



ANNUAL REPORT -- GENERAL 2004

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 2004. The goal of this document is primarily to provide insight into the activities carried out in 2004. 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 Kamer van Koophandel te Amersfoort. 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

The number of members on December 31, 2004 was 64, and made up of these nationalities: Belgium (2), Denmark (1), Germany (3), England (1), Netherlands (42), Norway (2), Spain (1), USA (12), Canada (1) and Australia (1).

In part due to our strict policy concerning payment of dues, several members (4) have been disbarred from the organization. Therefore it seems like there was no growth in the number of members. These members did not respond to repeated requests to pay the dues, and often had become impossible to locate.

4. BOARD

The board consists of the following people per December 31, 2004:

Dhr. A.F.R. van der Heijden	President
Mevr. J. Pronk-Visser	Secretary
Dhr. E.J. Rijnhart	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 such as Prof. Dr. P. Steijlen and Dr. Rieu.

5. VOLUNTEERS

The organization, including the board, is run almost exclusively by volunteers. Aside from the board, several volunteers are engaged in activities such as translation and fundraising. Apart from the board, 7 volunteers were active on December 31, 2004.

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, several clinical geneticists and a general practitioner. At this moment we are in contact with 27 doctors and professors in 4 countries. Various academic hospitals 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. They in turn use articles that we have translated into English.
- 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.

We have cancelled our membership in the both the Skin Federation and the NP/CF. Considering the costs involved with membership in especially the Skin Federation and the benefits associated with this, we were forced to cancel our membership.

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 2004:

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. At this meeting 31 people attended. Dr. Van Steensel gave an excellent presentation. During the afternoon session Dr. van der Schaar made an interactive presentation. One of our Norwegian members was present as well.

In conclusion this meeting can be considered to have been very successful.

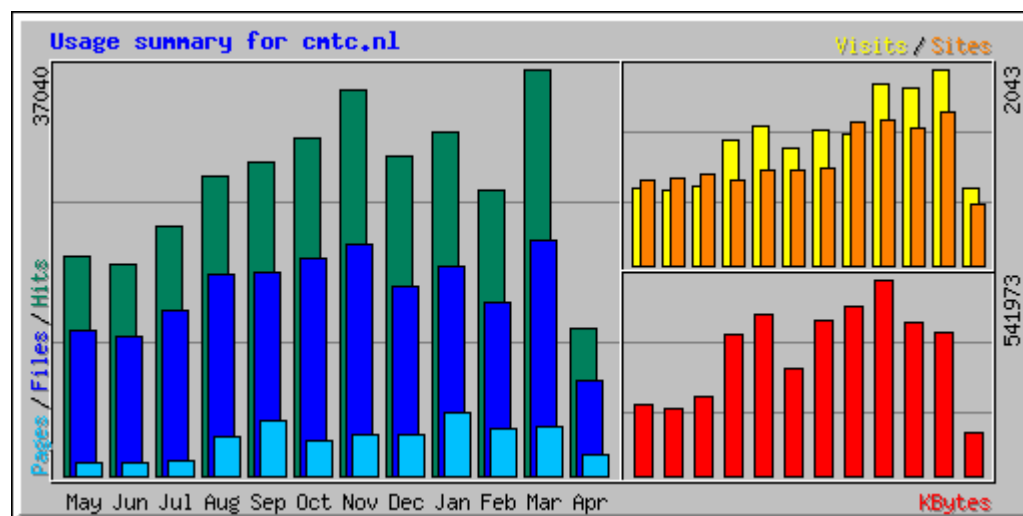
2. Newsletter. This appears to meet the need for information in large part. Especially parents whose children have this rare affliction are in need of a lot of information. Many parents appear to live in a continuous state of uncertainty. The newsletter is also distributed among doctors especially in 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.
4. Fairs and congresses. In collaboration with the Skin Federation we took part in fairs, such as the 50+ Fair. This year we participated as an organization in the NORD congress in the USA. This has yielded several interesting contacts which we expect to yield results in time.
5. Skin Week and Skin Info Line. Our membership in the Skin Federation included automatic participation in the National Skin Week. This is also true for the Skin Info Line.
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.
7. Poll. We have polled our Dutch members. The results have been processed and communicated to the members. Criticism, if any, is discussed at the meeting of the board, and subsequently actions are determined.

8. Arranging all activities surrounding the examination of two CMTC patients who came to the Netherlands from the USA. One of the members was even flown here for free with his mother. 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.
9. The use of MSN 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 in the USA.
10. The internet site has been expanded during the year. 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).

