

Annual Report 2009

Marijke Foundation



Table of contents

About the Marijke Foundation	1
Introduction	1
Status of the Marijke Foundation	1
Aims and activities	1
The year 2009	3
Results, overview	3
Aims, support, costs, interest	5
Board meetings	5
The Board	5
Chartered public accountant	6
Notary	6
Chamber of Commerce, registration	6
Charity Organisation, registration	6
Intentions 2010	7
Financial report 2009	8
Accounts	9
Income statement	10
Notes on the accounts, 31 st of December 2009	11

The original Annual Report 2009 is published 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.

About the 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 Kruyswijk - Oosterhout, aged 58, died of Multiple Arteriitis Temporalis.

Multiple Arteriitis Temporalis is scarcely known as the more severe and fatal multiple variant of Giant Cell Arteriitis (Arteriitis Temporalis). Giant Cell Arteriitis is a rheumatic inflammation of the arteries of the temples, a vasculitis. The walls of the arteries swell up, become stiffened and narrow so normal blood flow declines. In particular women of approximately 50 years and over, sometimes also men, come to suffer from the disease. It appears to occur more in northern than in southern countries.

Multiple Giant Cell Arteriitis not only affects the arteries of the temples but also those in the brain and the neck.

Both Multiple Giant Cell Arteriitis and Giant Cell Arteriitis are specific outbreaks of a complex of illnesses and medical complaints,

Polymyalgia Rheumatica: rheumatic inflammations throughout the body.

The cause of these diseases is yet unknown.

In our country, The Netherlands, each year about 2200 patients suffer from Giant Cell Arteriitis (source VUMC, Amsterdam - The Netherlands | the population of The Netherlands is about 16,5 million people).

Patients, suffering from Giant Cell Arteriitis - they suffer from Polymyalgia Rheumatica simultaneously - usually recover in two to ten years by therapy with (long existing) medicine, though the side effects of such medication can be aggravating and sometimes cause everlasting ailments.

However, in about 20 cases the illness progresses into the fatal Multiple condition of Giant Cell Arteriitis, in spite of the standard medication that is applied to cure Giant Cell Arteriitis and Polymyalgia Rheumatica and additional medication.

In The Netherlands about 14.666 patients come to suffer from Polymyalgia Rheumatica each year.

Multiple Giant Cell Arteriitis (MGCA), Giant Cell Arteriitis (GCA) and Polymyalgia Rheumatica (PMR) are often considered to be auto-immune diseases and are three of the six to eight thousand Rare Diseases, internationally also referred to as Orphan Diseases. In our country, The Netherlands, each year about one million patients suffer from an Orphan (Rare) Disease (source: VSOP, Soest - The Netherlands).

Status of the Marijke Foundation

The Marijke Foundation is not representing patients. On the contrary. The foundation represents the particular diseases themselves and all there is to it. There is only an indirect relation with patients that suffer(ed) from MGCA, GCA and PMR. So, the Marijke Foundation has no patient-members.

The Marijke Foundation is fully independent, has no profit motive and there are no other financial sources than donations and interest. The Marijke Foundation is recognized by and registered with the Dutch authorities as a charitable organisation.

Based on 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 members of the board of the Marijke Foundation, including the minutes secretary, contribute to the foundation and her work on voluntary basis, no salaries, fees or costs paid.

Aims and activities

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

1. Early Diagnosis - Symptomatrix[®]

Shortly after Marijke Kruyswijk - Oosterhout passed away the neurologist¹ stated that Marijke could have survived if (M)GCA had been diagnosed in an earlier stage.

It is hard to live with this statement..... However, the diversity of symptoms makes it difficult to diagnose GCA and PMR timely. Experience proves that specific complaints are not always recognised by GP's and specialists as a complex of symptoms pointing to GCA and/or PMR. As a result too much time elapses frequently before the diseases are properly diagnosed and adequate

¹ Not the specialist that I initially treated Marijke.

treatment is started. Consequently patients quite often have to suffer from unnecessary progression of GCA and/or PMR, in a number of cases even fatal progression.

The statement of the neurologist mentioned before resulted in the decision of the Marijke Foundation to choose Early Diagnosis as leading theme and to develop a dedicated symptom checker for that purpose, the Symptomatrix.

The Symptomatrix is a practical tool that lists scientifically known symptoms of GCA and PMR. By tick-marking the matrix of complaints potential patients in the first place, but also family doctors and medical specialists are enabled to recognize the upcoming illnesses in an earlier stage than is the case up to now. This may result in earlier diagnosis, earlier treatment, less suffering from diseases and medication, and faster recovery. But above all Early Diagnosis with the help of the Symptomatrix may prevent GCA from progressing into the fatal condition of MGCA.

