ANNUAL REPORT -- GENERAL 2003

ASSOCIATION FOR PEOPLE WITH THE 'VAN LOHUIZEN SYNDROME'

CMTC

Document code : CMTC/JAAR/ALG2003

Status : Approved

Author : A.F.R. van der Heijden

Date : May 25, 2004

Approved : Board

Edition : 1.0

1. DOCUMENT GOAL

This document contains the annual report of the patient association ‘Association for people with the 'Van Lohuizen syndrome” for the year 2004. The goal of this document is primarily to provide insight into the activities carried out in 2004. The financial annual report is contained in another document.

2. INTRODUCTION

The patient association is formally founded on January 22, 1997, by the notary public van Helden in Amsterdam, and subsequently entered into the registry at the Kamer van Koophandel te Amersfoort. The goal of the organization, which is documented in the statutes, is contained in the text below.

“Improving the well-being of people suffering from the ‘Van Lohuizen syndrome’ (CMTC), specifically for her own members, and fostering and developing activities that may improve this well-being. Fostering (scientific) research on CMTC, its causes and treatment, and everything related to this in the widest sense of the term.”

3. MEMBERS

The number of members on December 31, 2003 was 64 and made up of these nationalities: Belgium (4), Denmark (1), Germany (3), England (2), Netherlands (41), Norway (1), Spain (1), USA (9), Canada (1) en Australia (1).

4. BOARD

The board consists of the following people per December 31, 2003:

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

Dr. A.P. Oranje, Dr. M. van Steensel and Dr. W.W. van der Schaar are our active medical advisors.

5. EXTERNAL ORGANIZATIONS

We collaborate with several external organizations:

- Skin Federation. This is a general organization for people with skin afflictions. This organization collaborates among others with the National Skin Fund, for instance in the area of scientific research, education and fund raising. The most important goal of the Skin Federation is simply: collaboration. In this manner the influence of all associations is extended considerably, especially for small associations.

- Organization for Collaborating Parent and Patient Organizations (VSOP). This is an organization that is primarily concerned with hereditary or congenital conditions.

- Client Board for Academic Hospitals (CRAZ).

- Dutch Patiënt/Consumer Federation (NP/CF). This is a very large organization that protects the interests of both patients and consumers and also organizes courses for instance

- Doctors. Primarily through the newsletter we are in contact with dermatologists (one of them a professor), a paediatric surgeon, a paediatric neurologist, several clinical geneticists (two of them professors) and a general practitioner. At this moment we are in contact with 27 doctors and professors in 4 countries. Especially the Academic Hospital in Nijmegen refers patients directly to us.

  The Dutch Belgian Association for Paediatric Dermatology has approached us for collaboration. We consider this recognition of our association and reacted positively to their offer.

- Child and Hospital. In part because the majority of our members is young, and will visit hospitals primarily during their early years, collaboration with this organization is essential. We regularly publish articles from their newsletter in ours, always with their permission of course. They in turn use articles that we have translated into English.

- Genetic Alliance. This is an originally US organization that has members worldwide. As the name indicates, this is a worldwide alliance for all kinds of organizations that are concerned with genetics.

- National Organisation for Rare Disorders (NORD). This is an originally US organization concerned with rare disorders.

- Klippel-Trenaunay and Sturge-Weber. These disorders have certain similarities with CMTC.

- Vascular Birthmarks Foundation. This American organization is active worldwide, just like we are.

6. ACTIVITIES

The organization´s foundation has been laid. In addition several ´templates´ have been developed in order to function efficiently and effectively. This appears to have worked well, considering the reactions of various people such as doctors who have received the patient leaflet. Both the newsletter and the patient leaflet us published in color, and the newest version even contains color pictures, so that the ailment is more recognizable. After all, a picture is worth more than a thousand words.
Below is a list of activities carried out in 2003:

1. Annual meeting. Especially for parents whose children have this affliction this presents a very good opportunity to exchange experiences and to make and strengthen contacts with one another. At this meeting 34 people attended. Dr. Oranje gave an excellent presentation. The afternoon session was filled in interactively by the president. In addition two doctors decided to start research on CMTC, which we consider to be a great achievement!
   In conclusion this meeting can be considered to have been very successful.

2. Newsletter. This appears to meet the need for information in large part. Especially parents whose children have this rare affliction are in need of a lot of information. Many parents appear to live in a continuous state of uncertainty. The newsletter is also distributed among doctors especially in academic hospitals that have various specialties. The newsletters are also translated into English so that they can be made available to foreign members and doctors. The translation work is carried out primarily by the president’s colleagues in various countries, and they do this work for free.

3. Patient information leaflet. This leaflet provides a summary description of the affliction and explains what activities the organization undertakes. In addition this leaflet is made available to anyone who shows interest for instance during conferences that are organized by the Skin Federation.

4. Fairs and congresses. In collaboration with the Skin Federation we took part in fairs, such as the 50+ Fair. This year we did not participate directly in any congresses.

