



ANNUAL REPORT – GENERAL 2008

ASSOCIATION FOR PEOPLE WITH THE 'VAN LOHUIZEN SYNDROME'

CMTC

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1. DOCUMENT GOAL

This document contains the annual report of the patient association 'Association for people with the 'Van Lohuizen syndrome' for the year 2008. The goal of this document is primarily to provide insight into the activities carried out in 2008. The financial annual report is contained in another document.

2. INTRODUCTION

The patient association is formally founded on January 22, 1997, by the notary public van Helden in Amsterdam, and subsequently entered into the registry at the Chamber of Commerce in Amersfoort, Netherlands. The goal of the organization, which is documented in the statutes, is contained in the text below.

"Improving the well-being of people suffering from the 'Van Lohuizen syndrome' (CMTC), specifically for her own members, and fostering and developing activities that may improve this well-being. Fostering (scientific) research on CMTC, its causes and treatment, and everything related to this in the widest sense of the term."

3. MEMBERS

As of 1 January, 2009 there are 126 members world wide).

4. BOARD

The board consists of the following people per December 31, 2008:

Dhr. A.F.R. van der Heijden	President
Ms. J A. Kerkvliet-Molenaar	Secretary
Dhr. A. Fidder	Treasurer

Dr. A.P. Oranje, Dr. M. van Steensel and Dr. W.W. van der Schaar are our active medical advisors. Aside from them we collaborate closely with many other doctors from several countries.

5. VOLUNTEERS

The organization, including the board, is run almost exclusively by volunteers, including the board. Aside from the board, as of 31 December, 2008, there are 6 volunteers active in diverse functions. They are especially active in the area of translation and fund raising.

6. EXTERNAL ORGANIZATIONS

We collaborate with several external organizations:

- Organization for Collaborating Parent and Patient Organizations (VSOP). This is an organization that is primarily concerned with hereditary or congenital conditions.
- Client Board for Academic Hospitals (CRAZ).
- Doctors. Primarily through the newsletter we are in contact with dermatologists, a paediatric surgeon, a paediatric neurologist, several clinical geneticists and a general practitioner. Various academic hospitals in the Netherlands and the US refer patients directly to us.

We also collaborate with the Dutch Belgian Association for Paediatric Dermatology.

- Child and Hospital. In part because the majority of our members is young, and will visit hospitals primarily during their early years, collaboration with this organization is essential. We regularly publish articles from their newsletter in ours, always with their permission of course.
- Genetic Alliance. This is an originally US organization that has members worldwide. As the name indicates, this is a worldwide alliance for all kinds of organizations that are concerned with genetics.
- National Organisation for Rare Disorders (NORD). This is an originally US organization concerned with rare disorders.
- Eurordis. This is a European organization concerned with rare disorders.
- Klippel-Trenaunay and Sturge-Weber. These disorders have certain similarities with CMTC.
- Vascular Birthmarks Foundation. This American organization is active worldwide, just like we are. Meanwhile this organization has a British chapter that we are in contact with.
- HEVAS the Netherlands.

7. ACTIVITIES

Throughout the years the organization has been stable and is growing steadily in various ways. Becoming a more professional organization is a continuous activity which turns out well, considering the responses from both patients and doctors. The information on the website appears to be overwhelming, but in a positive way.

Since we control the entire process of automated work, including the website, we are very flexible and we can quickly respond to changing situations. The costs for this are minimal, while outsourcing this would be expensive.

Below is a list of activities carried out in 2008:

1. Annual meeting. Especially for parents whose children have this affliction this presents a very good opportunity to exchange experiences and to make and strengthen contacts with one another.
Dr. C. Oduber gave a presentation that was well received. Afterwards, she showed her expertise during the question and answer.
It is worth mentioning, that Dr. Oduber has done her Ph D on 'vascular malformations' and is directly involved in genetic research for the cause of CMTC.
In summary, this meeting was a huge success. Also, due to the possibility for the children to play in the other room with Wii, Playstation, tekenen, etc.
One member from the US also attended.
The meeting, and all the images and sounds of the presentations, is able to be viewed (via internet) by members all over the world.

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2. Newsletter. This appears to meet the need for information in large part. Especially parents whose children have this rare affliction are in need of a lot of information. Many parents appear to live in a continuous state of uncertainty. The newsletter is also distributed among doctors especially in academic hospitals that have various specialties. The newsletters are also translated into English so that they can be made available to foreign members and doctors. The translation work is carried out primarily by the president's colleagues in various countries, and they do this work for free.
3. Patient information leaflet. This leaflet provides a summary description of the affliction and explains what activities the organization undertakes. This leaflet is made available to anyone who shows interest.
Our leaflet is distributed in other countries during all kinds of events especially through Eurordis, NORD and Genetic Alliance.
4. This year we participated in the Genetic Alliance Congress in the USA. Doctors from the USA are becoming more aware of our organisation and are contacting directly in increasing numbers.
5. In May we participated in the Eurordis conference in Copenhagen.
6. Sponsor action. We have primarily used our members in order to recruit sponsors. This will become a permanent activity, as will recruitment of members.
We receive sponsorship from Microsoft and IBM.
7. Making arrangements for medical checks in the Netherlands of CMTC patients from abroad. So far, we have flown 15 patients from America, Australia, Canada, Croatia, Denmark, England, Greece, Italy and Norway to the Netherlands for free medical examinations. In many cases it was possible to arrange for free plane tickets.
Time and again it turns out that very little is known about CMTC worldwide and that the right knowledge and experience is available in the Netherlands.
8. The use of MSN and Skype in combination with a webcam, works simply and extremely well. It is now possible to see each other in moving images regardless of location. In this way we are in regular contact with various members from several countries.

