



**2021**

**ANNUAL REPORT**

**ALS Liga Belgium**

**Together we fight against ALS!**

Despite the impact of the Covid-19 control measures, thanks to you, we continued to co-fund ALS research in 2021. To the extent possible, our staff and volunteers as well as ALS patients and their loved ones, companies and sympathisers organised several campaigns coronaproof in which we put ALS more clearly on the map to generate even more support and especially funds.

Thanks again for your generosity!

in 2021

€ 236.796 was made available to ALS research at KU Leuven/VIB and UZ Leuven via "A Cure for ALS"

in 2021

more than 100 new patients registered with the ALS Liga Belgium

in 2021

the ALS Liga Belgium received more than 150 pALS and carers at its secretariat or via online meetings

in 2021

more than 70 pALS with their carers enjoyed a relaxing and coronaproof BEFORE and/or AFTER summer weekend in Middelkerke thanks to the National Lottery and its players

in 2021

projects, study days and activities where organised digital and coronaproof

Thank you for your support

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*In 2021, the ALS Liga Belgium has been fighting for an ALS-free world for more than 25 years. Together with you and thousands of other patients, volunteers, sympathizers and ambassadors, we work every day in an enthusiastic and professional manner to promote the well-being of ALS patients, their families and friends as well as to financially support scientific research for ALS. We do not only focus on Belgium but are also active at European and international level. We keep our finger on the pulse, think along with policy-makers and seize every opportunity to help eradicate ALS.*

## INTRODUCTION

Evy Reviere, CEO ALS Liga



2021 marked a second consecutive corona year for the ALS Liga Belgium.

When looking back, the sharpest edges of the memory of this difficult period have thankfully worn somewhat off.

But still, 2021 too was a year full of great challenges to guide our operation through the corona pandemic. With great flexibility and creativity, we weathered this storm. Whether we worked at the secretariat or from home, whether we met physically or through a digital way, all channels were always open to you!

Raising funds for ALS research by organizing actions and events where large groups of people come together physically was unfortunately still not possible in 2021. After the -90% dip that our research fund A Cure for ALS already took in 2020, it was under further pressure in 2021. Strong holders in 2021 were fortunately the many pALS, their families and friends who transferred private donations or organized a collective collection on the occasion of a special moment (birthday, wedding, wedding anniversary, ...), e.g. via platforms like Facebook Fundraiser.

Perhaps the most heartwarming moments from 2021 that I cherish are our BEFORE and AFTER summer weekends that we were once again able to organize coronaproof in care hotel Middelpunt in Middelkerke, where I was able to meet many of you.

2022 is heralding itself as a year in which more social interaction will again be possible. Together with all staff and volunteers, we look forward to this with confidence and enthusiasm. We see this as a unique opportunity to get back to a time when we can once again set up actions and activities to revive fundraising. The fight goes on and together we will help eradicate ALS!

Evy





**Danny,**  
**Thank you for your  
inexhaustible  
commitment to the  
ALS Liga Belgium  
over the years !**



The team of staff and  
volunteers of ALS Liga  
Belgium, ALS M&D and  
MyAssist.



## WHAT IS ALS?

**Amyotrophic Lateral Sclerosis (ALS)** is a fatal neuromuscular disease that can affect all muscle groups except autonomously controlled muscles (e.g. heart). ALS is a progressive degeneration of motor nerve cells in the brainstem and spinal cord. Motor nerve cells transmit stimuli from the brain, via nerves to the muscles. Because these stimuli are no longer transmitted properly, the muscles no longer work over time as they should.

ALS is a non-infectious disease whose cause has not yet been determined with certainty. To date, no conclusive treatment or prevention method is known. The average survival time after diagnosis and the specific course of the disease vary from patient to patient, making prognosis difficult. It is therefore important for patients not to focus on averages. Why could they not be the exception? Realistic thinking is of course desirable, but doom should be avoided. After all, stress and fatigue are factors that can accelerate disease progression.

On average, an ALS patient dies 33 months after diagnosis due to paralysis of the respiratory or swallowing muscles. However, there is a considerable spread in the eventual life expectancy of ALS patients.



