

Annual Report 2008

Marijke Foundation



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The original Annual Report 2008 is available in the Dutch language.

In order to avoid unnecessary costs, the report has been translated from Dutch into English by the board of the Marijke Foundation i.e. by people for which the English language is not their native tongue.

Marijke Foundation

Introduction

The Marijke Foundation (Dutch: Stichting Marijke MHKO Fonds) was initiated on the 20th of May 2003 and founded on the 30th of July 2003 by Han Kruyswijk shortly after his wife Marijke, aged 58, died of Multiple Arteriitis Temporalis, an illness scarcely known as the more severe and deadly multiple variant of Arteriitis Temporalis (Giant Cell Arteriitis). The illness not only causes narrowness in the arteries of the temples but also in those in the brain and the neck, resulting from rheumatic inflammation of the arteries.

Both Multiple Arteriitis Temporalis and Arteriitis Temporalis are considered to be specific breakouts of a complex of illnesses: Polymyalgia Rheumatica. In the Netherlands each year abt. 2.200 patients come to suffer from Arteriitis Temporalis (source VUMC, Amsterdam); in abt. 20 cases the illness progresses fatally. So far no medication and/or therapy exist that can prevent or cure this Multiple variant.

Multiple Arteriitis Temporalis, Arteriitis Temporalis and Polymyalgia Rheumatica are just three of the six to eight thousand so far known Rare Diseases, internationally also referred to as Orphan Diseases.

In our country, The Netherlands, about one million patients suffer from an Orphan (Rare) Disease (source: VSOP).

Status of the Marijke Foundation

The Marijke Foundation is not a patient organisation and has no (patient)members.

The Foundation is dedicated to the particular rare diseases themselves and all there is to it. In this respect it goes without saying that there is a strong relation with patients that suffer and suffered from (Multiple) Arteriitis Temporalis and, secondarily, Polymyalgia Rheumatica, including their carers, their relatives a.o.

On the basis of a flexible short and medium-term policy, the Marijke Foundation, i.e. the board, operates primarily as a working party - and if needed as a steering committee - : a small professional team aiming at practical results from which (potential) patients may benefit directly. Governing is of secondary importance.

The Marijke Foundation is fully independent. There are no other financial sources than donations and interest.

Aims and activities

In accordance with the regulations, the specific aims and related activities of the Marijke Foundation are, in order of importance:

1. To support scientific-medical research; keyword "Early Diagnosis"

For that the Marijke Foundation developed and continuously improves a special diagnostic method, the Symptomatrix[®] (public version), a tool to make it possible for potential patients to recognize the upcoming illness Multiple Arteriitis Temporalis - and hence also Arteriitis Temporalis and Polymyalgia Rheumatica - in a far earlier stage than is the case nowadays. This may result in more chances to survive for patients that come to suffer from Multiple Arteriitis Temporalis¹.

At the same time the Marijke Foundation aims at initiating scientific research, based on an extended version of the Symptomatrix, a questionnaire, in order to arrive at a Symptomatrix that will serve as a professional diagnostic tool for medical doctors and specialists for the same purpose: Early Diagnosis.

¹ In future the Symptomatrix may prove to be useful as well for earlier diagnosis of other rare diseases / auto-immune diseases.

2. Publicity

To generate more attention among the national and international public, the media, governments, the scientific society and so on for the particular orphan (rare) diseases Multiple Arteriitis Temporalis, Arteriitis Temporalis, Polymyalgia Rheumatic and, last but not least, the phenomenon of Orphan (Rare) Diseases in general and in a wider perspective, including patients, their carers, relatives a.o.

3. Fundraising

Funds are to be donated to scientific-medical research projects on the issue of “Early Diagnosis” methods and the origin and treatment of Multiple Arteriitis Temporalis, Arteriitis Temporalis and - consequently - Polymyalgia Rheumatica.

The year 2008

Results, overview

As was already policy during previous years, the Marijke Foundation has limited herself again to the three core activities mentioned before.

However, the year 2008 may be considered as remarkable as the Marijke Foundation reached some milestones.

In August 2008 the public version of the Symptomatrix reached such a stage of development that it could be published on the website of the Marijke Foundation. Because of that, the primary target of the Marijke Foundation, a significant contribution to Early Diagnosis, was realized. Even more so, as the Symptomatrix was not only published in Dutch, but also in the English and German languages as a result of cooperation with colleagues and specialists abroad.

Statistics showed that the website of the Marijke Foundation was visited more frequently since the Symptomatrix was published. Nevertheless, the Marijke Foundation could not determine whether or not the Symptomatrix was of help to potential patients in order to arrive at an early diagnosis of Multiple Arteriitis Temporalis, Arteriitis Temporalis and/or Polymyalgia Rheumatica. But there are reasons to assume that the Symptomatrix has done its job in a number of cases. Furthermore, the Marijke Foundation was satisfied with the response / feed back on the Symptomatrix, though to a certain extent. Initially, a number of filled out internet forms were received - such response forms provide essential data for the continuing process of improving the Symptomatrix.