The Symptomatrix is understandable and accessible for everyone. It has been published in 2008 on the website of the Marijke Foundation (keywords: odd complaints) in the English, German and Dutch languages. Versions in French and Spanish are to be published. The Symptomatrix is available in print as well.

Ongoing development and fine tuning of the Symptomatrix is also based on medical-scientific (epidemiological) research ².

2. Publicity

The Marijke Foundation attempts to generate more national and international public and media attention for the issue of Early Diagnosis of the diseases MGCA, GCA and PMR with the help of the Symptomatrix. In this respect the Marijke Foundation has already been (and will be) interviewed by radio/television stations and newspapers.

3. Fundraising

The Marijke Foundation raises funds to be donated to further development and fine tuning of the Symptomatrix, as well as to medical-scientific research on the issues of cause, cure and treatment of the diseases MGCA, GCA and PMR.

² In future the Symptomatrix may prove to be useful as well for earlier diagnosis of other rare diseases / auto-immune diseases.

The year 2009

Results, overview

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

Like 2008, the year 2009 can be considered as remarkable. Again, the Marijke Foundation reached some milestones.

The Symptomatrix, published on the website in the summer of 2008, was frequently filled out and sent tot the Marijke Foundation, though we received just a modest number in total (the statistical information that can be derived from the response forms provide essential data for the continuing process of improving the Symptomatrix.).

Statistics showed that the website of the Marijke Foundation was visited frequently, the main pages as well as the part of the website where the Symptomatrix can be found. But, as was already the case in 2008, The Marijke Foundation has limited means to determine whether or not the Symptomatrix was of help to potential patients in order to arrive at an early diagnosis of MGCA, GCA and/or PMR. Nevertheless, there are reasons to assume that also in 2009 the Symptomatrix has done its job in a number of cases.

The Annual Report 2008 already stipulated that a lot of publicity for the issue of Early Diagnosis and Symptomatrix in and outside The Netherlands is and remains necessary. The year 2009 proved as well that 'public and media awareness' is hard to achieve and consequently remains a continuing primary task for the Marijke Foundation and those with which the foundation cooperates.

Though a number of organisations are actively involved in Rare Diseases, either on European level or just in our country, also in 2009 the results with respect to publicity for more public and media attention for Rare Diseases, public awareness, remained poor.

Again, this did not at all contribute to the activities and the work of the Marijke Foundation and other organisations in The Netherlands that are dedicated to one or more rare diseases. In fact it proved to be a complicating factor again: before the Marijke Foundation is able to inform about the diseases MGCA, GCA and PMR a lot of time has to be invested in explaining what Rare Diseases are. Hardly anyone in our country is familiar with this phenomenon.

Even the Rare Diseases Day in April 2009 turned out to have minimal impact in this context, as was already the case in previous years. So, the Marijke Foundation contacted the organising parties, provided quite a number of suggestions for improvement and they were discussed in such a way that we may expect they will be implemented for the Rare Diseases Day 2010 and publicity activities in general. For the same purposes the Marijke Foundation published and distributed an article with the biting title "Rare without Care" (Dutch). Significantly, the discussions that followed about the subjects of organisation and publicity made clear that the Marijke Foundation is (quote) "light-years ahead in policy, activities, organising and professionalism". We accepted the compliment gratefully.

As already mentioned before, generating publicity is not an easy task and so the Marijke Foundation put a lot of effort in the subject. There was a modest reward on the 8th of July 2009. Dr. Ron Voorbij and Han Kruyswijk were interviewed in the medical half hour on Radio North Holland, the highest ranked radio station in the region. It was a success: during the broadcast quite a number of listeners called in, also afterwards, and the Marijke Foundation could support some of them with medical and practical information.

During the year 2009 the Marijke Foundation succeeded to expand her network and to intensify already existing contacts in and outside The Netherlands.

For the board meeting of the 5th of February 2009 Dr. Michiel Bots, epidemiologist at the UMC - Utrecht and colleague of Dr. Ron Voorbij, was invited for advice on the initiation of the scientific research project (epidemiology) that should lead to a professional version of the Symptomatrix, to be used in future by family doctors and medical specialists.

Dr. Bots offered to support and advise the Marijke Foundation, in particular with respect to the writing of the project and the requests for subsidies.

Furthermore the Marijke Foundation met members of the staff of ZonMW. The organisation initiates and subsidises scientific research projects on behalf of the Dutch Government.

The contact developed very well, business wise and cordially, and offers perspective for the future. The immediate result was the decision to mutually exchange relevant information, visions and to assist and support each other when needed.

