

# **ANNUAL FINANCIAL REVIEW 1999**

**THE ASSOCIATION FOR PEOPLE WITH VAN LOHUIZEN'S SYNDROME**

**CMTC**

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## **1. THE PURPOSE OF THIS DOCUMENT**

This document is the Annual Financial Review for 1999 of the patient organisation *The Association for People with Van Lohuizen's Syndrome*. This document is intended to provide details of the income and expenditure of the association. In combination with the Annual Review these provide an overview and a detailed explanation of the ins and outs of the Association.

## **2. REPORTING PERIOD**

This report covers the financial situation from 1 Jan 1999 to 31 Dec 1999 inclusive.

## **3. INCOME AND EXPENDITURE**

Income was made up of member contributions and a subsidy for operating costs from the Patients Fund (het Patiëntenfonds).

Notes:

1. The translation of medical articles into plain language has not yet happened, because of the great difficulty in finding suitable doctors.
2. The costs of membership of the Skin Federation (Huidfederatie) have remained the same as in previous years. It was expected these would rise to reflect increasing costs.
3. Membership of the National Organisation for Rare Disorders did not go ahead. We have doubts about the added value of membership for the Association and our members.
4. Membership of the European Organisation for Rare Disorders did not go ahead. It is possible this can be achieved via the VSOP.
5. The "miscellaneous" costs have, as requested by the Patients Fund been kept to a minimum. For example the chairman has purchased, at his own personal expense, a tape back-up device to ensure there are regular backups of the information and systems. Also at his own cost, a new computer system was purchased by the chairman. As a result of this upgrade a new system card was purchased for the scanner. The scanner is used to copy photos for our data bank and for publication on Internet. Further a fast printer was purchased which proved to be cheaper than budgeted (the developments in the computer world are fast) and one paper shredder instead of two.
6. Towards the end of the year there was an extra mail-shot to 114 hospitals. This was not originally budgeted.
7. Currency conversion between guilders and US dollars and German marks means that for example the membership contributions of international members converts to odd amounts rather than multiples of 25 guilders. There was also a backlog of payments from some members, which means some contributions will appear in the next financial year.
8. It is not practical to keep detailed records of smaller stationery costs (printer ink, postage, paper), and categorised into which purpose they are used (newsletters, letters to interested parties etc). So following discussions with the Patients Fund we have followed their advice and provided an estimate of the total costs, which are then divided over the categories. Larger investments, such as a new colour printer suitable for printing photos for our Patient Information Folder, are accounted for under the Office

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Articles category.

9. The Office Articles category seems very high, but this includes items such as paper and ink cartridges for the colour printers. There is currently a reasonable supply available, because of the often long delivery times of ink cartridges. The Office Articles category includes approx. 240 guilders for paper costs; approx. 1450 guilders for ink cartridges for colour printers. There are also approx. 450 guilders included for a power supply for the computer, which protects the computer against power surges and power failure. This protection is necessary because our computer has become the core of our association where all our information is kept and developed (our website, administration, information folders, newsletters etc.).  
The category Miscellaneous Office Articles also includes ZIP-disks, binders, etc.
10. The Patients Fund did not grant us the full amount (12,500 guilders) we requested to contribute to our operating costs. The amount we received (7,500 guilders) means some adjustments in our activities were necessary.