



ANNUAL GENERAL REPORT 2001

THE VAN LOHUIZEN SYNDROME (CMTc) ASSOCIATION

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1. DOCUMENT PURPOSE

This document contains the Annual General Report for our patients' organisation, The Van Lohuizen Syndrome (CMTC) Association, for the year 2001. The purpose of this document is primarily to give an overview of The Association's activities during 2001. The Annual Financial Report for 2001 is contained in a separate document.

2. INTRODUCTION

The Association was formally established on the 22nd of January 1997 by van Helden Solicitors, Amsterdam and was subsequently registered at the Amersfoort Chamber of Commerce. The aims of The Association, as formally laid down in The Association's statute, are described in the following text.

"To promote the welfare of people suffering from Van Lohuizen Syndrome (CMTC), especially those of the members of The Association, and to promote and develop activities to improve their welfare. The promotion of (scientific) research in the area of CMTC, the causes and treatment thereof and everything connected to this in the widest possible sense."

3. MEMBERSHIP

The number of members on 31st December 2001 was 49, with the following distribution Nederland (33), Belgium (4), Germany (2), United States of America (7), Denmark (1), Norway (1) and England (1).

4. DIRECTORS

As of 31st December 2000, the officials of The Association were as follows:

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

The Medical Advisor to The Association was Dermatologist Dr. R.F.H.J. Hulsmans. He has been succeeded by Dr. A.P. Oranje, Dr. M. van Steensel, Dr. W.W. van der Schaar and scientific researcher Dr. M. ten Hoor.

5. EXTERNAL ORGANISATIONS

We are working together with a number of external organisations:

- Medical Experts. Through the newsletter of The Association we are in contact with a number of Dermatologists (including a professor), a Paediatric Surgeon, a Paediatric Neurologist, a number of Clinical Geneticists (including two professors) and a General Practitioner. Currently the contacts total 23 doctors and professors in 4 countries. From the Teaching Hospital in Nijmegen CMTC patients are referred directly to us.

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- The Skin Federation. (*Huidfederatie*) This is an umbrella organisation for people with skin conditions that is, at present, comprised of 17 individual patient organisations. This organisation works together with, among others, The National Skin Fund (*Nationaal Huidfonds*) in areas such as scientific research, information provision and fund raising. The most important aim of the Skin Federation can simply be summarised in one single word – *Cooperation*. This significantly increases the influence of all the participating organisations and especially so for the smaller organisations.
- Netherlands Patient / Consumer Federation (NP/CF) (*Nederlandse Patiënten / Consumenten Federatie*). This is a large organisation that represents the interests of patients and consumers and which in addition organises a wide variety of educational courses.
- Association for Parent and Patient Organisation Cooperation (*Vereniging Samenwerkende Ouder- en Patiëntenorganisaties - VSOP*). This is an organisation that is concerned with genetic and or inherited conditions.
- Teaching Hospitals Client Council (*ClëntenRaad Academische Ziekenhuizen - CRAZ*).
- Genetic Alliance (*Genetic Alliance*). This is an U.S.A. based organisation that has members worldwide. As the name suggests they are a worldwide umbrella for all sorts of organisations concerned with genetics.
- National Organisation for Rare Disorder (NORD). This is a U.S.A. based organization that focuses on rare conditions.

6. ACTIVITIES

The basis for the organisation has now been laid down and various templates etc have been developed further so that we can work efficiently and effectively. This would appear to be working well judging by the reactions of a number of people such as the doctors who have received the newsletter and patient information folder. The newsletter and information folder were both printed in colour and the latest edition contains colour photos which allows for a better recognition of the condition - as they say, '*a picture says a thousand words*'.

Below is a summary of the activities undertaken during 2001:

1. Membership Meeting. This seems to be an excellent opportunity to exchange experiences and to make or to improve contacts, especially for parents of children with the condition. During this meeting 34 people were present from The Netherlands, Belgium and Germany. The meeting was held in a hotel conference facility for the first time due to the numbers of people expected. In summary we can say that this meeting was a great success!
2. Newsletter. This would appear to help substantially in the need for information that is especially large for this rare condition. Many parents continue to live in great uncertainty. The newsletter is distributed to a variety of specialist doctors, mainly at teaching hospitals. The newsletters are also translated into English so that they can be made available to members and doctors located outside of The Netherlands. The translation is carried out, on a voluntary basis, by colleagues of the chairman in a number of countries.
3. Patient Information Folder. The folder provides a summary of what the condition involves and what activities we undertake as an organisation. Additionally the folder is made available to those who are interested, for example during exhibition events organised by the Skin Federation

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4. Conferences and Exhibitions. Though the Skin Federation we take part indirectly in a number of exhibitions such as the "50+ *Exhibition*". This year we did not attend any conferences.
5. "*Skin Week*" and the "*Skin Info Line*". The participation of our organisation in the "*National Skin Week*" was arranged automatically through membership of the Skin Federation. This also applied to the "*Skin Info Line*".
6. The new Internet web site was activated on 6th October 2001. Within 24 hours we had already received our first very positive reaction from the U.S.A. by e-mail. The web site is largely developed by a professional graphical designer who has developed many web sites for large commercial organisations.

