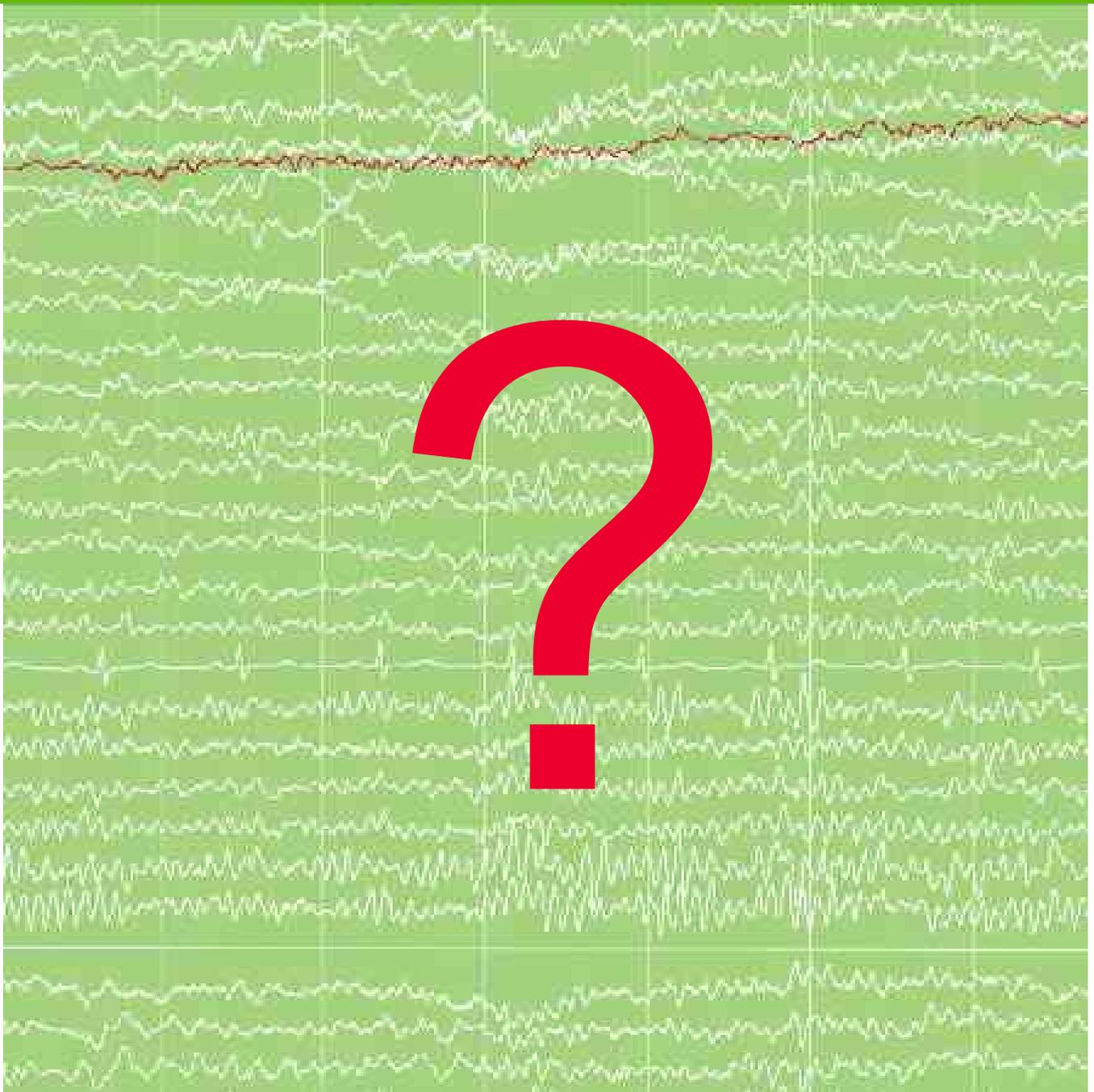


Epilepsy

a brief report



Nationaal Epilepsie Fonds

Introduction

One out of 150 Dutchmen suffers from epilepsy. Despite that, many people still know little to nothing about this condition. Maybe they once experienced someone having a tonic-clonic seizure. That is just one of the ways in which epilepsy manifests itself to the outside world. However, there are many other types of seizures. In general the following is true:

- Anyone can develop epilepsy at any age.
- There is no cure for epilepsy. However, many people who suffer from epilepsy can live a seizure-free life by using the right medication. That is why many of those around do not even realise someone suffers from epilepsy.
- In exceptional cases, the epileptic source can be surgically removed or disabled.
- There is no link between suffering from epilepsy and intellectual restrictions.
- It is true that people with intellectual restrictions suffer from epilepsy in greater numbers. In those cases, the brain damage responsible for the intellectual restriction is often also the cause of the epilepsy. Epilepsy is definitely not contagious.

What is epilepsy?

Epilepsy is a condition which manifests itself in the form of seizures. Seizures are caused by a sudden, temporary disruption of the brain's electrical balance. Seizures vary from person to person. Some fall down and start jerking their arms and legs. Others experience strange tingling, hear strange noises or stare in the distance for a short period of time.

The reason for this is that epilepsy has so many different causes. Those causes determine the type of seizure and their numbers. The prognosis also varies from person to person. Some forms of epilepsy are age-related. This means that the seizures appear within a certain age range and can then disappear as you get older. However, many forms of epilepsy are caused by predisposition, brain disease or brain damage. These seizures hardly ever disappear spontaneously.

You suffer from epilepsy if you have had multiple epileptic seizures within one year. Having had one seizure does not mean you suffer from epilepsy. The seizure could have been triggered by certain circumstances for instance. In that case, the chances of another seizure are very slim. It is also possible that the seizure is caused by another condition. Treatment can only be considered once 'epilepsy' has been diagnosed. Medication is the most common way to treat epilepsy.

Cause

Epilepsy can be caused by a large number of different conditions. In more than half of the cases, no cause can be found (yet). And if tests do indicate brain damage, it is often impossible to find out the cause. Sometimes the cause is predisposition. Heredity plays a major part in this.

All in all, the cause of epilepsy consists of multiple factors: part of these can be attributed to brain disorders; some are hereditary whereas others are caused by sudden, external (inductive) circumstances.

Examples of causes:

- Epilepsy can develop prior to or during birth. An infection or disease during pregnancy, a congenital brain abnormality or lack of oxygen during birth can result in epilepsy in later life. Minor brain damage in combination with a certain predisposition is sometimes enough to develop epilepsy later on.
- A serious disease such as meningitis or brain damage following an accident can be the cause. This does not mean that everyone develops epilepsy following a disease or brain damage. A certain degree of 'predisposition' is also required. Chronic and excessive use of alcohol or drugs can also damage the brain and lead to seizures.
- Sometimes a benign or malignant brain tumour is the cause.
- A frequent cause of epilepsy among older people is a brain haemorrhage or a type of attack (Cerebral Vascular Attack - CVA).
- Scar tissue as a result of a (previous) brain disorder - such as an infection, an abscess, lack of oxygen or after an operation - is often responsible for epileptic seizures. Abnormally functioning brain cells are often found within the edges of the scar.
- It is also possible that a (hereditary) predisposition is the sole cause. In that case, the threshold to get seizures is low. If one or multiple causes arise with that, the chances to develop epilepsy are higher compared to someone without a hereditary predisposition.

Inductive factors

It is often unclear why a person with epilepsy suffers from a seizure at a certain moment. The seizure as it were comes out of the blue. In some instances the reason is clear however: there is a distinct relation between a certain situation and having a seizure. Such occasions are also called triggers. As such, some people will have seizures:

- Following excessive use of alcohol.
- Prior to or after intensive nervous tension.
- Through lack of sleep, for example after a weekend 'out on the town'.
- Prior to or during periods (hormonal changes).
- As a result of intensive light sources, for example during computer games or disco lights.
- As result of intense fluctuation in body temperature, such as in the event of fever.