More information about the disease ALS can be found on our website [www.ALS.be](http://www.ALS.be)

## ALS LIGA BELGIUM: INAUGURATION, MISSION AND VISION

### ➤ Inauguration of ALS Liga Belgium

In February 1995 (Belgian Official Gazette 15.06.1995), the ALS Liga Belgium was officially founded by a group of patients and their family members. After all, there appeared to be a great need for good information, help and coordination of care in ALS.

The ALS Liga Belgium focuses mainly on Belgian ALS patients, but in recent years there have been more and more contacts with patients in France and the Netherlands. Its Board consists exclusively of ALS patients and their relatives. They know the disease ALS and its direct and indirect consequences very well.

The non-profit organization with company number ON 0455.335.321 is under the High Protection of Her Majesty the Queen of Belgium and is a member of the umbrella International Alliance of ALS/MND associations. On a European level, the ALS Liga Belgium is very active in the European Organization for Professionals and Patients with ALS (EUpALS). The aim of this European association which is currently led by Evy Reviers, CEO of the ALS Liga Belgium, is to advocate for pALS; put ALS on the map in Europe; improve access to and information about ALS research as well as create common rules for ALS research across Europe.

Meanwhile, the association grew into a professional patient association that is always ready to help ALS patients and their families. The ALS Liga Belgium has its own secretariat managed by the CEO, Evy Reviers, 3 permanent staff members and a large group of volunteers.

The ALS Liga Belgium relies on the expertise of colleagues at the non-profit organization ALS M&D to provide all kinds of resources to keep the ALS patient's life as comfortable as possible. ALS patients who are members of the association can use this service free of charge. Our resources include wheelchairs, from the simplest manual wheelchairs to the most sophisticated computer-controlled models, communication equipment, environmental control systems, bath and shower aids, electric high-low beds and tilting systems.

The ALS Liga Belgium is always ready to answer questions from pALS and their family members or refer them to medical professionals or the relevant authorities where necessary. We also inform the pALS about the facilities and/or financial allowances they are entitled to.

Finally, the ALS Liga Belgium advocates on behalf of ALS patients by defending their interests and constructively participating in policy for persons with rare diseases. In the past, our expertise and commitment to advocacy has already been transformed into legislative initiatives, such as the priority procedure for people with a rapidly degenerating disease when applying for a personal assistance budget, and the renting system for mobility aids of the Flemish Social Protection Department.



## ➤ Our mission and vision

The ALS Liga Belgium is a non-subsidized national patient association. Our mission is to represent the interests of the ALS patient both nationally and internationally. The ALS Liga Belgium and all its representatives always act with honesty and integrity, behaving in an ethically responsible manner. Specifically, this means that our operations and activities must have the sole purpose of eliminating ALS out of the world and to improve the patient's quality of life.

At the national level, we do this through providing expert care and support for pALS, both mentally and socially (MaMus). We support not only ALS patients, but also their loved ones and all parties involved. We achieve this by raising public awareness and financially supporting scientific research (A Cure for ALS). By calling on the expertise of our colleagues from Mobility & Digitalk, we can complete the support, including the physical level by providing aid goods.

The ALS Liga Belgium also plays a prominent role at the international level. It has already launched several international aid projects, both within and outside Europe, and actively participates within the International Alliance. For instance, under the impetus of Evy Reviere, CEO ALS Liga Belgium, EUpALS was founded. The European Organization for Professionals and Patients with ALS, with the aim of harmonizing European legislation for research and optimizing quality of life for the benefit of all ALS patients across Europe.

We do all this based on our vision that all ALS patients have an unconditional right to appropriate attention medically, socially, financially and morally, regardless of their personal background. To fulfil this mission, we rely on staff and volunteers who share our mission and values. Where the needs of ALS patients are inadequately addressed, we develop the necessary complementary initiatives to meet their needs and constructively work to adapt policies appropriately. We defend the rights of ALS patients and strive to promote their position in our society as much as possible.

## FINANCING SCIENTIFIC RESEARCH FOR ALS IS OUR PRIORITY

To date, no cure for ALS has been found. Nor is it yet clear how the disease develops. Scientific research is therefore vital and fundraising to support such research is a top priority for the ALS Liga Belgium.

We call upon regional, national and European governments to release more funding to allow scientists to accelerate their research. In doing so, we urge less stringent selection criteria for projects focused on rare diseases, and ALS in particular. Through our own ALS research fund 'A Cure for ALS', we are also relentlessly raising funds to support pioneering research.

