



ANNUAL FINANCIAL REPORT 2001

THE VAN LOHUIZEN SYNDROME (CMTc) ASSOCIATION

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Author : A.F.R. van der Heijden

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1. DOCUMENT PURPOSE

This document contains the Annual Financial Report of the patients' organisation *The Van Lohuizen Syndrome (CMTC) Association* for the year 2001. The purpose of this document is to provide an overview of the incomes and expenses of The Association. In combination with the Annual General Report this document provides a detailed review of the affairs of The Association.

2. REPORTING PERIOD

This report covers the financial reporting period from 1st January to 31st December 2001.

3. INCOME & EXPENSES

This year the incomes were comprised out of subscriptions from members and an operating subsidy from the *Patiëntenfonds* (Patients Fund).

For Financial Year 2001 onwards, the *Patiëntenfonds* has requested that variances of more than 15% (and more than f 1000) between actual and approved budgeted costs per activity or expense item be explained in the accounts. These sorts of differences do not occur for CMTC, as can be seen from the Operational Account, so formally we are not required to explain these kinds of variances.

However, we are prepared in any case to provide such a description as follows per income or expense group (Membership Contact, Information Provision, Promotion of Members Interests and Governance).

Membership Contact Expenses

1. Our Association has now outgrown a home living room meeting and for the first time we had to make use of an external meeting room and facilities. The budget for these activities was based on a small hall that was hired without facilities. During the year we decided to make use of a conference centre located centrally in The Netherlands because of the geographical distribution of our members. During the early years of The Association the majority of our members lived in the South of The Netherlands. This has changed significantly more recently.
2. Our Medical Advisor come speaker, encountering the usual traffic problems appeared no longer to be able to find the necessary time and enthusiasm for us. He turned around and returned home. This was an enormous disappointment. Consequently we "sacked" him and now have another Medical Advisor "in service". The chairman has made Function Descriptions for the various roles and has communicated on and agreed these with those concerned.

Information Provision Expenses

1. The redesign and content hosting turned out more expensive than expected. The provider has needed the extra hours to write scripts, set-up another virtual-server and install new applications (e.g. Discussion and Statistics)
2. The translation of medical articles into layman language has not happened as often as was the intention. Largely because it appears very difficult to find suitable doctors to do this. We had found a doctor who was prepared to take this task on but unfortunately he repeatedly failed to meet his commitments and we have decided not to make further call on his services. We have now found another doctor who is prepared to translate these articles and he has delivered his first translation during 2001.
3. Less information brochures were produced than intended. This was mainly due to a reduced number of requests and to the fact that we had not carried out a mailing this year. The brochure is available for download for everyone from CMTC the web site.

Members Interests Expenses

1. The VSOP meetings are held close to the home of the CMTC Chairman resulting in lower than budgeted travel costs.
2. The organisation *Kind en Ziekenhuis* (Child and Hospital) had a different financial year than expected (From 1st October) which meant that in the year of joining the subscription had to be paid twice.

Governance Expenses

1. A budgeted Subsidy course was not followed as this turned out to be during the day. Apparently it is still not clear for many organisations that the majority of patient organisations are made up of volunteers who carry out their activities in their (scarce) free time and prefer to use their vacation time for real holiday.
2. We had a secretarial change in 2002 after five years and this has been accompanied by some extra costs. The committee increased in size by one extra person who also needed a ZIP-drive. For various reasons we do not store our Association details on the computer hard disk.
3. On 22nd December 2001 the Association Committee held a meeting. The travel expenses for this fall in the Financial Year 2002 (due to delays in this period by the Postbank on payment processing)
4. We have spent more on a members "Cheer-up" gift to give an extra boost and gesture of support to more people with a little reward and greeting.

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General Expenses

As it is practically impossible to keep track of which purpose office supplies such as printer cartridges, postage stamps, paper etc are used for (information provision, members contact promotion of members interests and so on) an estimate is made and the proportional costs are allocated to the various activity groups. This approach has been adopted following discussion with the *Patiëntenfonds*.

Incomes

The administration of member subscriptions is a long term, ongoing activity. Various members are behind with payments resulting in subscriptions arriving in another Financial Year.