Heredity

Although it is clear that heredity can play a part in epilepsy, many questions remain unanswered. The chance of two people having a baby suffering from epilepsy can only be assessed based on experience rather than scientific research. It is known however, that some forms of epilepsy are more hereditary than others. Generally there is no need for those suffering from epilepsy to feel deterred when trying for children. The chances of having a baby suffering from epilepsy differ per parents anyway. Since there are various forms, the chances of a child developing epilepsy when one of the parents suffers from epilepsy is between 0 and 50 per cent. On average, the risk varies from 2 to 8 per cent. It does not matter whether it is the male or female suffering from epilepsy. However, the chances of having a baby suffering from epilepsy increase when the disorder is present among multiple people in one family. Chances only increase when both parents suffer. Epilepsy can also be part of another (hereditary) syndrome. As a result risk can increase, sometimes even by 25 to 50 per cent.

When you have questions about heredity and epilepsy, we would recommend discussing the issue with the doctor in attendance prior to conception. If necessary, you can be referred to one of the university hospitals where heredity research is carried out.

Still many uncertainties

Although it is reasonably understood what epilepsy is, what happens during a seizure and the hereditary aspects involved, there still are uncertainties. Medical scientists generally understand the process of signal transfer within the brain, but a lot of questions remain nevertheless. Hence research is carried out into epilepsy, so that more knowledge is available and treatment can be improved in the future.

Examination

Various examinations are carried out in order to diagnose epilepsy; EEG being the main one. The electrical brain signals are recorded by means of an EEG machine (electroencephalograph).

During an epileptic seizure the transfer of these electrical signals is disturbed. This can be seen in an EEG. In the event of epilepsy, the EEG may display a picture which is different than normal, also in-between seizures. A deviation in the EEG cannot always be detected. This is because an EEG provides a random indication. During the measurement, it is often not possible to detect epileptic related activity in the brain. Multiple EEG recordings would be required. Additional examinations are often carried out to find the cause of epilepsy. Using image-producing means such as CT or MRI scans allows highly accurate detection of brain deviations which are responsible for the epilepsy. It does occur that examinations do not yield anything conclusive; epilepsy must then be diagnosed on the basis of disease history and descriptions of seizures alone.

Treatment

Most people who suffer from epilepsy are treated with medication (anti-epileptics). The medication aims to prevent seizures. They do not cure epilepsy. Medication is effective among approx. 70 per cent of people suffering from epilepsy, although it may sometimes take a while to find the right dose.

Anti-epileptics ensure that a person is (practically) seizure-free. When a person has not had any seizures for a number of years, medication can sometimes be gradually reduced. This depends on a number of factors:

- Did medication bring the seizures under control quickly?
- Was only a single type of medication required?
- Did the epilepsy develop at an early age?
- Was there no conclusive cause for the epilepsy?

Medication is not effective among 30 percent of sufferers. If after one to two years the correct medication has not been found, you can be referred to one of the three epileptic centres or affiliated outpatient clinics. A leaflet detailing addresses can be obtained from the National Epilepsy Fund.

Operating is sometimes possible. In the Netherlands, approximately 60 people undergo an operation each year. This concerns people who do not or no longer react to medication and among whom a certain part in the brain can be indicated as the cause for the seizures (the epileptic source).

Types of seizures

Two main groups can be distinguished: partial and generalised seizures. The first involves a disturbance in part of the brain and in the second the disturbance is simultaneously present in both brain halves.

Partial seizures

The disturbance is present in a certain section (or part) of the brain. The symptoms vary greatly and depend on which part of the brain the disturbance occurs. Some seizures are experienced whilst conscious, other seizures involve loss of consciousness. Partial seizures are subdivided in *simple, complex and secondary generalised seizures*. The latter means that a partial seizure can develop into a generalised seizure.