In order to achieve more results, the Marijke Foundation concluded that a lot of publicity for the Symptomatrix in and outside The Netherlands is and remains necessary. The Marijke Foundation is not underestimating this particular issue and is aware of the amount of work that has to be done in future, on the one hand for the benefit of potential patients, on the other for the progress of the Symptomatrix projects - the public version and the professional version.

In the course of September 2008 the Marijke Foundation experienced the interest in scientific circles in her concept of the professional version of the Symptomatrix. This version, to be developed on the basis of epidemiological research, may in future become of value for general practitioners and medical specialists in order to arrive at early diagnosis of Multiple Arteriitis Temporalis, Arteriitis Temporalis and/or Polymyalgia Rheumatica.

By her prework the Marijke Foundation layed the foundation for the initiation of a scientific-medical research project. For the purpose, appropriate contacts in the Netherlands were established with epidemiologists and sources of subsidies.

Furthermore the website of the Marijke Foundation was published on her new webdomain. Until August 2008 the website could be found on a homepage. However, homepages on the internet are usually harder to find than websites that reside on webdomains.

At the same time and in view of the international ambitions of the Marijke Foundation the original website address (www.socrat.myweb.nl) was changed into www.marijke-foundation.eu. Consequently, the e-mail address changed from socrates-nl@orange.nl into info@marijke-foundation.eu.

Note: the website has been developed by the Marijke Foundation in 2003 and since maintained and updated as well by the Marijke Foundation herself at no cost.

The remarkable results, mentioned above, are the unquestionable effect as well of the way in which the Marijke Foundation kept on operating. Governing, continuous policy making and all there is to it, is only of secondary importance to the members of the board, contrary to many other organisations involved in the field of Orphan (Rare) Diseases. The Marijke Foundation, i.e. her volunteering and unpaid board members, may be proud, in particular in the year 2008, that their vision on how a foundation should operate pays out, for the benefit of (potential) patients, their carers, their relatives and others.

So far the milestones.

For the purpose of wider circulation and further development of both the public and the professional version of the Symptomatrix the Marijke Foundation has nationally and internationally been looking for cooperation.

In our country, The Netherlands, the possibilities turned out to be lean. In case chances were found, the Marijke Foundation met constraints and resistances that seem to be caused by bureaucracy, hierarchical perceptions, tunnel vision and strong self orientation.

Abroad, as one of the results of the publicity around the public version of the Symptomatrix in the English language, the Marijke Foundation had more luck and came across a combination of sister-organisations in the United Kingdom. To what extent these sister-organisations and the Marijke Foundation may mutually benefit from this contact could not yet be ascertained in 2008. However, the Marijke Foundation is quite optimistic about the possibilities in future. Even more as these sister-organisations are cooperating with organisations and individuals in the United States.

Our initial contact with Eurordis, a French organisation supported by the European Commission and aiming at coordinating and stimulating the work of European patient organisations in the field of Orphan (Rare) Diseases, was already brought to an end in the year 2007. Also in 2008 the board of the Marijke Foundation remained of the opinion that Eurordis is not of added value to the Marijke Foundation and her mission.

Since the Marijke Foundation pinpointed at her main activities, the Symptomatrixes, also considering the worsening financial climate by the end of 2007 and the outbreak of economic recession in the course of 2008, only secondary attention has been paid to publicity and fundraising.

As in previous years, in 2008 the financial means of the Marijke Foundation grew in a modest way.

Of course the Marijke Foundation wishes to express her sincere gratefulness for the donations received.

Cint MMedia - Amstelveen continued to support the Marijke Foundation by means of various facilities.

There have been no changes in the Board of the Marijke Foundation during 2008.

Aims, support, costs, interest

Substantial financial means are required for (the support of) scientific research projects. In spite of donations and interest received in 2008 the financial position of the Marijke Foundation is for the present inadequate to be able to support research projects or to start one, as has been the case during previous years. The financial paragraph of this annual report reflects the situation. As a result, there were no dedicated spendings in 2008.

In the near future, the financial position of the Marijke Foundation may however show to be sufficient for the initiation of a research project.

The Marijke Foundation administered her financial means in 2008 as she did over the past years, like a dedicated housewife. The financial figures show that there were hardly any costs except those of the bank account and the Chamber of Commerce. This complies with the original policy of the board that all incoming money should be spend on the primary aims of the Marijke Foundation without exception.

In order to receive more interest on the balance of the bank account of the Marijke Foundation a substantial amount has been transferred to a higher interest bank account with banker ING by the end of 2007. This already resulted in a small amount of interest over just a few months in 2007, received at the beginning of 2008. More substantial interest will be received by the beginning of each subsequent year.

