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Living with MS

What is MS?

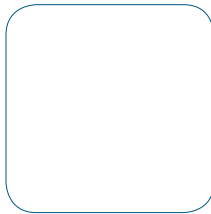
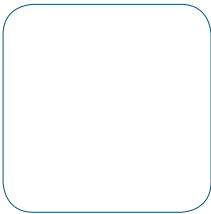
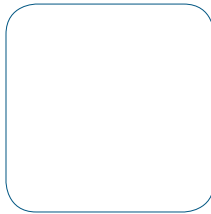
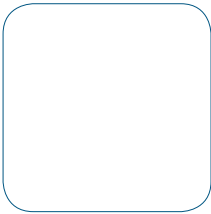




This booklet was created by Biogen. The information has been put together with great care, but it is not a substitute for the opinion, diagnosis or advice of a treating physician.

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1. Introduction

You just found out that you have multiple sclerosis (MS). This answers one question, namely: what is wrong with me? But the diagnosis MS raises a lot of other questions. There are probably a lot of things about this disease that you're not really clear about. This can lead to anxiety and uncertainty. Knowing more means having more grip on dealing with the situation. That is the reason for this information series.

The information series "Living with MS" provides more information about the condition called MS: the various symptoms, the possible treatments, and what you can do to make life with MS as easy as possible. Biogen developed this series of booklets with the help of specialists and experts. The booklets can help you prepare yourself, know what to expect and manage your life with MS.

This is booklet 1 in a series of five booklets:

Booklet 1: What is MS?

Booklet 2: MS and daily life

Booklet 3: MS and treatment options

Booklet 4: MS, sexuality and parenthood

Booklet 5: MS and cognitive function



2. What is MS?

What exactly does it mean to have MS? How, where and why does it start? And what happens over time? These questions are answered below. First of all, MS is not a muscle disease, as is sometimes thought. And not everyone with MS will eventually end up in a wheelchair.

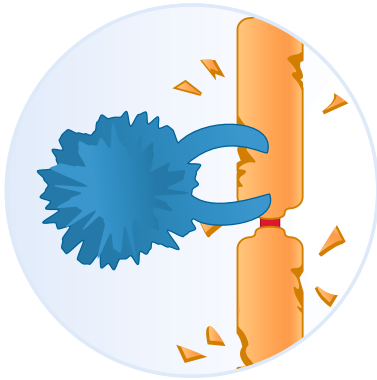


FIGURE 1

Myelin sheath around an axon (nerve fibers) is attacked by an immune cell.

2.1. The role of the immune system

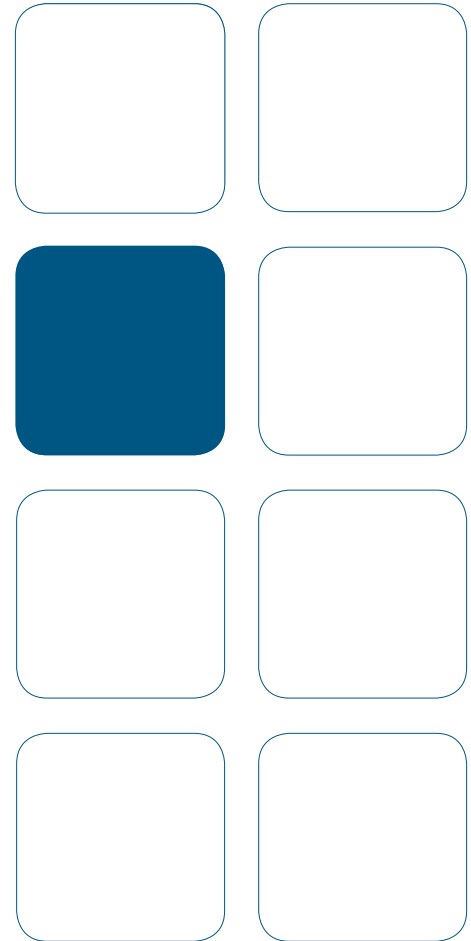
MS is an autoimmune disease. This means that the immune system attacks the body's own cells. This happens in the central nervous system (the brain and the spinal cord), which controls movement and physical functions. The protective layer (myelin) around the nerve cells in the central nervous system becomes inflamed, resulting in multiple scars. This is the literal meaning of multiple sclerosis: "multiple scars".