In addition, we have an active role in research communication to patients with ALS. Via our website and the ALS Newsletter, we inform about the latest developments regarding scientific research from all over the world. We inform about research trials for which ALS patients can sign up and are in close contact with Belgian research teams, in particular with the research teams of the Department of Neurology UZ Leuven of Prof. Philip Van Damme, and the Lab. Neurobiology KU Leuven/VIB of Prof. Ludo Van Den Bosch.

### ➤ Research fund 'A Cure for ALS'

A Cure for ALS is the research fund of the ALS Liga Belgium. Donations to this fund are fully invested in scientific research projects that harbor high chance of success, with no administrative fees charged when donating.

The design, purpose, costs and specific expectations of each supported project are described in detail on the ALS Liga Belgium website.

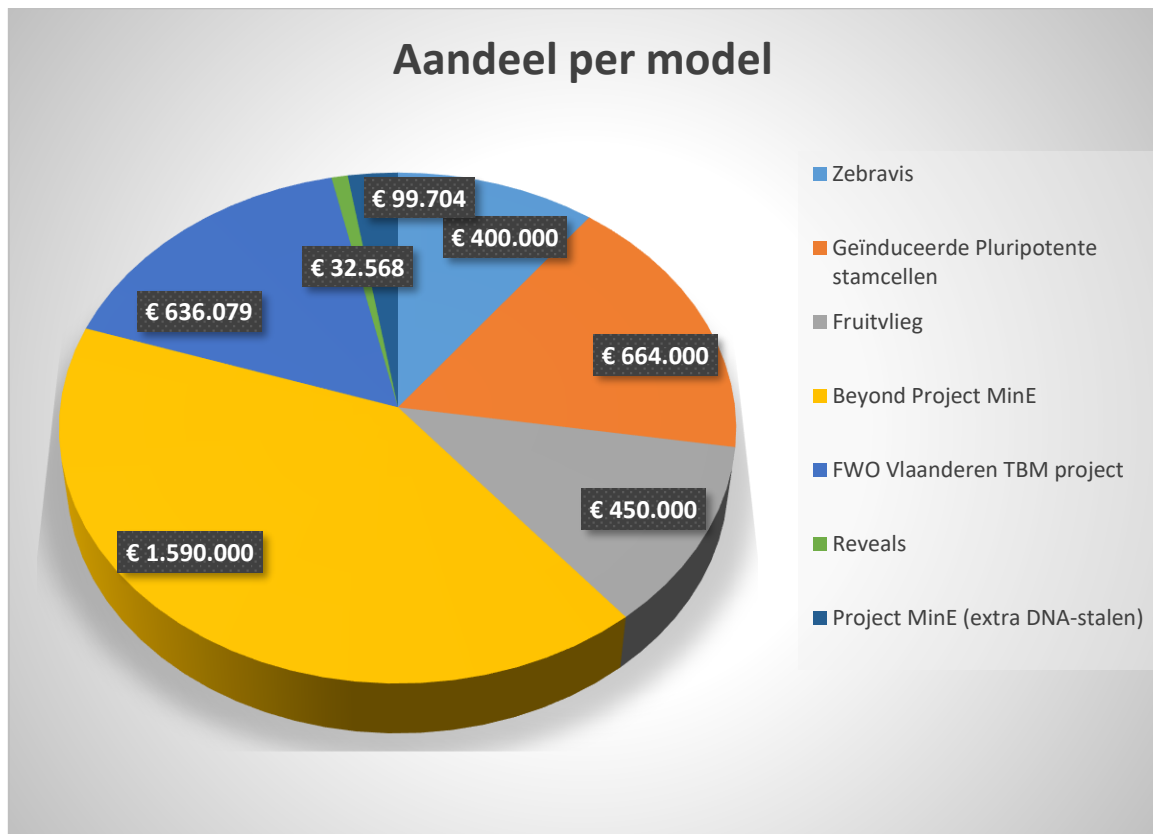
Prof Philip Van Damme and Prof Ludo Van Den Bosch have been specializing in both biomedical and clinical ALS research at KU Leuven/VIB and UZ Leuven for years.

