

# **ANNUAL REVIEW 1999**

**THE ASSOCIATION FOR PEOPLE WITH VAN LOHUIZEN'S SYNDROME**

**CMTC**

*Document ref* : CMTC/JAAR/ALG1999

*Status* : Final

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*Date* : 8 Jan 2000

*Approved by* : Management Team

*Version* : 1.0

## 1. THE PURPOSE OF THIS DOCUMENT

This document is the Annual Review for 1999 of the patient organisation *The Association for People with Van Lohuizen's Syndrome*. This document provides details of the activities carried out during the year. The financial review is provided in another document.

## 2. INTRODUCTION

The patient association was formally established on 22 Jan 1997, under the legal guidance of the notary Mr. van Helden from Amsterdam, The Netherlands. The association was then formally registered in the Dutch Chamber of Commerce (Kamer van Koophandel) in Amersfoort, The Netherlands. The purpose of the association, as defined in the statutes, is.

*"Promoting the well-being of people who suffer from Van Lohuizen's Syndrome (CMTC), in particular members of the organisation, and the stimulation and development of activities that improve this well-being. The stimulation of (scientific) research regarding CMTC, the causes and the treatment of CTMC, and everything which is related (in the widest possible interpretation) to this."*

## 3. MEMBERSHIP

On 31 Dec 1999 there were 26 members of the Association. Currently the membership comes from four countries (The Netherlands, Belgium, Germany and the USA).

## 4. MANAGEMENT TEAM

The Management Team on 31 Dec 1999 consisted of:

Mr. A.F.R. van der Heijden	Chairman
Mrs. J.D.M. de Bruijn	Administration
Mrs. J.C. van der Heijden	Treasurer

Our Medical Advisor is Mr. Dr. R.F.H.J. Hulsmans, dermatologist.

## 5. EXTERNAL ORGANISATIONS

We work together with a range of external organisations:

- Doctors and medical specialists. The newsletter is our main contact with dermatologists, a children's surgeon, a children's neurologist, a clinical geneticist and a general practitioner (doctor). Our contacts have developed at national and international level.
- The Skin Federation (Huidfederatie). This is a confederation of organisations for people with skin problems, currently made up of 19 patient associations. These associations work with (amongst others) the National Skin Fund (het Nationaal Huidfonds) on areas such as scientific research, providing information and generating funds. The most important purpose of the Skin Federation can be summarised in one word: co-operation. This considerably increases the influence of all the allied associations, in particular the smaller ones.

- The Dutch Patients/Consumers Federation (Nederlandse Patiënten/Consumenten Federatie: NP/CF). This is a very large organisation, which represents the interests of patients and consumers. For example they organise various courses.
- The Association for Parents and Patients Organisations (Vereniging Samenwerkende Ouder- en Patiëntenorganisaties: VSOP). This association concentrates on hereditary and birth defects.

## 6. ACTIVITIES

Just as last year, much time has been spent on initiatives to allow us to work more efficiently and effectively in the future. From the feedback we have had from doctors who have read the newsletter and received our Patient Information Folders, this appears to have been successful. The newsletter and the Patient Information Folder are published in colour, with the latest versions including colour photos to help in recognising the deformities. A picture is of course worth a thousand words.

Here is a summary of the activities carried out during 1999:

1. Members meetings. These are an excellent way for parents of children with an affliction to share experiences and to establish and develop contacts with each other. During our last meeting a doctor from the Academic Hospital Rotterdam gave a presentation about the progress of a number of CMTC patients that she has been treating over a number of years. Paper copies of the presentation were handed out during the session, and they have been made available on the Internet website in the members-only and doctors-only sections of our Internet website.
2. Newsletters. Parents of children with this rare syndrome continue to experience great uncertainty. The newsletters provide them much needed information. The newsletters are also distributed to doctors and medical specialists (of various medical disciplines), particularly in academic hospitals. The intention is to translate all newsletters into English so these can also be made available to international members and doctors. Currently 10 of the 16 newsletters have been translated.
3. Patient Information Folders. These folders provide a short summary of what CMTC involves, and the activities that the association carries out. The patient service centres of various hospitals have asked for copies of the folder. Further the folder is made available to anyone who is interested during, for example, the congresses held by the Skin Federation. Towards the end of 1999 a mailshot was sent to 114 hospitals in The Netherlands, including two copies of folder.
4. Exhibitions and conferences. Via the Skin Federation we are indirectly represented at exhibitions such as the 50+ exhibition. We did not take part in any conferences this year.
5. Skin-Week en Skin-Info-Line. Because we are part of the Skin Federation, we are automatically part of the National Skin-Week and also the telephone service the Skin-Info-Line.

