Annual General Report 1997

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 1997. The purpose of this document is primarily to give an overview of The Association's activities during 1997. The Annual Financial Report for 1997 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 1997, totalled 12. 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 two families from Canada and two from the USA. Based on these contacts it still appears that CMTC is a fairly rare condition.

4. DIRECTORS

As of 31st December 1997, 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:

- Medical Experts. 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.

- The Skin Federation. This is an umbrella organisation for people with skin conditions that is, at present, comprised of 16 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 and a conference for patients.

6. ACTIVITIES

Given that the Association has just been set up, 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 are both recently being printed in colour

Below is a summary of the most important preparation activities:

1. Design logo.
2. Construct letter template.
3. Construct patient information folder.
4. Establish contacts with dermatologists and (teaching) hospitals.

In addition we have carried out the following activities during the course of the year:

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.

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.

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.

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. The intention is to start the project early in 1988. In the meantime some related activities have already been completed. At the same time the project aims to increase membership numbers. In the process more information should become available, hopefully to the benefit of others.

5. Conferences and Exhibitions. The Chairman attended the patients conference organised on 28th October by the NP/CF in Zwolle. Several new contacts were established. Thanks to our membership of the Skin Federation we were indirectly represented at exhibitions, for example “The 50+ Exhibition” and at a conference for (para)medical staff.

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. Policy Plan. Before starting something it is essential at some point to set down on paper *what* actually is to be achieved. This is laid down in the Policy Plan that will be completed and approved during a General Meeting in January 1998.

8. Personal Details Registration Law. Considering that we hold confidential (medical) information we intend to manage these details correctly. To this end we have registered with the appropriate registration body.

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 1998 and especially as a result of the new project.

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 will also increase and we hope that the first members from abroad will register with us. The consequence of this is that the information that we make available to our members at the moment such as the newsletter and the patient information folder will need to be translated, at least into the English language.

In 1998 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.

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

3. Recruit new members.

4. Maintain contacts with medical specialists such as dermatologists.

5. Publish photos of and text on the condition via the worldwide Internet network amongst other channels.

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

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. By means of the project “Information and Membership” we would like to combine a number of activities. The primary aim of the project is the provision of information to patients, parents or carers of patients, doctors and other interested parties. At the same time the project hopes to increase membership of The Association. The other aspect of the project is member recruitment that in fact aims to inform people, to collect their experiences and medical details and to make there available for other members to use. These details will of course be handled in strict confidence and only made available to others when permission is given by or on behalf of the patient. Considering that the condition is inherited it is important to inform Maternity Clinics and Paediatricians.

11. Develop further our use of computers and 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.

8. AVAILABLE PEOPLE & 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 especially in the start-up phase of an organisation. The 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 ex-work colleague from England translates the newsletters into English.

Resources, especially financial resources, are extremely limited. Our current membership of 12 generates just f 300 in income. There are various possibilities for requesting subsidies and in 1998 in particular it will be possible to apply for a *structural subsidy* from the Patients Fund.