Also in 2021, the ALS Liga Belgium helped financially enable their ongoing projects by generating the following amounts. The amounts communicated include funding for projects running over several years, including 2021:

- ✓ Zebra fish model (Prof. Ludo Van Den Bosch): 400.000 euro (financing completed – research model is sustainably used)
- ✓ Induced Pluripotent Stem Cell model (Prof. Philip Van Damme): 664.000 euro (financing completed – research model is sustainably used)
- ✓ Fruit fly model (Dr. Elke Bogaert and continuation): 450.000 euro (financing completed – research model is sustainably used)
- ✓ Beyond Project MinE (Prof. Philip Van Damme and Prof. Ludo Van Den Bosch): 1.590.000 euro (financing completed – genetic data are the basis for future research)
- ✓ FWO-Vlaanderen TBM project: The FWO-Vlaanderen financed via its programme Applied Biomedical research with a primary Societal finality (TBM) the 4 year project 'Randomised Clinical Trial with lithium carbonate in pALS with UNC13A risk mutation' of Prof. Philip Van

Damme for a total amount of 636.079 euro. The ALS Liga Belgium and EUpALS have a commitment in the advisory committee of this project that runs over the period 01/10/2019 to 30/09/2023.

- ✓ REVEALS study, to investigate the relation between lung function, management of secretion and airway infections: 32.568 euro.
- ✓ Analysis of additional DNA samples by the Lab. Neurobiology of KULeuven/VIB and the NMRC UZ Leuven, as the Belgian branch of Project MinE that investigates the genetic cause of ALS: 99.704 euro.



Once again, researchers made a lot of progress in our understanding of how motor neurons die prematurely in patients with ALS.

In the ALS research at Leuven, we try to contribute to basic research as well as clinical research with patients. We try to better understand the causes and mechanisms of motor neurone death, but we also focus on clinical research. This way, we try to better characterise the disease in patients and contribute to the development of new treatments for the disease.

*Ongoing clinical studies*✓ **Apellis MERIDIAN study with pegcetacoplan**

This phase 2 study is sponsored by the company Apellis Pharmaceuticals and investigates whether inhibiting complement activation has an effect on ALS disease progression. It is a multicentre placebo-controlled study comparing pegcetacoplan with placebo. Pegcetacoplan is an inhibitor of complement protein C3. Complement activation plays a role in neuromuscular junction damage in patients with ALS. By inhibiting this type of inflammation, it is hoped to demonstrate a beneficial effect on disease progression.

The medication is administered by subcutaneous injection twice a week. ALS patients who are at least 18 years old, have not been ill for more than 18 months, have a lung function (SVC) of more than 60% and have an ALS-FRS-R score of  $\geq 30$  are eligible to participate in this study. There will be 228 patients worldwide participating in the study. The study lasts 52 weeks and will be followed by an 'open-label' study (in which all patients receive the active product) of another 52 weeks.

✓ **Ionis FUSION study with FUS ASO**

A multicentre, double-blind randomised placebo-controlled phase I-III study to assess the effect, safety, pharmacokinetics and pharmacodynamics of intrathecally administered ION363 in patients with amyotrophic lateral sclerosis (ALS) with an FUS mutation.

This phase I-III study is sponsored by IONIS Pharmaceuticals and investigates whether reducing FUS protein levels using antisense oligonucleotides directed against the messenger RNA molecule of FUS has a beneficial effect in ALS patients with an FUS mutation.

FUS mutations are a rare inherited cause of ALS and aggregation of the protein FUS occurs in these patients. ION363 is an antisense oligonucleotide or ASO administered intrathecally to inhibit the formation of the FUS protein. A dose of 100 mg is investigated in this study; after several loading doses, the drug is administered once every three months. In the first phase, 1 in 3 patients will receive placebo. A second phase of the study is an 'open label' study, in which all patients are administered the active product. Patients who deteriorate significantly during the first part of the study will be able to switch to the second part of the study at an accelerated rate. Globally, 50-60 patients will be included.

✓ **Biogen ATLAS study with SOD1 ASO in presymptomatic carriers**

A phase III, double-blind randomised placebo-controlled study with a run-in period and an open-label extension period, to investigate the effect of BIIB067 in presymptomatic adult carriers with confirmed mutation in the Superoxide Dismutase 1 (SOD1) gene. BIIB067 is an antisense oligonucleotide treatment, administered monthly intrathecally, that decreases the expression of the SOD1 protein. It is a promising treatment for ALS patients with an SOD1 mutation.

