



## **ANNUAL REPORT – FINANCIAL 2005**

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

**CMTC**

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## 1. DOCUMENT GOAL

This document contains the financial annual report of the patient 'Association for people with the "Van Lohuizen syndrome" for the year 2005. 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 2005.

## 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 that 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 from IBM, which saved us about €150.

### Expenses for education

No comments.

### Expenses for looking after our interests

1. In 2005 we attended the Genetic Alliance congress in de US and several American members have organized their first meeting.  
During this congress the contacts wit the director of the Rare Diseases Office of the American organization National Institute of Health have been tightened. We try to attend one congress in the US each year.

Especially when dealing with rare diseases it is important to build a worldwide network.

### Expenses for facilitation

No comments.

### **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.  
We had CMTC pens printed to use as promotional material.

### **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.

IBM and various sponsors have increased our income from donations drastically. IBM donated € 1000 and another sponsor even donated € 2000 (over three years).

Microsoft sponsors us by providing free licenses such as XP and MSOffice.