Among other things the web site contains a photo gallery where various degrees and complications of CMTC are shown. For members of the public and for Association members it is possible to start a discussion, to respond to a question etc. Of course the whole site is presented in Dutch and English.

During a general meeting of the VSOP organisation our web site was referred to as an example by the VSOP Webmaster. Based on statistical information collected since mid January 2002 it is easy to determine for example where site visitors come from and which pages they looked up.

CMTC Members can among other things view and download the following:

- Newsletters.
- Medical details of other patients (of course only from members that have given permission for this)
- Annual reports.
- Minutes.
- Presentations from the General Members Meeting.
- Translated medical articles.

Non-members can, among other things, view and download information concerning the condition, register as members, submit questions and link to other web sites related to our organisation.

7. FUTURE PLANS

In practice, it seems to take several years before a patient organisation is able to gain wide recognition. All sorts of address listings are only updated once per year, which means that it can take at least one year before a given organisation can be found in the source guides. Considering the rarity of the condition we expect a slow growth in the organisation over the coming years.

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International contacts will also increase further as will the number of foreign members. Through Internet technology we would like to strengthen our worldwide network and act as an intermediary between doctors themselves and between doctors and patients.

In 2001 we note that practically all new members have come across us via the Internet. This is one of the reasons that we give so much attention to our web site. Worldwide, currently some 500 million people have access to the Internet. In The Netherlands some 50% of the population has access to the Internet and the numbers are expected to increase.

In 2002 we would like to develop the following activities:

1. Issue a quarterly newsletter for members. A special anonymous edition of the newsletter is sent to doctors in a number of disciplines at various teaching hospitals. All newsletters will be translated from Dutch into English.
2. Maintain contacts and work together with patients and other patient organisations both nationally and internationally
3. Recruit members worldwide.
4. Maintain contacts with medical specialists such as Dermatologists both in The Netherlands and internationally.
5. Investigate the possibilities for research into the causes of CMTC. The first contacts have already been made with a molecular biologist interested in this cause. We also hope to make research contacts via the VSOP organisation. Amongst our number we now count a Scientific Researcher and a Clinical Geneticist in Leiden.
6. On a regular basis, search the Internet for information relevant to the condition and (if necessary) have this translated into easily understandable language for people of a non-medical background.
7. Organise get-together meetings to maintain personal contacts and exchange information.
8. Build a "data-bank" concerning all people known to us. Naturally this would take into account the confidentiality of medical information
9. Translate medical articles to Dutch and English in for medical laymen understandable language.
10. Recruit donators and obtain subsidies in order to obtain more recognition for The Association, with the most important aims of being able to support more people and to collect more information on the condition

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11. Develop further our use of the Internet. This can realise a significant time and cost saving in an environment where there is a fundamental shortage of time and financial means. By making information available in electronic form, the pressure on the organisation will be appreciably reduced, as people will be able to obtain the material themselves without intervention of organisational staff. Another large advantage of making material available in this form is that there is almost no cost to updating the detailed information. The Chairman is active as the Webmaster of the site so changes, extensions etc can quickly be effected.
12. Become more professional particularly in the areas of financial and membership administration. We do wish however to keep these areas under our own control. Due to the limited number of members any outsourcing of these activities would not be useful.
13. Maintain security against risks from Internet usage. The most important of these are virus and hacker attacks on the computers used by the directors when connected to the Internet. In view of the fact that our computer contain (medical) details of our members we consider this an extremely important issue.

8. AVAILABLE PEOPLE AND RESOURCES

The number of people available is fairly limited in any small association such as ours. However, the amount of work to be done is not proportional to the size of the association, which means that a significant effort is required.

The organisation directors was three strong during the year 2001 but during the directors meeting on 22nd December 2001 it was decided to enlarge this group by one. Only translation work is carried out outside this group.

Resources, especially financial resources, are extremely limited so we are largely dependent on subsidies for financial support.