.

MONITORING AND CONTROLS

Our financial administration primarily set up in such a way that we can monitor “budget versus actuals” so that at least monthly we can make adjustments as needed in time.

Secondly, we report our progress to our members during our global conference in the Netherlands.

Thirdly, we publish our activities and progress via our website, social media and newsletter.

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