

The GCA/PMR Symptomatrix ® ©

The Symptomatrix is intended *in the first place for (potential) patients* around the world for Early Recognition of their complaints as symptoms of Giant Cell Arteritis (GCA) and/or Polymyalgia Rheumatica (PMR). But also as a tool for GP's and medical specialists to diagnose and treat both (rare) diseases faster.

The Symptomatrix, upgraded to version 3.0

In the course of 2014 the Symptomatrix has undergone some upgrades since it was first published in 2003-2004.

Over the years the Symptomatrix has proven to be *an adequate, efficient and effective tool*. So no changes were required in the original design, method and structure.

Furthermore, taking the condition of most (potential) patients into account, the acclaimed easy accessible content and lay out remained unchanged as well: common language, simple one click websites, no trendy disturbing decoration, fancy moving images, ads, colours and so on.

But technologically a lot has changed. Search engine optimisation (SEO) has been applied all over so that (potential) patients around the world find the Symptomatrixes 3.0 on the internet much faster.

Another improvement is the distinction among visitors of the Symptomatrix sites. The introductory pages now offer a choice:

1. *For patients without a diagnosis* - the main target group: the Symptomatrix for Early Recognition and Early Diagnosis of GCA and PMR. (Potential) patients find the Symptomatrix sites by searching the internet with terms corresponding to (a combination of) their complaints.
2. *For patients with a diagnosis, being treated or already cured*: the Symptomatrix for Feedback. Their data are important for the epidemiological research of the Marijke Foundation that runs since 2008. These visitors find the Symptomatrix sites mainly by the search terms Giant Cell Arteritis, Polymyalgia Rheumatica, GCA and PMR.

The Symptomatrix and the future

By these changes the Symptomatrix i.e. the Symptomatrix Team of the Marijke Foundation meets again the requirements of the future and (potential) patients; like before, the first time in 2003-2004, as pioneers - which we obviously still are.

After all, since the Symptomatrix was first published, practice proves that a growing number of people search the internet for an explanation for their complaints *before* they visit a doctor. There are many signs that the majority of people around the world, connected to the internet, will do so in the near future ¹. Including patients without a proper diagnosis *after* having consulted doctors and/or other (para)medical care, but are *left with unexplained persisting complaints* and thus without treatment.

These developments have interesting impact and cause some unavoidable and irreversible changes.

They lead to *more emphasis on the cooperation between patients and family doctors*. A well prepared patient, in this respect with the help of the Symptomatrix, supports the family doctor in fast recognition of GCA and PMR, which enables GP's in the first place to diagnose the diseases without delay and to start treatment instantly in most cases.

This, and applicable to a lot of other diseases, is already becoming common practice in our country, The Netherlands, and other countries: 'Self-Triage' and 'the GP at home', a rapidly developing very valuable trend.

GCA/PMR, the future and the significance of the Symptomatrix

Taking these developments into account, in our view the best would be to concentrate - money, time et cetera - on research to find the cause of GCA/PMR, particularly targetting at the *development of new, less invasive and less harmful drugs* to replace the old fashioned steroids.

¹ *Dedicated Symptomatrixes* - similar to ours - for other diseases, rare or not, in particular those depending on early recognition > early diagnosis for a better prognosis, are as yet scarce on the internet, but over the years the number will certainly grow.

We believe this should be *an international cooperative project*, involving experts on GCA/PMR around the world. The estimated number of incidences each year, over 4 million worldwide ², seems to be advantageous enough for a pharmaceutical company to be interested. We know that one company already is and we sincerely hope *they will take the initiative*.

Investments in new guidelines, procedures, faster diagnostic techniques and methods and so on are undoubtedly important but a limited added value in relation to the *primary problem* with GCA and PMR: *late recognition and consequently delayed diagnosis and treatment*. It is evident that the major part of this primary problem *does not reside behind but outside the doors of the GP practice, hospitals, clinics and health centres*, and is therefore a problem that cannot be solved by them alone, and definitely not in the first place.

On the contrary, the Symptomatrix does the job. The *Symptomatrix helps indeed to solve the primary problem*, being the only available (public) tool to really gain essential, and in a number of cases even crucial, speed by guiding people with complaints well prepared to the GP and/or medical specialist without delay. Major benefits: preventing patients from going from one doctor to the other in vain, from risks and severe physical damages, some of which are irreversible and cannot be cured (for instance blindness, loss of eyesight, ischemic damage), from occasional fatal progression of GCA, from prolonged suffering from GCA and/or PMR and delayed recovery, from prolonged treatment with steroids and other drugs, and all harm they do.

Moreover *it's the less costly way*. Benefits: less pressure on health care systems, funds, research funds, tax payer's money, patient's money, insurances and other sources.

The persisting significance of the Symptomatrix and final words

It is a matter of realism and common sense to determine that *Early Recognition* will remain the *keyword*, regardless of whatever cause will be found, risk factors are discovered, new drugs will be developed, advanced diagnostic techniques and methods will be designed, guidelines will be published, networks of centres for GCA/PMR specific medical care are organised and so on. So, the *Symptomatrix* will remain *indispensable*.

Thinking differently belongs to the past. It's 2014, time to cross the borders of conventions, resistances of whatever kind and personal interests and ambitions, for the mere benefit of patients.

Though the Symptomatrixes on the internet prove their value for (potential) patients on their own and do not depend on it, any contribution to public awareness of their existence and essential function from everyone involved, concerned and interested, is a welcome added value.

Of course we remain open for cooperation and contributions, for the benefit of (potential) patients.

² Derived from 2003 data from VUmc, Amsterdam - The Netherlands, calculated for 2008.