This phase III study is sponsored by Biogen and will investigate whether monthly intrathecal administration of BIIB067 can prevent or delay the onset of ALS in SOD1 mutation carriers.

Only specific mutations in the SOD1 gene, associated with a rapidly progressing form of the disease, are eligible. During an initial phase of the study, asymptomatic mutation carriers will be followed with monthly blood draws to monitor neurofilaments. If an increase in

neurofilaments occurs (typically several months before disease onset), study participants will start BIIB067 or placebo. When the disease becomes clinically evident, all participants will be able to be administered BIIB067.

By this, it is investigated whether preventive treatment with BIIB067 is effective.

✓ **Ferrer ADORE study with FAB122 (oral formulation of Edaravone)**

A multicentre, double-blind randomised placebo-controlled study to assess the effect and safety of FAB122 (oral form of Edaravone) in patients with Amyotrophic Lateral Sclerosis (ALS).

This phase III study is sponsored by Ferrer Internacional and will investigate whether taking Edaravone by mouth can inhibit disease progression in ALS. In 2017, the FDA approved an intravenous form of Edaravone for the treatment of ALS. A study found that an intravenous administration of 60 mg per day for 10-14 days per month slightly slowed the disease progression. Edaravone is a drug that can scavenge free radicals and thus reduce oxidative stress. The current study is studying the effect of continuous treatment with Edaravone by oral route. Patients receive either Edaravone (100 mg daily) or placebo in a 2:1 ratio and the effect on disease deterioration is measured. The study lasts 48-72 weeks.

Patients with ALS who are between 18 and 80 years old, have been ill for less than 24 months, have a lung function (SVC) of  $\geq 70\%$  and have a disease progression of 0.35 to 1.5 points per month on the ALS-FRS-R are eligible to participate in this study.

✓ **Cytokinetics COURAGE study with Reldesemtiv**

Phase III, multicentre, double-blind, randomised, placebo-controlled study to assess the effect and safety of Reldesemtiv in patients with Amyotrophic Lateral Sclerosis (ALS).

This phase III study is sponsored by Cytokinetics, INC.

Patients with ALS who are aged between 18 and 80 years, have been ill for less than 24 months, have a lung function (SVC) of  $\geq 65\%$  and have a score of 44 or less on the ALS-FRS-R scale are eligible to participate in this study. The study medication is taken by mouth and should not be crushed.

Reldesemtiv is being investigated as a possible new treatment to improve muscle function.

In the first phase, two in three participants will receive two tablets of Reldesemtiv twice daily and one in three will receive placebo (these are tablets with no active ingredient). Allocation into the groups is done randomly. Neither the patient nor the researcher can choose which treatment group someone is assigned to. This first part lasts for 24 weeks. This is followed by a second part of the study, in which all participants will be administered Reldesemtiv.

This study will involve about 555 participants around the world.

✓ **TRICALS MAGNET study with Lithium Carbonaat in pALS with UNC13A variation**

A multi-arm, adaptive, group sequential research network for individuals affected by amyotrophic lateral sclerosis, aiming to investigate the effectiveness of treatments. The research network is organised by TRICALS. The current study arm aims to compare the effect of the drug Lithium Carbonate (Lithium) with a placebo.

This is a phase III, multi-arm, double-blind, randomised, placebo-controlled study. Lithium is a drug, currently approved and registered, to treat mood disorders. However, lithium affects multiple biological mechanisms involved in amyotrophic lateral sclerosis. Previous research has shown that the drug has, potentially, an inhibitory effect in patients affected by ALS with a variation in the UNC13A gene.

Based on DNA testing, the investigator determines eligibility for participation in this study. Only patients with a variation in the UNC13A gene are eligible to participate. One has a 2/3 chance of receiving the active substance and a 1/3 chance of receiving a placebo. In Belgium, UZ Leuven is participating in this study.

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*"The ALS Liga Belgium is proud of the Belgian researchers and the progress they are making. This is precisely why we have chosen to support them through donations to the ALS Liga Belgium," says Evy Reviere, CEO. "For years, we have enjoyed a good collaboration with KU Leuven and are happy to work with them to achieve a breakthrough."*

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Scientific research into ALS has many facets, that is proven by the several young researchers affiliated to the KU Leuven/VIB Lab Neurobiology (Prof. Ludo Van Den Bosch and Prof. Philip Van Damme) who defended their PhD, which was co-funded by the ALS Liga Belgium.