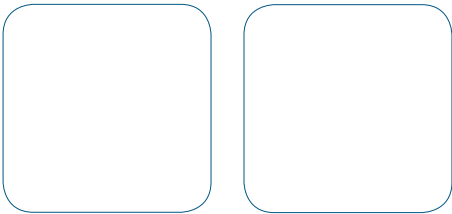
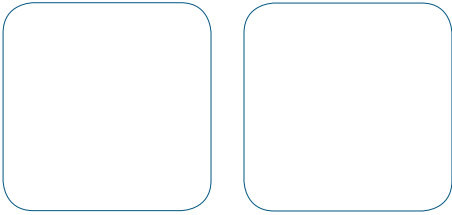
The physical symptoms that may occur as a result vary widely between individuals.

The same applies to the course of the disease, which is unpredictable. More and better MS medications are continually being developed, but there is no cure for the disease yet. The main MS medications suppress the immune system, which slows down the damage to the central nervous system.

Risk factors

A lot of research is being conducted on MS, but we still don't know why the immune system attacks the body's own cells in MS. It could be a combination of genetic and environmental factors.





Heredity

MS is not a hereditary disease, but the risk of developing MS is slightly higher (three percent) if another family member already has the disease, particularly in the first degree (i.e. a parent, brother or sister).

National and international DNA research is being conducted on the role of genes in MS. The DNA of thousands of people with MS and their relatives is tested for genes that might be involved in the onset of MS. A few “MS genes” have already been identified.

Previous viral infections

Previous viral infections, such as Pfeiffer’s disease, slightly increase the risk of MS as well. The theory is that the virus stimulates inflammation in the central nervous system, but how this happens is not clear.

Environment

The risk of developing MS is not the same around the world. The closer you live to the equator, the smaller the risk. MS is most common in Caucasians in Europe, North America and Australia. MS is much less common in (sub) tropical regions.

(Young) age and gender

The first signs of MS usually appear between the ages of 20 and 40. The number of women with MS is almost twice that of men.