Simple partial seizures

Consciousness during these seizures is unaffected. People therefore are fully aware that they are experiencing a seizure and are able to describe their experiences during a seizure. They cannot stop the seizure. The duration can differ strongly: from seconds to minutes. These seizures are so mild that others do not even notice. The seizure can manifest itself in the following ways:

- Sudden uncontrolled movement of arms or legs
- Smelling unpleasant smells or having an unfamiliar taste in the mouth
- Feeling sensations and/or tingling in hands, arms, legs or feet.
- Twitches around the mouth
- Briefly hearing or seeing things which others cannot see or hear.

Complex partial seizures

Consciousness is affected at all times. The addition 'complex' means that consciousness has been partly or wholly lost. The symptoms vary strongly. Depending on the positional discharge in the brain, various types of complex partial seizures can occur. The temple seizures starting from the temple lobe of the brain rank among those best known. These seizures are often preceded by an aura, as are tonic-clonic (large) seizures. An aura (in fact a little partial seizure) only lasts a couple of seconds and often involves a rising feeling from the stomach area, a strange indefinable feeling which moves up along the gullet. Sometimes an unpleasant taste in the mouth or a strange smell is experienced. A person may also experience an unreal feeling. Sometimes the seizure stops there, other times it continues and consciousness further reduces. Because consciousness reduces, people are no longer aware of their surroundings. They do not respond to anything, not even pain stimuli. When a person comes into contact with hot objects during a seizure, he or she is not aware and can sustain serious injuries as a result. When addressed, no reply will be given or the answer is wrong. Nearby people are not recognised. The eyes are staring, as if someone is looking through you. During these seizures the person will turn white or red in the face. The pupils are dilated and there often is some saliva discharge. Some people display strange behaviour during the seizure. They start wriggling, plucking, shuffling, walking around or open cabinets and doors for instance. They can also make strange facial movements: Pulling faces, whistle movements with the mouth, swallowing and eating sounds.

During complex partial seizures people with reduced consciousness can put themselves into dangerous situations, for example by walking out onto the road. Grabbing unexpectedly or stopping using force can be interpreted incorrectly. People may resist forcefully and sometimes even react violently. This is partly due to reduced consciousness. The best practice is to try and prevent dangerous situations gently. After a few minutes consciousness returns; often preceded by a short period of disorientation. Subsequently, a lot of people suffer from headaches or fatigue. Sometimes there are no symptoms. When no aura, headache or other symptoms are present, people are often unaware that they have had a seizure.

Secondary and generalised seizures

A simple partial seizure can develop into a complex partial seizure and/or a generalised (tonic-clonic) seizure. The local discharge is then extended throughout the brain (both brain halves, left and right). Such a seizure is called secondary generalised, since it only develops into a tonic-clonic seizure in second instance.

Generalised seizures

The disturbance is always present throughout the brain; both in the left and right brain halves. Consciousness is affected at all times. People who experience this do not remember what happened during the seizure. The most common forms are: *absences, myoclonic and tonic-clonic seizures*.

Absences

The word absence is self-explanatory. The seizure progresses very mildly with mostly only a short disturbance of consciousness. These types of seizures are mostly seen during childhood. Unconsciousness sets in and ends suddenly, often without others noticing. During the seizure the person gazes in front of him and does not respond to his surroundings. The eyes temporarily roll away or blink. Sometimes little shocks can be felt in the hands; the head may tilt face down or backwards. To an outsider it seems as if someone is daydreaming. After the seizure people will normally continue what they were doing. Normally absences last less than a few seconds up to one minute. However, it is possible that they occur multiple times a day, sometimes even very frequently. People are unaware of the fact that they are experiencing an absence. It ends as unexpectedly as it started. People are sometimes aware that they have 'returned', for instance when they forget what they were saying. The complexion does not change nor is there a saliva discharge. The absence can be so short-lived that they can hardly be recognised; they manifest themselves in concentration disturbances. These often cause problems at school.