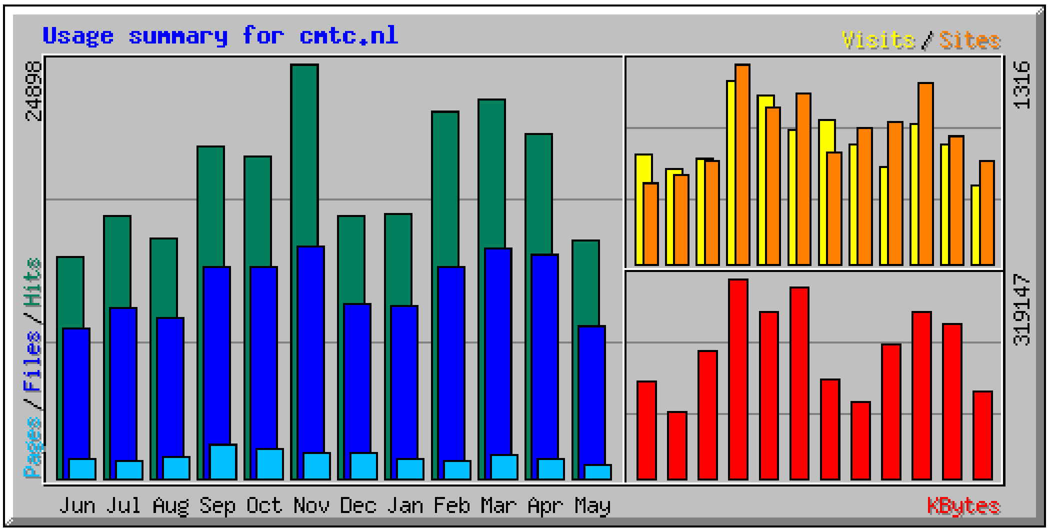
5. Skin Week and Skin Info Line. Our membership in the Skin Federation included automatic participation in the National Skin Week. This is also true for the Skin Info Line.

6. The internet site has been expanded during the course of the year. Considering the reactions we have received, we can conclude that the website is well received among our target audience. We frequently receive compliments for our website (both nationally and internationally). The website includes a photo gallery that shows the various gradations and complications of CMTC. Also there is space to start a discussion, react to a question, etc. both publicly and in a members-only area. Of course the entire site is bilingual (Dutch and English).
   Using statistics it is simple to find out where visitors come from and what pages they looked at. Members of our organization can visit pages and access the following information:

   - Newsletters.
   - Medical information of other patients (of course only from members who have given permission to do so).
   - Annual reports.
   - Meeting notes.
   - Presentations given during our general annual meeting.

- Translated medical articles.

Non-members can look at and download general information on CMTC, they can become a members, ask questions and link to websites that have a relationship with our organization. Third parties such as Child and Hospital can access the censured newsletters.



Summary by Month										
Month	Daily Avg				Monthly Totals					
	Hits	Files	Pages	Visits	Sites	KBytes	Visits	Pages	Files	Hits
May 2004	622	396	32	22	679	138147	523	745	9121	14326
Apr 2004	687	447	40	26	836	246718	784	1201	13430	20614
Mar 2004	732	446	44	29	1182	264466	920	1383	13833	22714
Feb 2004	761	438	35	22	938	213319	643	1043	12723	22074
Jan 2004	511	333	38	25	890	121624	789	1204	10349	15845
Dec 2003	510	337	47	30	734	157586	945	1479	10454	15815
Nov 2003	829	463	52	29	1118	304153	877	1571	13911	24898
Oct 2003	623	411	56	35	1032	264078	1107	1764	12743	19336
Sep 2003	664	424	66	39	1316	319147	1196	1988	12723	19943
Aug 2003	465	310	42	22	673	202931	694	1302	9626	14428
Jul 2003	506	328	31	19	578	106470	618	984	10198	15707
Jun 2003	443	298	38	23	527	155727	713	1147	8963	13313
Totals						**2494366**	**9809**	**15811**	**138074**	**219013**

7. A LOOK AHEAD

Experience tells us that it takes several years before a patient organization becomes known to the public. CMTC is a rare condition and this slows down the process.

All address guides are edited once a year, which means it can take up to a year before a new organization can be found in such guides. Considering the rarity of the condition we expect a slow progress in the years ahead.

International contacts will increase as will the number of foreign members. Through internet technology we will strengthen our worldwide network and function as a coordinating point between doctors, and between doctors and patients.

In the past years we noticed that all new members reach us through internet. This is one reason we pay so much attention to our website. In part considering the growth in the number of people who have access to internet, we expect that our website will play an increasingly prominent role in our organization.

In 2004 we want to develop the following activities:

1. Publish a quarterly newsletter for members. A special anonymous version of the newsletter is sent to a number of doctors with a variety of specialties in several (academic) hospitals. All newsletters are translated into English.

2. Maintain and expand contacts and collaborate with patients and other patient organizations in the Netherlands and abroad.

3. Maintain and expand contacts with medical specialists such as dermatologists in the Netherlands and abroad.

4. Research into CMTC, especially genetic research on DNA of patients.

5. Regular internet searches for information surrounding the disorder and translating it into a language understood by people who do not have medical training.

6. Organising a meeting for personal contacts and exchange of information.

7. Build and maintain a data bank concerning all persons known to us, while of course maintaining medical confidentiality.

8. Translating medical articles between Dutch and English in a language understandable to those with no medical background.

9. Recruiting new members and sponsors and obtaining subsidies to promote the reputation of the organization. This is done to be able to support more people and collect more information about this affliction.

10. Expanding the use of internet. Using internet generates considerable savings in time and costs in an environment with a structural shortage of funds. By making information such as patient leaflets available electronically, the organization has a lighter workload because people can access information without any help. Another important (financial) advantage of making information available electronically is that making changes to the content is practically without any cost.
    The president is also ´webmaster´ of our website so any changes and expansions are carried very quickly.

11. Professionalizing especially financial and members administration. We want to keep control over this. In part due to the small number of member, outsourcing is not an option.

12. Maintaining a good firewall. The most important risks are viruses and computer hacking when members of the board are using internet connections. Few people fully realize the dangers associated with internet use. Since our computers contain all (medical) data of our members, we take this issue very seriously.

8. AVAILABLE PEOPLE AND FUNDS

A small organization has only few people available. However, the amount of work is disproportionate to the size of this organization, which means that a lot of work needs to be done. The board consisted of three people during 2003. Only translation work is performed by people who are not members of the board.
Our financial means are limited, and in financial terms we are dependent on subsidies.