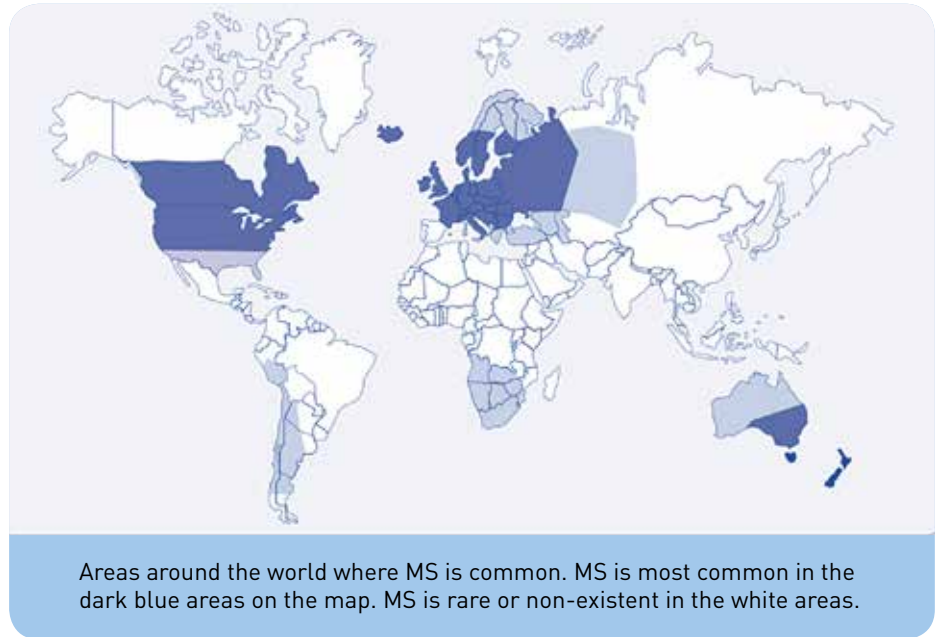


FIGURE 2

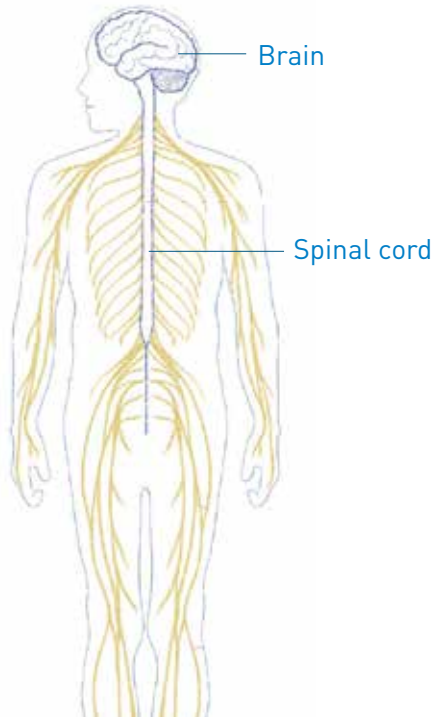


FIGURE 3

The central nervous system consists of the brain and the spinal cord

2.2 The central nervous system and MS

The central nervous system

The central nervous system consists of the brain and the spinal cord. It “controls” the body together with the peripheral nervous system, which branches out through the rest of the body. The peripheral nervous system consists of nerve bundles, which send signals from the senses to the central nervous system. They also receive instructions from the central nervous system for the muscles and organs.

To a large extent you consciously send these signals yourself. This enables you to walk, talk, drive your car and pour the tea, for example. These actions involve the part of the nervous system you can control with your mind: the “voluntary” nervous system. The other part of the nervous system is “involuntary”. This is also called the autonomous nervous system. It controls

functions you cannot influence at will. Examples are the beating of the heart and the contraction of the intestines (peristalsis) to move the contents along.

Insulating layer

The central nervous system consists of nerve cells. Because of its colour, this tissue is sometimes referred to as “grey matter”. The nerve cells are connected to each other and to the body by means of nerve fibers, or “axons”. The central and peripheral nervous systems use these axons to send signals back and forth.

FIGURE 4

The nervous system is the control centre of the body. The nerve fibers are responsible for conducting information. These fibers are used to send external signals, such as sounds, sights and sensations, to the brain (blue arrows) and to send signals from the brain to the rest of the body (red arrows).



A. Nerve cell

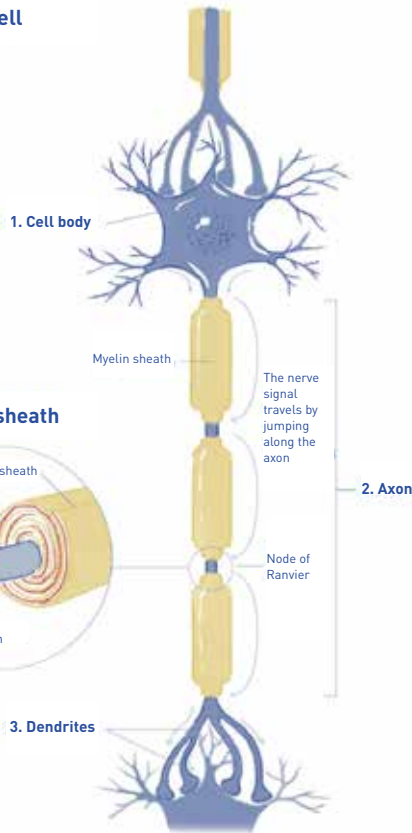


FIGURE 5

An enlarged image of nerve fibers.