Myoclonic seizures

Myoclonic seizures involve the sudden jerking of arms and/or legs. Sometimes it is a single jerk, other times a whole series. On occasion the whole body jerks. The jerks are so short-lived that consciousness is not or unnoticeably disturbed. When the muscle contractions are fierce, a person may fall over. A myoclonic seizure lasts a short period of time and people rapidly recover following a seizure.

Tonic-clonic (large) seizures

Tonic-clonic means 'contorted and jerking'. The name indicates what happens during a seizure. This is the best known type of seizure, but it is not the most common. During a tonic-clonic seizure, also called a large seizure, sufferers become fully unconscious. Many tonic-clonic seizures start off as a small partial seizure, also called aura (see page 10). When no aura occurs, a person suddenly loses consciousness.

Three phases can be distinguished during a tonic-clonic seizure:

- Tonic phase
- Clonic phase
- Relaxation phase

Tonic phase

This first phase of the seizure lasts about half a minute. As a result of a massive discharge of the brain cells, all the muscles in the body contract, stiffening the body. The contraction of the pectoral muscles squeezes the air out of the lungs. This may result in some sort of yell. The yell is not an expression of fright or pain, as at that moment the person is already unconscious and thus does not feel anything. During the contortion of the chest and because a lot of energy is used at the same time as a result of the massive muscle contraction, breathing is disturbed and people may turn blue. Since swallowing is not possible, saliva accumulates in the throat. The sudden contraction of the jaw may jam the tongue between the teeth. This 'tongue bite' causes a small wound to the tongue or cheek, as a result of which blood may run from the mouth. This often looks worse than it is. The heartbeat is sometimes slightly irregular, after that it is faster than normal.

Clonic phase

This first phase of the seizure lasts about half a minute. The discharges in the brain trigger a defence mechanism as a result of which the body relaxes for a short period of time, followed by the muscles re-contracting. This alternating relaxing and contracting causes the arms, legs and face to jerk. In the clonic phase (jerk phase) breathing is restored, albeit jerkily. The accumulated saliva (sometimes mixed with some blood) is blown out as foam.

Relaxation phase

In the third phase - which can last one to several minutes - the jerks gradually reduce and the relaxation periods increase until the entire body is relaxed. The skin is often pale and breathing is deep and unclear. Sometimes there is loss of urine or the person vomits.

After the seizure

When the jerking has stopped the seizure is over, but he or she will remain unconscious for a little while longer as the brain is exhausted. When a person regains consciousness, he or she is often confused and does not know what has happened. This often involves a headache and the desire to go to sleep. Sometimes there is direct transition from being unconscious to being asleep. In the period following the seizure, people may suffer from muscular pains. The duration of the recovery phase however may proceed in various manners: some are able to continue work after five minutes, others need an entire day or longer to recover.

In the event of an absence, a myoclonic seizure or a simply partial seizure:

- You can do little as a bystander. These types of seizures only last a short period of time and usually stop without intervention. It may help to talk to the person reassuringly and to stay with him or her until the seizure is over.

In the event of a complex partial seizure:

- It is better not take hold of a person suddenly, this may be wrongly interpreted.
- Correct the person in a gentle voice when he or she moves towards danger.
- Keep potential dangerous objects out of reach.
- Stay with him or her until the seizure is over and reassure the person.
- Explain to those around that someone is still somewhat confused or may be irritated in their responses following the seizure, but cannot help themselves.

In the event of a tonic-clonic (large) seizure the general advice is as follows:

Allow the seizure to run its natural course. A large seizure consists of violent movements of the entire body. This often does not last longer than a couple of minutes and stops automatically. Intervention therefore is mostly unnecessary. In addition, it is often useless. During a seizure, a person will not respond since consciousness is disturbed.

