

Profile Marijke Foundation, status, aims and activities

● History

“Your wife could have survived if the diseases were recognized in an earlier stage,” according to a prominent Dutch specialist..... Hard to live with. But it has led to the Marijke Foundation, initiated on the 20th of May 2003 and founded on the 30th of July 2003 by Han Kruyswijk after his wife Marijke, aged 58, died of Multiple Giant Cell Arteriitis (Multiple Arteriitis Temporalis), an illness scarcely known as the more severe and deadly multiple variant of 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 illnesses are specific outbreaks of a complex of diseases and medical complaints: Polymyalgia Rheumatica. Multiple Giant Cell Arteriitis (MGCA), Giant Cell Arteriitis (GCA) and Polymyalgia Rheumatica (PMR) are often considered to be auto-immune diseases and three of the six to eight thousand actually known Rare Diseases, internationally also referred to as Orphan Diseases.

● Status

Worldwide the Marijke Foundation is about the only pioneer in Early Recognition and Early Diagnosis of Rare Diseases, in particular Giant Cell Arteriitis and Polymyalgia Rheumatica.

So, the Marijke Foundation is *not* a patient organisation. Of course there is an indirect and functional relation with patients that suffer(ed) from MGCA, GCA and PMR. But the Marijke Foundation has no patient-members. The board of the Marijke Foundation are the only members. They form the Symptomatrix [developing] Team.

The Marijke Foundation is fully independent, has no profit motives and there are no other financial sources than donations, interest and financial contributions by the members of the board.

The Marijke Foundation is registered with the Dutch authorities as a charitable organisation: file # 21960, RSIN # 8124.26.101.

● Aims and activities in order of priority:

1. Early Recognition/Diagnosis › Symptomatrix[®]

Since 2003 the Marijke Foundation developed a tool for Early Recognition/Diagnosis of GCA and PMR: the Symptomatrix. It is a practical tool that lists scientifically known symptoms of both diseases in a specific order. 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 risks of irreversible physical damage (such as loss of eyesight, ischemic brain damage), less suffering from the diseases and the side effects of medication, and faster recovery. But above all Early Recognition/Diagnosis with the help of the Symptomatrix may prevent GCA from progressing into the sometimes fatal condition of MGCA.

Nowadays more and more patients search the internet for an explanation for their odd and vague complaints and symptoms, in particular patients that are sent from one specialist to the other and remain without a diagnosis. Therefore, the Symptomatrix is primarily ‘public-oriented’ i.e. simple, understandable and accessible for everyone. It was originally published in 2004 and has been published on the websites of the Marijke Foundation in 2008 (keywords: odd complaints) in the Dutch, English and German languages, in 2010 also in French and Spanish. Other languages, among them Russian, Chinese, Turkish, Polish and Swedish, are in preparation.

Ongoing development and fine tuning of the Symptomatrix is also based on medical-scientific (epidemiological) research¹.

2. Publicity

The Marijke Foundation attempts to generate more national and international public awareness and media attention for the issue of Early Recognition/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, magazines 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.

¹ The concept of the Symptomatrix[®] may prove to be useful as well for earlier diagnosis of other diseases / auto-immune diseases, rare or not.

● **Board (Symptomatrix Team)**

Chair	Eric W. Gerritsen; former Secretary to the Board of a large Dutch company in insurance and banking
Treasurer	Rob G. Berkhof; Certified Public Accountant, Registered Master ICT, recently active in health- and related care
Secretary	Han Kruyswijk; former Publisher new and multi media of a leading international scientific publishing company
Science Support	Ron Voorbij MD PhD; Medical Specialist Mariëtte Sibbing MA; Psychologist.

● **Financial/Fiscal Advisor (Chartered Accountant)**

Rob A. van Kessel.

● **Contacts in The Netherlands and Europe**

The Marijke Foundation maintains contacts with [The Netherlands:] University Hospital Groningen, ZonMW - governmental organisation, the Reuma Patient Organisation, the Reuma Foundation, the Vasculitis Foundation (formerly the Friedrich Wegener Foundation), the Orphan Drugs Foundation, the Rare Diseases Fund; [Europe:] Orphanet, Eurordis, RareConnect and other professional organisations in The Netherlands and elsewhere in Europe that are involved in Rare/Orphan Diseases.

● **International Contacts and Cooperation**

Aiming at further development and fine tuning of the Symptomatrix the Marijke Foundation cooperates with organisations and specialists/experts abroad, among them PMR-GCA UK i.c. Professor Bhaskar Dasgupta of the Southend Hospital - Southend, UK, and Support Groups.
In the United Kingdom, the Symptomatrix has been adopted by rheumatologists as standard diagnostic tool for (Multiple) Giant Cell Arteriitis and Polymyalgia Rheumatica.
The National Medical Research Foundation in Arizona/USA embraced the Symptomatrix as a break-through for Early Diagnosis of (Multiple) Giant Cell Arteriitis and Polymyalgia Rheumatica. In cooperation with their sister-organisations they recommend and promote the use of the Symptomatrix all over the USA.

Let everyone know:

Odd Complaints that may point to
Giant Cell Arteriitis and/or Polymyalgia Rheumatica

and no diagnosis ?

Symptomatrix[®]

Earlier Recognised = Earlier Diagnosis = Better Prognosis

www.marijke-foundation.eu