



ANNUAL REPORT – FINANCIAL 2004

ASSOCIATION FOR PEOPLE WITH THE 'VAN LOHUIZEN SYNDROME'

CMTC

Documentcode : CMTC/JAAR/FINAN2004

Status : Approved

Auteur : A.F.R. van der Heijden

Date : June 14, 2005

Approved : Board

Edition : 1.0

1. DOCUMENT GOAL

This document contains the financial annual report of the patient 'Association for people with the 'Van Lohuizen syndrome' for the year 2004. The intent of this document is to provide insight into the debits and credits of the organization. This report provides a detailed overview of the events and activities of this organization, when read in combination with the general annual report.

2. PERIOD OF REPORTING

This report covers the financial reporting time period from January 1 to December 31 2004.

3. CREDITS & DEBITS

The credits for this year consist of the members contribution and the exploitation subsidy of the FondsPGO.

Starting 2001, the FondsPGO has requested explanation of deviations of more than 10% (and more than €2000) per activity or cost item between the approved budget and the real costs. Such differences do not occur as we can see in the operating account, and therefore we do not need to explain any deviations. However, we are quite willing to provide an explanation per cost item (contact between patients, education, looking after the organizations interests and facilitation).

Expenses for contact between patients

1. Our organization has been using an external meeting room with facilities. We have been able to borrow a beamer, which saved us about €150.

Expenses for education

1. The costs for hosting our website ('content hosting') and maintenance of the website were less than expected. Maintenance costs are now minimal because the president can do these activities quickly and easily through an ADSL connection.
2. The costs for graphic adjustments to the website are less than expected due to the new site structure.
3. The translation of medical articles to language of the common man has only taken place to a small extent because it is very difficult to find doctors who can do this.

Expenses for looking after our interests

1. In 2004 we did not attend any VSOP meetings.

Expenses for facilitation

1. In 2004 we did not attend any courses.
2. We needed a lot fewer computer parts and items than expected.

General expenses

Since it is impossible to keep track of the specific use of stamps, cartridges, paper etc (for education, or facilitation etc.) we made an estimate and spread the costs over the main activities. FondsPGO has advised us to use this approach.

In discussion with FondsPGO we eliminated several activities in order to allocate funds for attending a large NORD (National Organisation for Rare Disorders) congress in the USA. Aside from providing and obtaining information, we intended to do a lot of networking. This way we came into contact with one of the directors of the National Institute of Health. Networking is a core activity for any organization, especially for an organization that deals with rare diseases. It is essential to expand and also maintain the network. The latter means we need to stay in contact regularly through email and also by phone.

Income

Collecting contributions is a long range activity. Various members are or were in arrears which means that the contributions were collected in another financial year. Such items are listed in the balance sheet.