

Let's throw ourselves into the breach for ALS!

Does it tickle your fancy to organise an action for a good cause? Are you a born organiser? Do you want to take on a new challenge? Then support patients with the life-threatening disease ALS and sympathise with those who are chained to their wheelchairs or beds. Set up a fundraising activity together.

In order to stop ALS, Money is needed for **A cure for ALS**, our scientific research fund. You can help, for example by taking part in a fundraising action. The ALS League would like to support your action, for example, by providing promotional materials. Send an email to events@ALS.be for more information.



Raise funds online

It is possible to raise funds online. On our platform www.ALSacties.be you can easily help the ALS League Belgium with collecting the money needed for research into ALS. You can start a fund-raising action yourself or join an event. On this platform, you can start a fundraising action yourself or participate in a campaign to raise money.

Do you have a Facebook profile? You can create a donation page, tell us why you want to support ALS League, invite your friends to donate and ask them to share your donation page.



SUPPORT US

BE28 3850 6807 0320

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For yearly donations as of € 40, you will receive a tax return document.

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Founded in 1995

Member of :



International Alliance
ALS/MND Associations

What is ALS?

ALS stands for Amyotrophic Lateral Sclerosis, a progressive, non-contagious but deadly disease characterized by the necrosis of motor neurons and nerves in the brainstem and spinal cord.

Amyotrophy means that muscles no longer receive impulses, leading to their disappearance or atrophy. Sclerosis is the hardening of motor neurons and nerves that are located sideways in the spinal cord.

What are the impacts of ALS on patients and their family and friends?

Progressive paralysis

Because of the loss of motor neurons, muscles become uncontrolled causing the onset of paralysis. This phenomenon may emerge in any muscle group and eventually leads to a complete paralysis of the limbs. Speaking, chewing, swallowing and breathing functions will also be affected. However, mental and sensory capacities usually remain intact, making the disease even more dreadful.

Aid devices

As the disease progresses, the patient becomes dependent on an ever increasing amount of high tech, expensive aid devices, such as an electric wheelchair with adapted navigation systems, a respiratory device or a speech computer. Therefore, the disease implies a considerable financial burden. The family income therefore decreases while costs increase at an alarming speed.

Care

The disease imposes a considerable burden on the patient's family and friends. In addition to the psychosocial consequences, family members will usually start fulfilling roles as major caregivers. The efforts required increase systematically as the disease becomes more prominent.

Who can develop ALS?

Sporadic or hereditary

ALS is not contagious. 90% of the patients contract the sporadic or non-familial form (sALS). They develop the disease "by accident". In only 10% of the cases, the hereditary or familial ALS (fALS) occurs. In the case of hereditary ALS, every descendant of a person with ALS has a 50% chance of inheriting the defective gene and thus of developing the disease. The symptoms of both forms, fALS and sALS, are similar.

More than 200 death every year

There are approximately 1.000 ALS patients in Belgium. Every year, more than 200 patients die and about 200 people are diagnosed with the disease. After diagnosis, a patient is left with an average life expectancy of 33 months. ALS can occur at any age, but it rarely happens that children are affected. Men are more frequently affected than women.

What does the ALS League do?

The ALS League Belgium (ALS Liga België vzw / Ligue SLA Belgique asbl) was founded in 1995 by a group of patients and their family members. The association slowly developed into a professional organization that stands side by side with ALS patients and their family members. These are the specific goals of the League:

- Stimulate and finance scientific research on ALS drawing on our research fund A Cure for ALS.
- Lend technical and logistic devices free of charge (ALS Mobility & Digitalk).
- Inform patients, family members and others about ALS.
- Offer psychosocial support to patients and their families.
- Provide adequate support and care: Budget d'Assistance Personnelle (BAP) and convention INAMI (Wallon region) or PersoonsVolgend Budget (PVB)

and RIZIV-conventie (Flemish region),

- Raise funds in favor of ALS patients.
- Offer home care (liaison) and accommodation at the care center Middelpunt (MaMuze).
- Create public awareness.
- Defend the rights of patients within the different governmental authorities.
- Establish contacts with international organizations to collect and exchange information.
- Organize contact moments / symposiums at a national and international level.

What can you do?

The ALS League does its utmost to help, inform, buy and lend materials, spread awareness and raise funds. However, we do not receive any structural governmental grants; therefore, we completely depend on your financial help. There are many ways to support the League: for yearly donations of € 40 or more, you will receive a tax certificate. Or, you can include ALS League in your will. An overview of all possibilities to donate and of the subsequent allocation of the budgets collected is available at www.ALS.be/en/Support.

An external action is of course a perfect opportunity to support the ALS League as well. You may even want to organize your own fundraising event !

For more general or any additional information, please contact our secretariat or consult www.ALS.be