

## Profile of the Marijke Foundation

### History

The Marijke Foundation was initiated on the 20<sup>th</sup> of May 2003 and founded on the 30<sup>th</sup> of July 2003 by Han Kruyswijk shortly after his wife Marijke, aged 58, died of the intensive treatment with high dosed multi-medication of Giant Cell Arteritis (GCA, AT, Arteritis Temporalis) and Polymyalgia Rheumatica (PMR), which was the result of a far too late diagnosis of in particular GCA.

### GCA and PMR in short

GCA is a rheumatic inflammation of medium and large size arteries, a vasculitis. It is mainly found in the arteries of the head, in particular in the temples.

PMR is an ailment with inflammation of the muscles, in particular those in the neck, shoulders, upper arms, pelvis and upper legs. Significantly, pain is in both sides of the body.

GCA and PMR are usually considered as auto-immune illnesses. They belong to a group of six to eight thousand Rare Diseases, also referred to as Orphan Diseases.

### Aims and activities

#### 1. Early Recognition/Diagnosis > "Symptomatrix" <sup>®</sup>

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 illnesses in a far earlier stage than is usually the case. This may lead to earlier diagnosis, earlier treatment, and as a result less risk 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.

The "Symptomatrix" is primarily 'public-oriented' i.e. simple, understandable and accessible for everyone. The "Symptomatrix" was originally published in 2004 and has been published on the websites of the Marijke Foundation since 2008 in the Dutch, English, German, French and Spanish languages.

#### 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 GCA and PMR with the help of the "Symptomatrix". In this respect the Marijke Foundation has been (and will be) interviewed by radio/television stations, magazines and newspapers.

### Status

Worldwide the Marijke Foundation is the only pioneer in Early Recognition and Early Diagnosis of GCA and PMR. So, the Marijke Foundation is *not* a patient organisation. Of course there is an indirect and functional relation with patients that suffer(ed) from 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 commercial or profit motives. 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 (in Dutch: ANBI): file # 21960, RSIN # 8124.26.101.



## Contacts and Cooperation in The Netherlands

The Marijke Foundation maintains contacts with the University Hospital Groningen, ZonMW - governmental organisation, the Reuma Patient Organisation, the Reuma Foundation and the Vasculitis Foundation (formerly the Friedrich Wegener Foundation).

## 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 PMRGCA Support Groups.

In the United Kingdom, the "Symptomatrix" has been adopted by rheumatologists as standard diagnostic tool for GCA and PMR.

The National Medical Research Foundation in Arizona/USA embraced the "Symptomatrix" as a break-through for Early Diagnosis of GCA and PMR. In cooperation with their sister-organisations they recommend and promote the use of the "Symptomatrix" all over the USA.

Throughout the world, the Marijke Foundation maintains contacts with the Orphan Drugs Foundation, the Rare Diseases Fund, Orphanet, Eurordis, RareConnect and other professional organisations that are involved in Rare/Orphan Diseases.

## Board of the Marijke Foundation (also the members of the Symptomatrix Team)

- Chair : Eric W. Gerritsen, former Secretary to the Board of a leading Dutch company in insurance and banking
- Treasurer : Rob G. Berkhof; Certified Public Accountant, Registered Master ICT
- Med. Science : Ron Voorbij MD PhD, Medical Specialist; chair of the Symptomatrix Team and co-editor of the content of the websites
- Secretary : Han Kruyswijk, former Publisher new and multi media of a leading international scientific publishing company; co-editor of the content of the websites
- Deputy Secretary : Mariëtte Sibbing MA; Psychologist.

## Communication

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