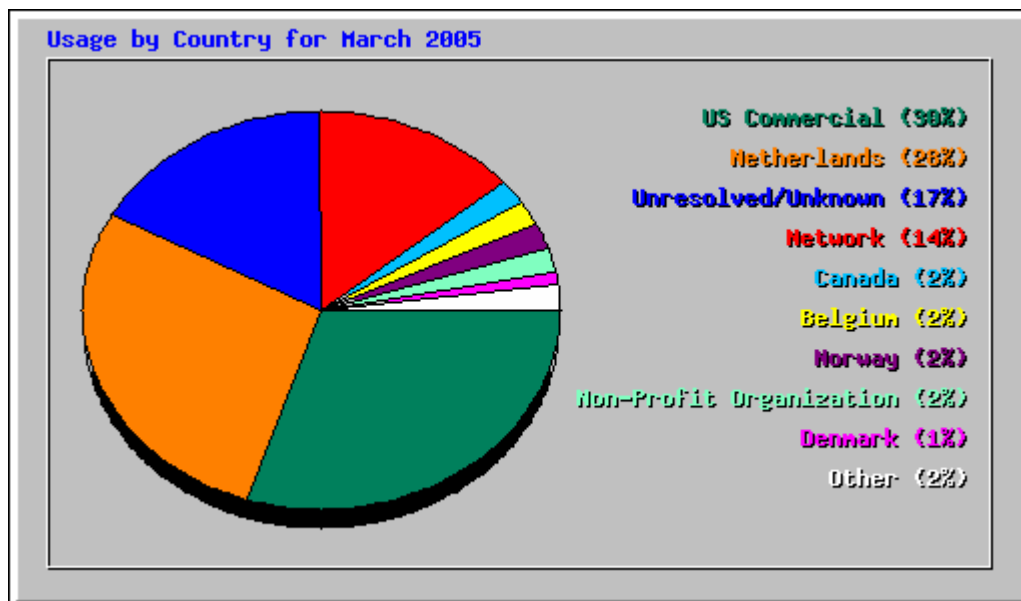
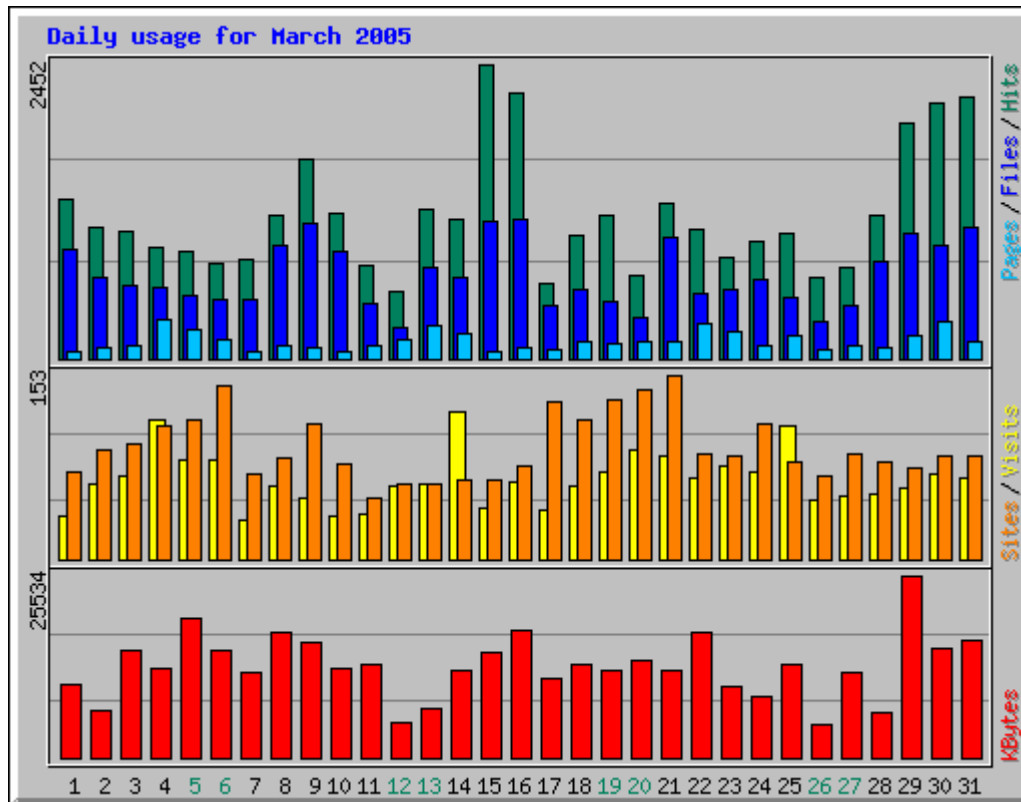
Using statistics it is simple to find out where visitors come from and what pages they looked at. Members of our organization can visit pages and access the following information:

- Newsletters.
- Medical information of other patients (of course only from members who have given permission to do so).
- Annual reports.
- Meeting notes.
- Cases.
- 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 censored newsletters.



Annual report -- General 2004
 'Association for people with the Van Lohuizen syndrome' (CMTC)



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.

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 2005 we want to develop the following activities:

1. Publish a 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.
2. Maintain and expand contacts and collaborate with patients and other patient organizations in the Netherlands and abroad.
3. Maintain and expand contacts with medical specialists such as dermatologists in the Netherlands and abroad.
4. Research into CMTC, especially genetic research on DNA of patients. In February 2005 genetic research started that we participate in. 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 patients.
5. Regular internet searches for information surrounding the disorder and translating it into a language understood by people who do not have medical training.
6. Organising a meeting for personal contacts and exchange of information.
7. Build and maintain a data bank concerning all persons known to us, while of course maintaining medical confidentiality.

8. Translating medical articles between Dutch and English in a language understandable to those with no medical background.
9. Attending (international) congresses on rare diseases, especially Eurordis, NORD and Genetic Alliance congresses.
10. Fundraising to broaden our financial base and spread risk. Being dependent on one sole sponsor is a risk to the continuity of our organization.
11. 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.
12. Doing a poll among the foreign members.
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.
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 2004. 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.