



BVBE for ALS 2018

Dear all,

Allow us to introduce ourselves: we are a beards club (Bearded Villains Belgium – BVBE) which, besides having fun by sharing a beer, a nice meal and lots of talks about grooming products, also want to give something back to society and therefore, each year, we're putting our shoulders under several charity projects.

1 Of our members, Alain Verspecht, is fighting the ALS disease. Alain is also founder of the non-profit organization 'Een hart voor ALS vzw' and the fund of the same name at the Catholic University of Leuven. This is why, this year, we want to support '**Een hart voor ALS**' with our major charity event in Ghent on August 18th, 2018.

With your help as a sponsor, we want to support '**Een hart voor ALS**' with one clear focus: maximum fundraising for the benefit of scientific research into ALS. We want to realize this by organizing a charity event at: *Eskimofabriek, Wiedauwkaai 23, 9000 Ghent*. Besides several sales stalls, a beard contest and a tombola we are bringing two live bands (Scarved and Good Vibes) on stage and we finish the event with a party with DJ.

ALS or Amyotrophic lateral sclerosis, also known as Lou Gehrig's disease and Charcot disease, is a specific disorder that involves the death of neurons. In the United Kingdom, the term motor neuron disease (MND) is commonly used, while others use that term for a group of five conditions of which ALS is the most common. ALS is characterized by stiff muscles, muscle twitching, and gradually worsening weakness due to muscle wasting. This results in difficulty speaking, swallowing, and eventually breathing.

[Een hart voor ALS](#) has a clear mission: to support and promote the scientific research into Amyotrophic Lateral Sclerosis (ALS). In 2013, the association founded the 'Hart voor ALS fund' at the University of Leuven. Donations to the Fund will go directly to the Belgian ALS research team that consists of more than 20 members and is led by three principal investigators: Prof. Dr. Wim Robberecht, Prof. Ludo Van Den Bosch and Prof. Dr. Philip Van Damme. ALS is a very complex disease, still too little known, and this makes the development of new treatments more difficult.

Thanks to sustained research the knowledge of the causes and mechanisms of motor neuron death, characteristic for ALS, is greatly increased. The research team is also participating in a large-scale international project in which the hereditary code of thousands of ALS patients is examined, which already has led to the discovery of 2 hereditary risk factors for ALS. In addition, a new diagnostic test has been developed to diagnose the disease progression better and faster. That the costs run high for this type of research is obvious. ALS is a fairly rare disease and so it is not always easy to get research funding.

All profits made by this event go entirely towards 'Een hart voor ALS, vzw'

You can also contribute to the research for ALS. This is possible through sponsoring our event. We have different formulas of sponsoring that we would like to explain in appendix.

We are grateful for any kind of sponsorship and/or help.

Best regards,

The BVBE crew.