Annual General Report 1998

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 1998. The purpose of this document is primarily to give an overview of The Association's activities during 1998. The Annual Financial Report for 1998 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.MEMBERS

The membership, as of 31st December 1998, totalled 17. At present we are not aware of the overall number of people with this condition in The Netherlands. During the year there have been various contacts with families from Canada and the USA. Based on these contacts it still appears that CMTC is a fairly rare condition.

4.DIRECTORS

As of 31st December 1998, 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

Medical Advisor to The Association is Dermatologist, Dr. R.F.H.J. Hulsmans.

5. EXTERNAL ORGANISATIONS

We are working together with a number of external organisations:

- <u>Medical Experts</u>. Through the newsletter of The Association we are in contact with a number of Dermatologists, a Paediatric Surgeon, a Paediatric Neurologist, a Clinical Geneticist and a General Practitioner.

- <u>The Skin Federation</u>. 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 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). This is a large organisation that represents the interests of patients and consumers and which in addition, for example, organises a wide variety of educational courses.

6. ACTIVITIES

As during the previous year, a lot of time has been spent setting up various things with the aim of being able to work efficiently and effectively in the future. 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 1998:

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 the last Membership Meeting the parents of an aspiring new member discovered that their child did not suffer from CMTC. Working together with out Medical Advisor we are currently determining which condition she is, in fact, affected by.

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 doctors with a variety of specialisms, mainly at teaching hospitals. Pretty well all newsletters that have appeared to-date have been translated into English so that they can be made available to members and doctors located outside of The Netherlands.

3. Patient Information Folder. The folder provides a summary of what the condition involves and what activities we undertake as an organisation. A number of hospital patient service departments have requested the folder. Additionally the folder is made available to those who are interested, for example during exhibition events organised by the Skin Federation.

4. 'Information & Membership' Project. Initially a lot of work needed to be done in the areas related to the provision of information for both parents or carers and doctors. Considering that the condition is inherited at birth and appears to be very rare, it is often not recognised with the consequence that parents or carers are left in a state of uncertainty. This project is now completed and a report will be finalised in January 1999. The project duration was longer than expected due to the fact that that the activities were carried out in peoples' free time and often together with other Association activities.

5. Conferences and Exhibitions. Though the Skin Federation we took part indirectly in a number of exhibitions such as the "*50+ Exhibition*". This year we did not attend any conferences.

6. "*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*".

7. The CMTC Web Site. The Internet site will be active at the start of 1999 and has been designed and built by us. Members of the organisation can, amongst other things, download newsletters, look at and download medical information concerning other patients (of course from members that have given their permission for this), and look at and download medical articles. Non-members can, amongst other things, look at and download general information on the condition, request membership, submit questions and link to web sites related to our organisation.

7. FUTURE PLANS

In practice, it seems to take at least a year before a patient organisation is able to gain some 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. During the year we have been approached by various hospital patient service departments requesting a general information folder. We expect the number of these requests to rise significantly during 1999.

The number of patients will undoubtedly also increase but this will not be a spectacular rise given the rare nature of the condition.

International contacts have also increased as have the number of members from abroad. We have already translated our patient folder and most of our newsletters into English.

In 1999 we would like to continue and 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.

2. Maintain contacts and work together with patients and other patient organisations both nationally and internationally.

3. Introduce new members to The Association.

4. Maintain contacts with medical specialists such as Dermatologists both in The Netherlands and internationally.

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” on people known to us and in several languages. Naturally this would take into account the confidentiality of medical information.

8. 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.

9. 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. Early in 1999 our web site will be on-line in the Dutch and English languages.

8. AVAILABLE 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, currently three strong, actually carry out all the tasks and activities themselves with the exception of one activity that is carried out outside of this group – an old colleague from England translates the newsletters into English. During 1999 we expect to receive more support from a new member for the translation of medical articles into language that is understandable for people of a non-medical background.

Resources, especially financial resources, are extremely limited. Our current membership of 17 generates just f 425 in incomes.