- Do ensure that a person does not endanger himself/herself during a seizure. Pull someone away from a busy street or the waterfront.
- Try and protect the head by using your hands or laying a coat underneath.
- Do not try and stop the seizure by trying to prevent the violent movements of arms or legs. This may result in fractures or muscle tears.
- Because the airways are blocked, mouth-to-mouth resuscitation is pointless.
- Sprinkling water onto the face to bring someone round is pointless also.
- Do not put anything between the teeth. A seizure is often so sudden that you will be too late to prevent a tongue bite. Attempts to try and put something between the teeth will be in vain, as the jaws are already clinched tight. If you try nevertheless you may hurt your fingers, the person's teeth or block the airways.
- Try and find information, for example a medical information card, an SOS wristlet or necklace.

After a tonic clonic seizure:

- You should allow the person time to recover and keep bystanders at a distance. The person is relaxed and unconscious. Undo any tight clothing. In order to keep the airways free, the person must be put in the recovery position with the head slightly tilted backwards. This allows saliva and blood, if any (following a tongue bite), to be released via the mouth. As the muscles are allowed to relax, the tongue is prevented from sliding back into the pharynx closing it off.
- Check for any loose items in the mouth.
- Do not allow the person to drink water, because of the drowsiness there is a reasonable chance of choking.

Calling a doctor?

This is only required in isolated cases and is recommended in the following cases only:

- If the seizure lasts longer than 5 minutes or when multiple seizures follow each other in quick succession - see status epilepticus.
- If the person is still unconscious after fifteen minutes; do not confuse this with a deep sleep following a seizure.
- If he or she is hurt, for example after a fall.
- If the person has swallowed water in a bath or swimming pool.
- If it is not clear whether it involves an epileptic seizure.

Status epilepticus

Status epilepticus is in fact not a certain type of seizure, but a seizure which continues to last. It is a prolonged seizure or a series of seizures during which one seizure starts where the other ends, without having recovered from the previous one. The situation can be defined as status epilepticus when the seizure or series of seizures lasts longer than 30 minutes. A status epilepticus can occur regardless of the type of epilepsy, but is reasonably rare. It could be triggered for example when a person suddenly stops his or her medication. Medical assistance is (usually) required.

How do you recognise a status?

When you are familiar with the seizures of a certain person, you will probably recognise when something goes wrong and whether a (potential) status epilepticus may be developing. In such instances it is advised to intervene and call for help (alarm number: 112). When you are not familiar with the seizures or when in doubt, the rule is that a seizure may not last longer than 5 minutes. There may be no cause for alarm, but since it takes a while for aid to arrive it is advised to take precautions and call a doctor or 112.

Administering medication

In the event of a status epilepticus it is necessary to administer medication which will stop the seizure or which prevents subsequent seizures. It is mostly the doctor who decides whether this is required and he will personally administer the medicines. Relatives or acquaintances may administer a rectiol. This is a small tube filled with liquid medication which is administered rectally and which stops the seizure after about 5 minutes. The doctor and the person with epileptic enter into prior agreements in this respect.

Tonic-clonic status

In the event of a status epilepticus of large seizures a life-threatening situation may arise as a result of breathing problems. A doctor must be called immediately. Admission to hospital will also be necessary.

Other status types

Status forms such as simple or complex partial statuses pose less of a direct threat. Yet, adequate treatment and guidance is of course required in those instances also. This can be done by administering additional medication, if so required.

About the National Epilepsy Fund

The National Epilepsy Fund (NEF) actively endeavours to ensure proper treatment and guidance for people suffering from epilepsy. The means which are generated from fund raising are used for educational purposes, scientific research, organising alternative holidays, specialised epilepsy care, individual aid and epilepsy projects in the developing countries. These activities require a lot of money and no government grants are given. This explains why the NEF tries to raise funds independently by arranging annual collections for instance. Donors too contribute to the cause.

The National Epilepsy Fund (NEF) ranks among the oldest funds in the Dutch healthcare system. For over a century the fund has been active in the fight against and research into epilepsy. Do you want to support the National Epilepsy Fund? If so, then please complete and return the campaign voucher in this brochure. You are a donor for as little as € 18.50 per year. On your request, you will receive the informative magazine Episcoop: a joint publication of the National Epilepsy Fund and the Dutch Epilepsy Association (patients' association).

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