A. The arrows show the signals jumping from node to node along the myelin-coated axons.

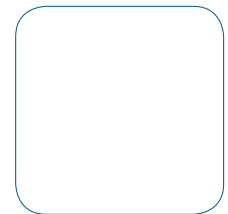
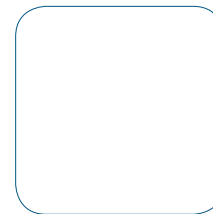
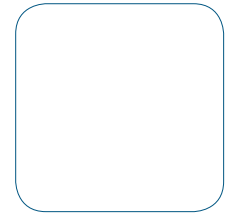
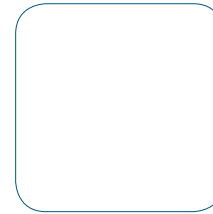
B. A cross-section of a nerve cell in the central nervous system. Layers of myelin form a sheath around the nerve fiber (axon). In reality the axon is covered by many more layers of myelin.

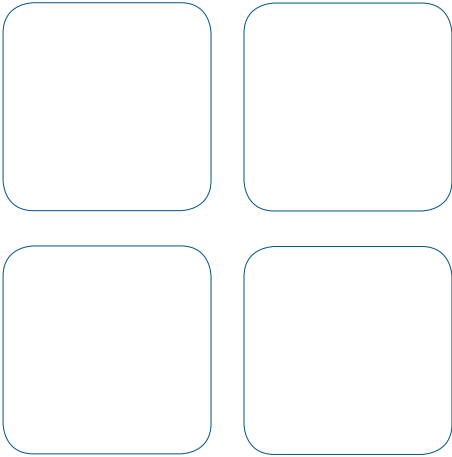
Another way to picture axons is as extremely small electricity cables. These cables have a protective layer, and so do axons. The insulating layer of the axons consists of a fatty substance called myelin. Since myelin is white, it is sometimes called “white matter”. This insulating myelin layer allows signals to travel faster by leaping from node to node. This is especially important if signals have to travel a long way, to the legs for example.

Inflammation

Certain types of white blood cells in the immune system play a crucial role in MS. These cells are called T lymphocytes, or T cells. They are only supposed to attack cells that do not belong to the body. For reasons that are not clear, in MS the T cells also attack the central nervous system, i.e. the body's own cells. The central nervous system is protected by the so-called blood-brain barrier, but the T cells are able to get through.

The T cells end up in the brain, where they start attacking the protective myelin around the nerve projections. The myelin is damaged and becomes inflamed. This results in a type of scarring. At the site of these scars, the myelin protection is less effective. The conduction of signals between the central and peripheral nervous systems becomes less efficient as a result. This is what causes symptoms.





