



## **FINANCIAL REPORT 2002**

**ASSOCIATION FOR VAN LOHUIZEN SYNDROME**

**CMTc**

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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 2002. 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 2002 to 31st December 2002.

## 3. INCOME & EXPENSES

This year our income was comprised of subscriptions from members and an operating subsidy from the 'Patients Fund' (*Patiëntenfonds*).

From the financial year 2001 and onwards, the *Patiëntenfonds* has requested that variances of more than 15% (and more than € 2000) between actual and approved budgeted costs per activity or expense item should be explained in the accounts. Differences of this sort do not occur in the case of CMTC, as can be seen from our Operational Account, so formally we are not required to explain the actual variances.

However, we are pleased to provide in any case this information for our income and our expense groups as follows - *Membership Contact, Information Provision, Promotion of Members Interests and Governance*.

### Membership Contact Expenses

1. Our Association has been making use of external meeting rooms and facilities for two years now. This year we have needed to hire additional facilities such as a 'beamer'.
2. We have not yet made a start with setting up 'cases' partly because, in cooperation with our medical advisors, a 'template' needs to be prepared first.

### Information Provision Expenses

1. The costs for the 'content hosting' and management of our website have been less than expected. The management costs are now minimal as the chairman is quickly and simply able to do this himself thanks to the ADSL connection.
2. Costs for graphical changes to the website have been less than expected due to the new site structure.
3. The translation of medical articles into 'layman's language' has only taken place on a limited scale so far due to the difficulty of finding suitable doctors. The doctor that was helping this effort moved in the course of 2002 to a different region of the country and is busy there setting up a new organisation which is very time consuming - as a consequence the translation work has been halted.

### Promotion of Members Interests Expenses

1. The chairman has not attended VSOP meetings in 2002.
2. The subscription to 'Genetic Alliance' has not been paid due to their own administrative fault.
3. The application procedure for NORD appears to take a long time due to the limited number of 'board meetings' during which new organisations are discussed and eventually admitted.

### Governance Expenses

No training courses were following in 2002. The intention was that the secretary would follow an MS Word 'Computer Based Training' but this proved unnecessary thanks to the 'templates' developed by the chairman.

1. The chairman attended more meetings and conventions etc than had been expected - A meeting with one of our medical advisors and a convention organised by the National Skin Fund (*Nationaal Huidfonds*) and NIZW.
2. The need for a number of 'anti-virus' software licences, an essential requirement, turned out to be more than was budgeted for.
3. The quantity of computer articles needed was substantially less than expected.
4. Two medical advisors did not wish to receive expenses for their efforts or travel costs.

### General Expenses

As it is practically impossible to keep track of for 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*.

In the financial year 2002 an item for € 149,75 has been posted which can be traced to the balance sheet for 2001 under the description 'outstanding expenses' (nb: The balance for 2001 is presented in Dutch Guilders). The item relates to travel expenses for two board members for a board meeting on 22 December 2001.

### Incomes

The administration of member subscriptions is a long term, ongoing activity. Various members are behind with payments resulting in annual subscriptions arriving in a subsequent financial year. Such situations are included in the balance sheet presentation.