6. Setting up an Internet website which went live in early 1999. This website was designed and built totally by us. Now members can access newsletters, look at medical information including information from other patients (of course only those who have given permission) and read medical articles. Non members can obtain general information about the syndrome, can join on-line, can ask questions and can go to related websites. During the year our site was consulted approx. 50,000 times, particularly towards the end of the year which saw a significant growth in use. Finally we registered 'CMTC' as a keyword on various Internet search engines so that when people do a search on 'CMTC' they will almost always find our site.

## **7. LOOKING AHEAD**

In practice it seems to take at least a year before a patient association achieves a level of awareness. For example directories of organisations are typically updated yearly, so it takes this time before a new organisation even appears in the listings. During the year we have been contacted by a number of patient service centres of hospitals requesting a folder. We expect that such requests will increase significantly, for example as a result of the mailshots we have carried out. During 2000 we will also be featured on the CDROM of the VSOP which is distributed to consultancy agencies.

While the number of patients will of course grow, given the rarity of the syndrome this will not be spectacular growth. Particularly during Oct 1999 we saw a relatively large growth in the number of members.

International contacts will also grow, along with a growth in international members. We will build on our co-operation with a Canadian doctor, who carried out an autopsy of a child that died as a result of the fatal complications that can arise from CMTC.

In 2000 we intend to carry out the following activities:

1. Publishing a quarterly newsletter for members. A special version, edited to ensure anonymity of cases, will be sent to doctors and specialists in a number of (academic) disciplines. All newsletters will be translated as soon as possible into English.
2. Maintaining and expanding contact and co-operation with both patients and other patient associations, both in The Netherlands and internationally.
3. Recruiting members from all over the world.
4. Establishing and maintaining contacts with medical specialists such as dermatologists, both nationally and internationally.
5. Finding out what the possibilities are for promoting research into the cause of CMTC. We have already made a start with a molecular biologist who is willing to put some effort into this. We also hope to use the VSOP to generate contacts for possible research.
6. Regular searches of the Internet for information on the syndrome and translating relevant articles from medical jargon into clear understandable language.
7. Organising meetings for personal contact and exchanging experiences.
8. Building up and developing a database of our contacts. Of course we respect and protect the confidentiality of medical information.
9. Translating medical articles into clear understandable language, both Dutch and English.
10. Bringing in donors and obtaining subsidies to increase the awareness of the association,

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with the ultimate goal of providing support to more people and spreading more information about the syndrome.

11. Expanding our use of Internet. This can achieve considerable savings in time and cost, which are particularly scarce in our association. By making information such as Patient Information Folders, available on-line, people can instantly access the information they require, and the overhead on the organisers is considerably reduced. Another significant (financial) advantage is that information available electronically can be updated with minimal costs.
12. Improving and automating the administration, in particular the financial and member administration.
13. Improving the security of our computer system from the dangers of Internet. Possible threats include computer viruses and hacking into our systems. While few people realise the risks that are involved with Internet, we see this as a major issue given that all our (medical) information is held on the computer.

## **8. AVAILABLE PEOPLE AND RESOURCES**

We are a small association and so there are a limited number of people available to help. However the work required is proportionally much larger meaning a lot of work has to be put off. The Management Team, currently made up of three people, carries out all the tasks and activities of the association. Only the translation work is carried out by other people. The other resources, particularly financial, are very limited, so we rely greatly on organisations providing subsidies.