It was quite stimulating that the contacts in the United Kingdom, established in 2008, could be intensified, in particular and respectfully with the PMR GCA Tayside (Dundee) and PMR GCA North East (Newcastle upon Tyne) Support Groups of, respectively, I. Jean Miller en Mavis Smith - initiators and both still suffering from Giant Cell Arteriitis and Polymyalgia Rheumatica. During 2009 the Marijke Foundation was pleased with these opportunities to add to the international public awareness of the significance of Early Diagnosis and the existence of the Symptomatrix by means of providing relevant information both Jean Miller and Mavis Smith agreed to insert in the information packs of their Support Groups.

Jean Miller and Mavis Smith also introduced the Marijke Foundation with Prof. Bhaskar Dasgupta, reumatologist at the Southend Hospital (near London). Prof. Dasgupta is member of the expertise team PMR and GCA that is preparing a standard procedure for diagnosis of

both diseases by family doctors and medical specialists.

Eric Gerritsen (chair), Dr. Ron Voorbij (medical science) and Han Kruyswijk (secretary) had the opportunity to meet Prof. Dasgupta in Amsterdam in September 2009. During an extensive discussion and exchange of information it showed that Early Diagnosis and Public Awareness are major issues for Prof. Dasgupta as well. And so Prof. Dasgupta and the Marijke Foundation decided to cooperate on that. Prof. Dasgupta praised the Symptomatrix as (quote): 'the first really useful instrument for Early Diagnosis he has ever seen' and the tool was instantly denominated as part of the Patient Education Program in the United Kingdom (a project supported by the National Health Service).

For further development of the Symptomatrix Prof. Dasgupta agreed to provide the Marijke Foundation with statistical data from his patient dossiers - about 200 cases.

The Marijke Foundation, in turn, provided Prof. Dasgupta on his request with the English version of the extensive questionnaire the Marijke Foundation uses to gather statistical data from patients in and outside The Netherlands, as well as a detailed medical case history of Marijke Kruyswijk - Oosterhout.

This led to an invitation by Prof. Dasgupta to attend to the launch of PMR GCA UK on the 10th of March 2010 in London; Marijke's case history would be part of a paper Prof. Dasgupta was planning to present during that launch.

So far about networking and cooperation.

GCA and PMR are closely related diseases. A majority of patients that suffer from PMR, develops GCA as well; patients that come to suffer from GCA, usually already suffer from PMR.

This being the outcome of many scientific research projects, in 2009 the Marijke Foundation decided to focus on PMR as well. However, the order of focus remains: MGCA, GCA, PMR.

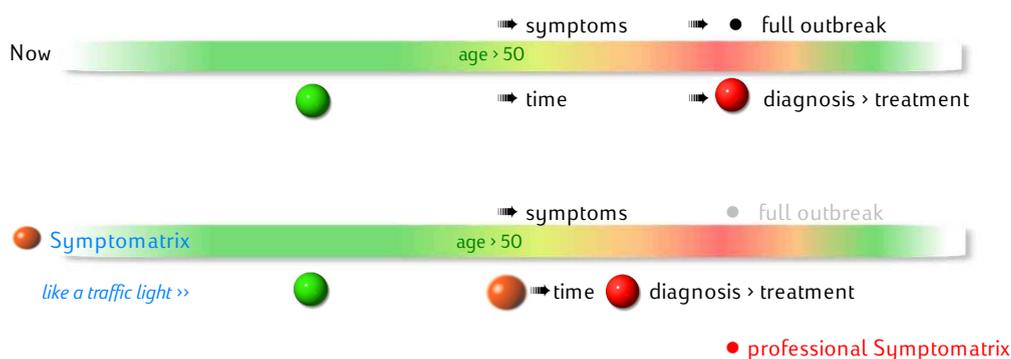
For quite some time the Marijke Foundation considered to initiate a scientific research project (epidemiology) in order to develop a professional version of the Symptomatrix to be used in future by general practitioners and medical specialists for the purpose of Early Diagnosis.

However as time went by, doubts grew whether GP's and specialists would indeed adopt such a tool. And by the end of 2009 the question was answered with 'no, they will not'. But even more important was the question whether or not such a project complies with the initial objectives of the Marijke Foundation. Again, the answer was 'no'.

Furthermore it would be very difficult to automate such a Symptomatrix and even more complicated to get the module incorporated in automated systems GP's and specialists already use.

On top of this, after discussions with parties that could provide subsidies, we concluded that it would at least take about five to ten years before any practical result could be expected; a very long way.

By the end of 2009 the Marijke Foundation considered not to go that long way for various reasons mentioned above, but mainly because Early Diagnosis is the principal objective of the Marijke Foundation and that objective is very effectively served by the present Symptomatrix which function is comparable to that of the orange light in a traffic light, a signal to consult a doctor as soon as possible if certain symptoms are recognized by potential patients - suspicion GCA and/or PMR:



The illustration shows what the present Symptomatrix (●) can and a professional version to be used by GP's and specialists (●) can not achieve. As a matter of fact, at the moment the professional version would be used, the diseases have already progressed to full outbreak. The present Symptomatrix (●) is particularly meant to prevent just from that.