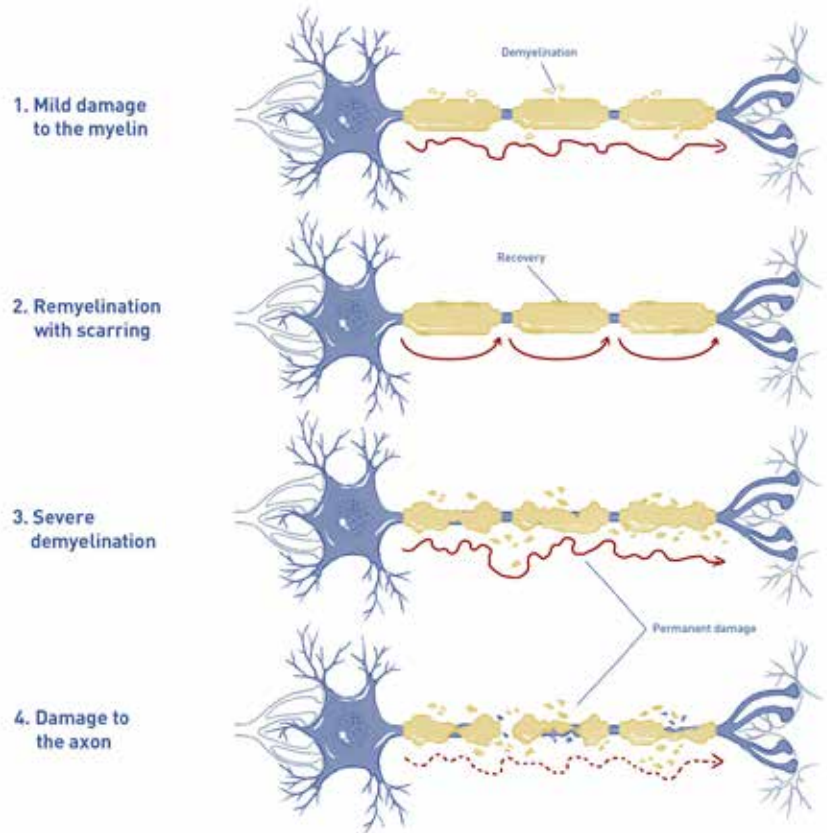
The blood-brain barrier

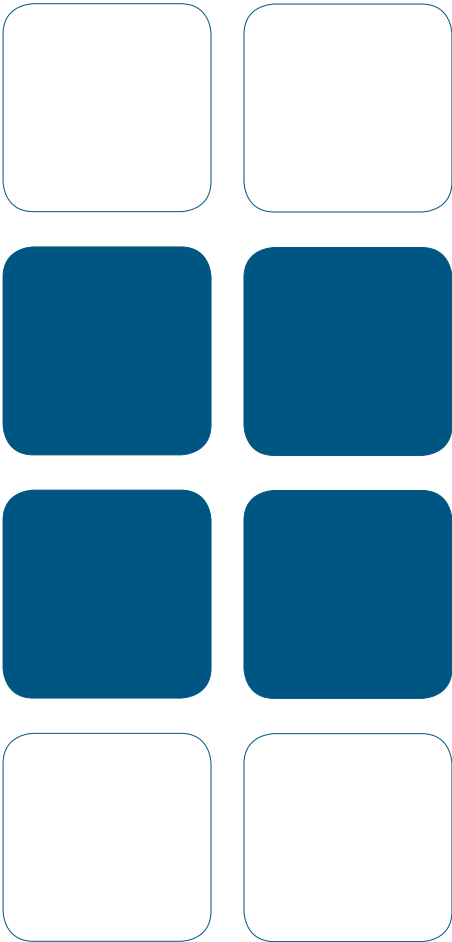
The central nervous system is protected by the “blood-brain barrier”, a wall in the blood vessels around the brain. This wall consists of cells and proteins, which prevent viruses, bacteria, toxins and other foreign substances from getting into the central nervous system. In MS, however, the immune cells (T cells) do manage to get through this barrier and damage the nerve endings in the brain.



FIGURE 6

1. A nerve becomes inflamed, and some of the myelin is lost as a result.
2. The damaged nerve recovers, and the transfer of signals resumes.
3. The nerve becomes inflamed again, but this time there is lasting damage to the myelin which makes the transfer of signals slower and more difficult.
4. Previously damaged myelin becomes inflamed again. This time the nerve projection (axon) is damaged as well, making transfer of information impossible.





Incomplete myelin recovery

The inflammation usually subsides after a few weeks.

The nerve tissue and the myelin recover and signal conduction resumes (Figure 6). Unfortunately this recovery is not always complete, especially if the same location becomes inflamed again. The scars make it more and more difficult for the signals to travel. Eventually it becomes impossible and the nerve fiber is lost. This process is called demyelination.

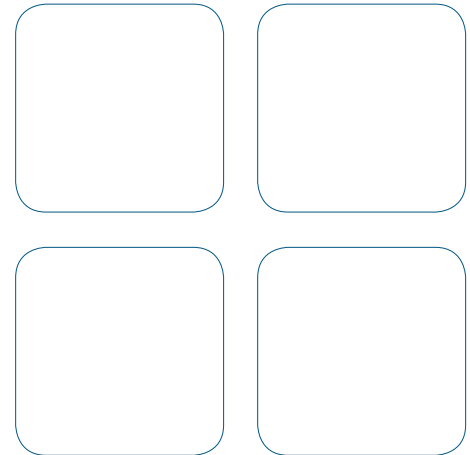
Often there are several (multiple) inflammations, and therefore multiple scars (sclerosis), in different locations in the central nervous system. The resulting symptoms depend on the locations of the inflammations. The severity of the symptoms is different for each patient. Sometimes there are no symptoms at all.

