

# **ANNUAL FINANCIAL REVIEW 2000**

**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 2000 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 2000 to 31 Dec 2000 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 only happened on a limited scale, because of the great difficulty in finding suitable doctors. We did find a doctor willing to translate the documents, but unfortunately he continually failed to carry out the activity. Regretfully we have decided not to continue with his services.
2. The costs of membership of the Skin Federation (Huidfederatie) have risen substantially, because of "bottom-up" financing.
3. The scanner of the administrator is broken. Despite repeated requests by phone, and one by registered letter, the supplier did not meet his obligations. Given the low costs of scanners, and the bankruptcy of the previous supplier, we have decided to buy a new scanner.
4. An extra mail-shot was sent to 114 hospitals in Oct 2000. This was not originally budgeted. It was and remains very difficult to establish ourselves fully in the medical world. It is encouraging that we have received many requests for information from doctors. Even more, we gained a member who referred to us by a doctor from one of the academic hospitals.
5. 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. One generous supporter from abroad also contributed more than required.
6. 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
7. The Office Articles category seems very high, but this includes items such as paper and ink cartridges for the colour printers. The category Miscellaneous Office Articles also includes ZIP-disks, binders, etc.

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8. The Patients Fund did not grant us the full amount (16,730 guilders) we requested to contribute to our operating costs. The amount we received (10,730 guilders) means some adjustments in our activities were necessary. The activities 2.4.2 'translate newsletters' and 4.14 'advise administration' have been dropped. Following a discussion with the management authorities, and their kind support, a registered accountant carried out a quick scan of our reporting. Some points of advice were given, almost all of which have been implemented.
9. The costs for activity 2.1.2 'Internet provider maintenance costs' have only been partially used. We had intended that the new website would be active by the end of 2000. However the computer with the required files was stolen and the developer had no backup. This means the costs will be occurred in 2001 rather than 2000.
10. Budgeted telephone costs are lower because more communication is happening by e-mail. Almost all doctors and members have access to e-mail.
11. We anticipate that because of growing numbers the Annual General Meeting in 2001 will no longer be held in someone's house. We have reserved funds for hiring a hall.
12. The costs for 'producing and distributing newsletters' and 'publishing an information brochure' have increased, because we want to achieve a substantial increase in our visibility in 2001. We are considering mailshots to, for example, doctors' organisations. During 2000 we will see if the amounts reserved have been sufficient. Given the relatively small size of the activity, we do not want to treat it as a separate project.
13. We have paid for the costs of medical photos of a patient, because these are interesting for our members. The photos are on our website, where we will build up a photo gallery.
14. We have bought a binding machine, primarily to bind our quarterly and yearly newsletters. Our newsletters are relatively thick.