Board meetings

In 2008 there have been three 'live' board meetings:

- . 5th of March 2008
- . 23rd of May 2008
- . 6th of October 2008.

The regulations of the Marijke Foundation dictate at least four board meetings per year. However, for efficiency reasons the board of the Marijke Foundation prefers to benefit from modern technology and so from the advantages of electronic meetings and e-mail consultations. As a result, the board of the Marijke Foundation has 'met' far more than the required four times a year.

All e-mail messages and relevant documents were archived by the secretariat of the Marijke Foundation as minutes.

The Board

Chairman : Eric W. Gerritsen (63), retired;

former secretary to the Private Division Board of Centraal Beheer (now Achmea), a leading Dutch company in insurance and banking

Treasurer : Rob G. Berkhof (57), Certified Public Accountant, Registered master ICT;

managing director Finance and ICT with De Stromen, a large Dutch organisation active in the field of health and related care

Secretary : Han Kruyswijk (64);

managing director of Cint MMedia, a small publishing company, formerly publisher new technology and multi media with Elsevier Science Publishers (now Reed Elsevier)

Science : Dr. Ron Voorbij MD (49), Medical Doctor Clinical Chemistry;

head of the dept. Clinical Chemistry with the University Medical Centre UMC at Utrecht and advisor of the Dutch 'Heart Foundation'.

Supported by Drs. Mariëtte Sibbing, psychologist, as minutes secretary.

All 'personnel' contribute on a voluntary basis; no fees paid.

Chartered public accountant

Horlings at Amsterdam - The Netherlands, i.c. Rob A. van Kessel, Certified Public Accountant.

Notary

Smith Bentum Amson at Amstelveen - The Netherlands.

Chamber of Commerce, registration

The Marijke Foundation is registered with the Chamber of Commerce, Amsterdam - The Netherlands, under number 34193947.

Charity Organisation, registration

The Marijke Foundation has been acknowledged by and registered with the Dutch Tax Authorities as a Charity Organisation since the 11th of November 2003 (dossier number 21960).

Intentions 2009

Primary:

- Early Diagnosis:
further development and maintenance of the Symptomatrix (public version), if necessary and possible in cooperation with patients, carers, relatives, patient organisations, general practitioners, medical specialists a.o.
- Early Diagnosis:
initiating scientific-medical research in order to arrive at the professional version of the Symptomatrix to be used by general practitioners and medical specialists
- Cooperation:
extending and exploration of national and international contacts, in particular with sister-organisations operating in the same way as the Marijke Foundation: as a working party and steering committee
- Publicity:
extending the activities in order to generate more (public) attention for the public version of the Symptomatrix, the aims and work of the Marijke Foundation and the phenomenon of Orphan (Rare) Diseases in general, in particular through nation wide, regional and local media (radio, television, newspapers, magazines, events a.o.)
- Publicity:
if possible and if adding to the aims and work of the Marijke Foundation, involvement in the organisation of Orphan (Rare) Diseases Days and relevant events in The Netherlands in order to generate more attention of society for the phenomenon of Orphan (Rare) Diseases in general.

Secondary:

- acquiring donor-members of the 'Friends of the Marijke Foundation'
- fundraising: sponsoring, subsidies, incidental donations a.o.

Governing:

The Marijke Foundation will comply with the regulations as to board meetings. At least four meetings are planned for 2009. However, the members of the board of the Marijke Foundation, including the minutes secretary, contribute to the foundation and her work on voluntary basis; the majority of this 'personnel' works in trade and industry and the non-profit / health care sector. So, time is of value and limited.

Therefore, the board will continue to follow the trend since 2008 to make use of modern electronic facilities for the purpose of efficiency in daily work and board meetings.

Financial report 2008

ACCOUNTS

Amounts in €

	31-12-2008	31-12-2007
<u>Assets</u>		
Cash	7.093	6.783
	<hr/>	<hr/>
	7.093	6.783
	<hr/> <hr/>	<hr/> <hr/>
<u>Liabilities</u>		
Proprietor's equity	7.093	6.783
	<hr/>	<hr/>
	7.093	6.783
	<hr/> <hr/>	<hr/> <hr/>

INCOME STATEMENT

Amounts in €

	2008	2007
Income		
Gifts	365	310
Interest	17	6
	<hr/>	
	382	316
	<hr/> <hr/>	
Losses		
Chamber of Commerce	27	22
Bank charges	45	43
Surplus	310	251
	<hr/>	
	382	316
	<hr/> <hr/>	

NOTES ON THE ACCOUNTS, 31ST OF DECEMBER 2008

Amounts in €

	2008
Equity, 31 st of December 2007	6.783
Surplus 2008	310
	<hr/>
Equity, 31 st of December 2008	<u><u>7.093</u></u>