2.3 The course of the disease

MS is an unpredictable disease. Periods of stable disease (which may last a long time) are often interrupted by inflammatory attacks. There are various terms for these attacks: relapse, episode, blip, flare-up, exacerbation (worsening). We distinguish between three main types of MS. The neurologist cannot determine which type you have until some time has passed and you have developed symptoms.

The three types of MS are:

- Relapsing remitting MS;
- Secondary progressive MS;
- Primary progressive MS.



A

Relapsing remitting MS

The course of the disease consists of flare-ups (relapse) and periods of recovery (remission). Around 85% of people with MS have this type during the early stages. After each relapse, the myelin layer around the nerve projection makes a full or partial recovery. The number of relapses and the extent of the recovery is different for each patient.

B

Secondary progressive MS

Once the myelin layer does not fully recover after a relapse to the point that holes start to appear, recovery is no longer possible. The relapsing remitting MS then becomes secondary progressive MS. This type of MS is characterised by “disease progression”. There may be a slow, gradual loss of physical functions. No one can predict when MS will move to this phase.

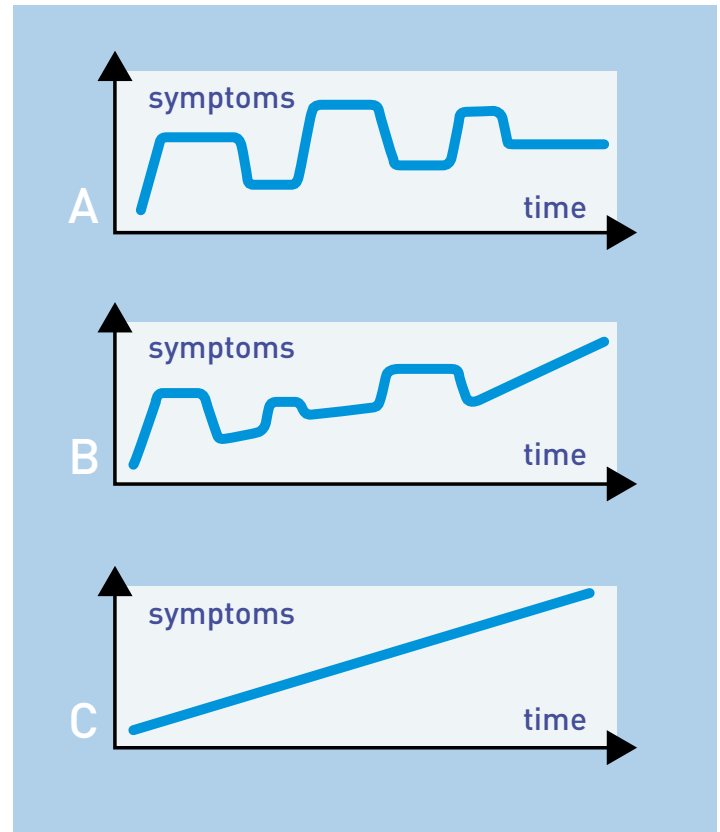
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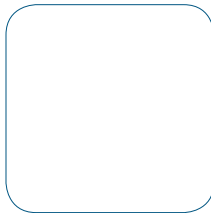
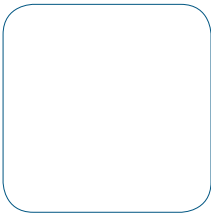
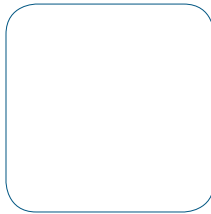
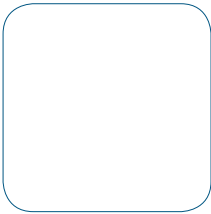
Primary progressive MS

Primary progressive MS is characterised by a lack of myelin recovery right from the start after the first relapses. There is a gradual loss of physical functions; there are no periods of relapse and recovery. Sometimes MS presents with this picture right away. This type of MS occurs in less than 15% of all MS patients.

