



ANNUAL REPORT 2002

ASSOCIATION FOR VAN LOHUIZEN SYNDROME

CMTc

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1. DOCUMENT PURPOSE

This document contains the Annual General Report for the patients' organisation, 'Association for Van Lohuizen Syndrome (CMTC)', for the year 2002. The primary purpose of this document is to give an overview of The Association's activities during 2002. The Financial Report for 2002 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 2002 was (57) with the following distribution: Netherlands (38), Belgium (4), Germany (3), U.S.A. (8), Denmark (1), Norway (1), U.K. (1) and Spain (1).

4. THE BOARD

As of 31st December 2002, the officials of The Association were as follows:

Dhr. A.F.R. van der Heijden	Chairman
Mevr. E.M. de Roode	Secretary
Mevr. J.C. van der Heijden	Treasurer
Mevr. J.D.M. de Bruijn	Member

Medical advisors Dr. A.P. Oranje, Dr. M. van Steensel, Dr. W.W. van der Schaar and scientific researcher Dr. M. ten Hoor were actively involved with The Association during the year 2002.

5. EXTERNAL ORGANISATIONS

We are working together with a number of external organisations:

- 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.

- 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 (*CliëntenRaad Academische Ziekenhuizen - CRAZ*).
- 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.
- 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 27 doctors and professors in 4 countries. From the Teaching Hospital in Nijmegen CMTC patients are referred directly to us.
- Child and Hospital (*Kind en Ziekenhuis*). Because the majority of our members are young and especially in the early phase of their life will regularly visit hospitals, cooperation with and organisation such as this is essential. We often reproduce articles from their house magazine, with permission of course, in our newsletter. In turn they make use of articles that we have translated into English.
- 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.
- Klippel-Trenaunay en Sturge-Weber. These conditions have certain similarities to CMTC.

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'.

The following is a summary of the activities undertaken during 2002:

1. Membership Meeting. This does appear 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 37 people were present from The Netherlands, Belgium and Germany. Presentations to the meeting were made by various doctors and a medical psychologist led an interactive session. In summary we can conclude that this meeting was a great success!

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2. Newsletter. This does appear to help substantially in the need for information that is especially important for people with 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. These translations are carried out on a voluntary basis. Colleagues of the chairman in a number of countries are involved.
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
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. Our internet website has been extended further during the year. Judging by the reactions from interest groups the site appears to have been well received. We regularly receive compliments about the site and the graphical designer has also received a commission from the (*Huidfederatie*) Skin Federation for the design of their own new website. Among other things the website 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. Based on collected statistical details we are able to determine information such as where visitors come from and which pages they have referred to. 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.

External organisations, such as (*Kind en Ziekenhuis*) Child and Hospital are able to obtain [non-confidential version] CMTC newsletters.

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.

We expect that international contacts will also increase further as will the number of our foreign members. Through Internet technology we would like to strengthen our worldwide network and act as an intermediary, both doctor-to-doctor and between doctors and patients.

In the last two years we have seen that practically all our 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. In view of the expected growth in the numbers of people worldwide that have access to the internet we expect that the site will assume an increasingly prominent role in our organisation.

In 2003 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. Maintain contacts with medical specialists such as Dermatologists both in The Netherlands and internationally.
4. Research using tissue from CMTC patients. Contact has already been established with clinical geneticists and a molecular biologist.
5. 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.
6. Organise get-together meetings to maintain personal contacts and exchange information.
7. Build a "data-bank" concerning all people known to us. Naturally this would take into account the confidentiality of medical information
8. Translate medical articles into both Dutch and English and at the same time into a, for laymen, readily understandable language.
9. 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.
10. 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 and extensions etc can quickly be implemented.

11. 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.
12. 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 computers do contain (medical) details of our members we consider this to be an extremely important issue.

8. AVAILABILITY OF PEOPLE AND RESOURCES

The number of people available is fairly limited in any small association. However, the amount of work to be done is not proportional to the size of the team, which means that a significant effort is required. The organisation was four strong during the year 2002. Only translation work was carried out outside of this group. Resources, especially financial resources, are extremely limited so we are largely dependent on subsidies for financial support.