Considering the response we have had, the website is much appreciated by our target audience. We regularly receive compliments on our website (both nationally and internationally).

The website contains a photo gallery that shows the different gradations and complications of CMTC. There is also the possibility to start a discussion, react to questions, both in a public and a members only section. Of course the entire site is bilingual (English and Dutch).

Using statistics it is simple to find out where visitors come from and what pages they looked at. Members of our organization can visit pages and access the following information:

- Newsletters.
- Medical information of other patients (of course only from members who have given permission to do so).
- Annual reports.
- Meeting notes.
- Presentations given during our general annual meeting.
- Presentations given during various congresses such as the NORD congress..

Non-members can look at and download general information on CMTC, they can become a members, ask questions and link to websites that have a relationship with our organization. Third parties such as Child and Hospital can access the censured newsletters.

9. In 2008, we achieved ANBI (Institution for General Benefit) status. Donations to our organisation are tax deductible. All donators have been informed per post.

8. A LOOK AHEAD

Experience tells us that it takes several years before a patient organization becomes known to the public. CMTC is a rare condition and this slows down the process.

All address guides are edited once a year, which means it can take up to a year before a new organization can be found in such guides. Considering the rarity of the condition we expect a slow progress in the years ahead.

International contacts will increase as will the number of foreign members. Through internet technology we will strengthen our worldwide network and function as a coordinating point between doctors, and between doctors and patients.

Contacts through Eurordis, NORD, VBF and Genetic Alliance are expected to increase and provide us with entry and possibilities that would not be available for a small organization like ours, if we were to try this on our own.

In the past years we noticed that all new members reach us through internet. This is one reason we pay so much attention to our website. In part considering the growth in the number of people who have access to internet, we expect that our website will play an increasingly prominent role in our organization.

In 2009 we want to develop the following activities:

1. Expand the quarterly newsletter for members. A special anonymous version of the newsletter is sent to a number of doctors with a variety of specialties in several (academic) hospitals. All newsletters are translated into English.
Especially the personal experiences of the patients really appeal to the other members.
2. Maintain and expand contacts and collaborate with patients and other patient organizations in the Netherlands and abroad.
3. Set-up a CMTC organisation in the USA.

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4. Maintain and expand contacts with medical specialists such as dermatologists in the Netherlands and abroad.
5. Research into CMTC, especially genetic research on DNA of patients. For some time, we have been participating in genetic research. This research is a collaborative effort between the academic hospitals of Maastricht, Rotterdam and Amsterdam. Aside from this several genetic centres in Germany and England are included in the research. We 'provide' the people that are willing to participate in this research and communicate the information surrounding this research to both members and doctors..
6. Regular internet searches for information surrounding the disorder and translating it into a language understood by people who do not have medical training.
7. Organising a meeting for personal contacts and exchange of information.
8. Organising day out in an informal environment where the families and the patients can enjoy a day together. For example, it could be a day at the Efteling amusement park in the Netherlands.
This will provide an opportunity to meet others and to share experiences and knowledge.
9. Building and expanding the website which would include a list with questions and answers that we've collected over the years. And would also include a data bank concerning all persons known to us, while of course maintaining medical confidentiality.
10. Attending (international) congresses on rare diseases, especially Eurordis, NORD and Genetic Alliance congresses.
11. Fundraising to broaden our financial base and spread risk. Being dependent on one sole sponsor is a risk to the continuity of our organization.
12. Recruiting new members and sponsors and obtaining subsidies to promote the reputation of the organization. This is done to be able to support more people and collect more information about this affliction..
13. Expanding the use of internet. Using internet generates considerable savings in time and costs in an environment with a structural shortage of funds. By making information such as patient leaflets available electronically, the organization has a lighter workload because people can access information without any help. Another important (financial) advantage of making information available electronically is that making changes to the content is practically without any cost.
The president is also 'webmaster' of our website so any changes and expansions are carried very quickly.
Since 2007 kunnen leden en donateurs zich aanmelden via de website en veilig betalingen verrichten
14. Maintaining a good firewall. The most important risks are viruses and computer hacking when members of the board are using internet connections. Few people fully realize the dangers associated with internet use. Since our computers contain all (medical) data of our members, we take this issue very seriously.

9. AVAILABLE PEOPLE AND FUNDS

A small organization has only few people available. However, the amount of work is disproportionate to the size of this organization, which means that a lot of work needs to be done. The board consisted of three people during 2008. The use of extra volunteers has made a lot of translation work and other activities possible.

Our financial means are limited, and in financial terms we are dependent on subsidies. Through fundraising we hope to improve our financial position, so that we can develop more international activities, with the general goal to be able to help more CMTC patients.