FIGURE 7

- A. Relapsing remitting MS. The line going up represents a relapse. Recovery after a relapse is not necessarily complete.
- B. Secondary progressive MS. After a period of repeated relapses and recovery periods, there is a point where the patient begins to experience gradual deterioration with intermittent periods of relapse.
- C. Primary progressive MS. There is gradual deterioration, without relapses, with increasing symptoms of the disease and gradual loss of physical functions.





2.4 Continue reading

This brochure has given you an idea of what MS is and what happens to the nervous system. The symptoms you may experience are described in the second brochure in this series, as well as possible treatment and other tips for daily life. They can help you optimise and maintain your quality of life for as long as possible.

The effective treatments that are currently available play an important part in this; brochure 3 tells you more about this. Because MS often starts in young adults, there is a separate brochure that specifically addresses MS, sexuality and parenthood.

Brochure 5 describes the cognitive changes that might happen in people with MS and suggests strategies to help patients with cognitive changes.

Useful addresses

Stichting MS Research (MS Research Foundation)

Postbus 200

2250 AE Voorschoten

t +31 71 560 0500

e info@msresearch.nl

Nationaal MS Fonds (National MS Fund)

Mathenesserlaan 378

3023 HB Rotterdam

t +31 10 591 9839

e info@nationaalmsfonds.nl

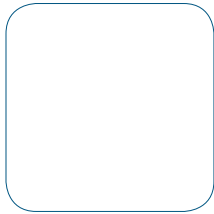
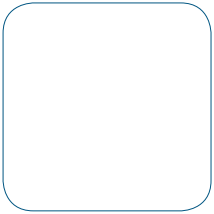
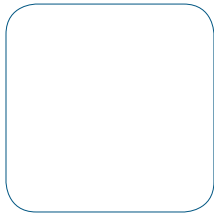
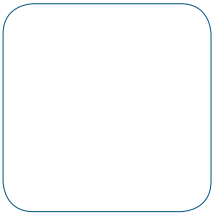
Multiple Sclerose Vereniging Nederland (MSVN, Dutch MS Society)

De Corridor 5c

3621 ZA Breukelen

t +31 88 374 8585

e info@msvereniging.nl

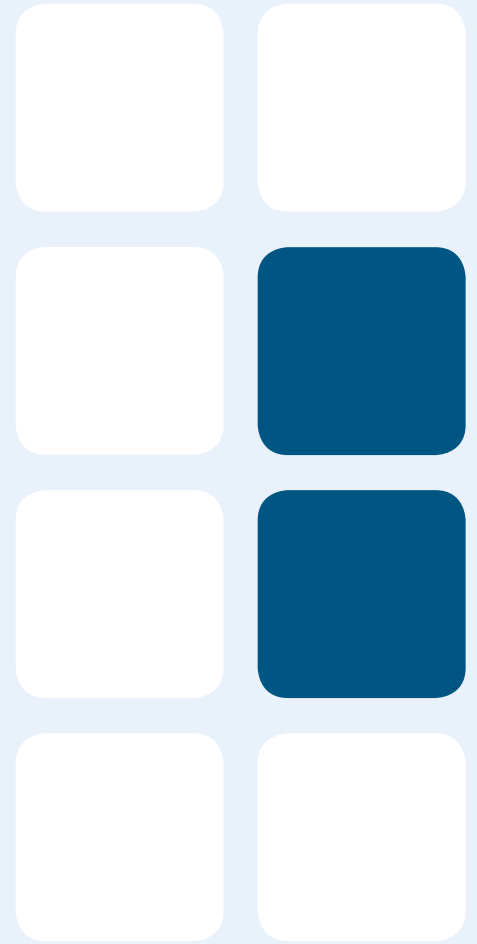


Would you like to know more?

You can find more information about MS at
www.toekomstmetms.nl (in Dutch)

For information about medicines you can consult
www.ema.europe.eu







Biogen Netherlands B.V.

Prins Mauritslaan 13-19

1171 LP Badhoevedorp

Phone: +31 20 542 2000

Fax: +31 20 542 2300

www.biogen.nl