Moreover, the present Symptomatrix has already the effectiveness of a professional version. It can also help GP's (and specialists) to arrive at a definite diagnosis faster than is the case up to now by the inventory of complaints a potential patient presents when she/he consults a GP with a filled out Symptomatrix form.

The foregoing lead once more to the conclusion not to go the 'long way' and thus to terminate initiatives with respect to the development of a second, a professional version of the Symptomatrix.

The effectiveness of the present version of the Symptomatrix is what the Marijke Foundation initially aimed at. Focussing on

improvements, fine tuning, upgrading and strengthening of the medical-scientific basis adds to the effectiveness of the present version of the Symptomatrix.

Moreover, this decision enables the Marijke Foundation to concentrate on another major issue: generating national and international publicity for Early Diagnosis and the Symptomatrix.

The results in 2009 were again the unquestionable effect 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 that their vision on how a foundation should operate pays out, for the benefit of (potential) patients, their carers, their relatives and others.

Contrary to previous years in 2009 the financial means of the Marijke Foundation decreased, in spite of donations received. It is caused by increasing costs, mainly for the rent of the webdomain. Also the donations were slightly less.

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 2009.

Aims, support, costs, interest

Substantial financial means are required for (the support of) scientific research projects on the cause of the diseases GCA and PMR. In spite of donations and interest received in 2009 the financial position of the Marijke Foundation is still inadequate to be able to support research projects or to initiate 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 or donations in 2009.

The Marijke Foundation administered her financial means in 2009 as she did over the past years, like a dedicated housewife. The financial figures show that there were hardly any costs except for those of the bank account, the Chamber of Commerce and the annual 'rent' of the webdomain. 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.

Board meetings

In 2009 there have been three 'live' board meetings:

- . 4th of February 2009
- . 19th of May 2009
- . 20th of November 2009.

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, together with those of the 'live' meetings.

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 Opmaat Group, a large Dutch organisation active in the field of health and health related care |
| Secretary | : | Han Kruyswijk (65);
managing director of Cint MMedia, a small publishing company, formerly publisher new technology and multi media with Elsevier Science Publishers (now Reed Elsevier) |
| Science | : | Ron Voorbij MD PhD (50), Clinical Pathologist;
project director Medical Diagnostic Centre of the Groene Hart Hospital and also advisor of the Dutch Heart Foundation. |

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

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 2010

Primary

- **Publicity**
major focus on activities in order to generate more public and media attention (public awareness) for the issue of Early Diagnosis of GCA and PMR with the help of the Symptomatrix, nationally and internationally;
in the Netherlands emphasis will be on nation wide, regional and local media (radio, television, newspapers, magazines, events a.o.)
- **Early Diagnosis (incl. Prevention)**
further development, fine tuning, maintenance and strengthening of the medical-scientific basis of the Symptomatrix (in 2010: upgraded version 2.0), if necessary and possible in cooperation with patients, carers, relatives, patient organisations, general practitioners, medical specialists a.o. in The Netherlands and abroad
- **Scientific Research**
exploring the possibilities to stimulate and to contribute to scientific research with respect to the cause of GCA and PMR, including improvements in treatment and medication
- **Cooperation**
extension and exploration of national and international contacts i.e. individuals, medical specialists, scientists and in particular sister-organisations that operate in the same way as the Marijke Foundation.

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. Four meetings will be planned for 2010. However, 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 2009

Accounts

Amounts in €

	31-12-2009	31-12-2008
<u>Assets</u>		
Cash	7.053	7.093
	<hr/>	<hr/>
	<u>7.053</u>	<u>7.093</u>
 <u>Liabilities</u>		
Proprietor's equity	7.053	7.093
	<hr/>	<hr/>
	<u>7.053</u>	<u>7.093</u>

Income statement

Amounts in €

	2009	2008
Income		
Gifts	290	365
Interest	98	17
	<hr/>	<hr/>
	388	382
	<hr/> <hr/>	<hr/> <hr/>
Losses		
Chamber of Commerce	26	27
Bank charges	39	45
Project costs	363	
Surplus	- 40	310
	<hr/>	<hr/>
	388	382
	<hr/> <hr/>	<hr/> <hr/>

Notes on the accounts, 31st of December 2009

Amounts in €

	2009
Equity, 31 st of December 2008	7.093
Surplus 2009	- 40
	<hr/>
Equity, 31 st of December 2009	<u><u>7.053</u></u>