PhD's were also defended in corona times, without an audience, but very valuable nonetheless. Our congratulations to the doctoral students.

Joni Vanneste received her PhD on 25 March 2021 on the topic "The role of nucleocytoplasmic transport in C9orf72 amyotrophic lateral sclerosis".

Laura Famagalli received her PhD on 21 September 2021 on the topic "Axonal transport defects in C9orf72 ALS/FTD: the role of dipeptide repeat proteins".

Looking to the future, the ALS Liga Belgium keeps putting research project funding at the top of its agenda. For an overview of the studies already accomplished, please visit our webpage.

*And you too can help !!!*

*Join us and the researchers in the fight against ALS.*



### ➤ Project Mine and Beyond Project MinE

Launched in 2017, Project MinE is a large-scale international study that investigates the genetic cause of ALS and serves as the basis for concrete leads to develop an effective treatment for ALS. By comparing the genetic DNA of 15,000 ALS patients with 7,500 control subjects, the aim is to identify the differences between the two and thus develop tentative steps towards a possible cure for ALS. This project was also supported in Belgium, and not least by the ALS Liga Belgium.

In 2018, the Lab Neurobiology (KULeuven/VIB) was the first international Project MinE partner to finalise the 750 DNA samples allocated to Belgium.

Thanks to the support of our donors, we were able to give an additional €99,704 to the Belgian branch of Project MinE in 2021 to have an additional 103 pALS DNA samples analysed. This brings the number of DNA samples analysed by Belgium to 853, which is 114% of the original target.



In Beyond Project MinE (which ran over a 3-year period), these scientific results were further validated in different animal models and induced pluripotent stem cells (iPSC) from ALS patients.

More information about this project:



## ➤ TRICALS

TRICALS - the Treatment and Research Initiative to Cure ALS - is a European collaboration to find better and more effective treatments for ALS under the motto *the right drug for the right patient at the right time*. There, ALS top scientists join forces with EUpALS, for involvement of all European pALS and to seek advice from the EUpALS Patients and Carers Expert Board. After all, it is very important for pALS to be involved in clinical research for a cure for ALS from the earliest stages! To raise the necessary financial resources, the 14 ALS top research centres from the 14 participating countries cooperate with their national ALS association. Belgian partners in TRICALS are the NMRC UZ Leuven (Prof Philip Van Damme) and EUpALS (Evy Reviers), of which the ALS Liga Belgium is a member.

TRICALS received approval from the European Medicines Agency (EMA) to conduct ALS clinical trials via an innovative platform approach. The first arm on the TRICALS MAGNET platform recently started, testing the effect of lithium carbonate in pALS with a UNC13A variation.

In September 2021, the scientific journal *Journal of Medical Internet Research* published the article 'A Road Map for Remote Digital Health Technology for Motor Neuron Disease' co-authored by EUpALS (Evy Reviers), describing an innovative platform approach for remote follow-up of pALS.

**TRICALS**  
The highway towards a cure

## IMPACT ON POLICY AND PROJECTS

By its expertise, the ALS Liga Belgium provides input into, and cooperation with; the various governments so that persons with a rapidly degenerative condition can receive the necessary support when they need it. In doing so, we often work closely with Mobility and Digitalk to include their expertise in the field of assistive devices and strive for a global, efficient and effective policy that works for pALS and persons with a rapidly degenerative condition.

Over the past year, we have kept a finger on the pulse as well as taken action to weigh in on achieving and optimising an adapted policy on topics such as:

- Palliativ status
- End of life decision
- Reimbursement of home adaptations and aid goods
- The age limit of 65 years old for benefits from the Flemish Agency for People with Disability (FAPD)

The ALS Liga Belgium and a number of other associations for people with disabilities entered a FAPD collaborative project in 2019 that will run over a 3-year period. The aim of this project is to find out how often people with a disability or condition call on the information function of patient associations and other user associations. In this way, the Flemish government hopes to get a clearer picture of the type of questions and the importance of these organisations, which are too often the first point of contact for patients and people with disabilities.

Furthermore, the ALS Liga Belgium asked, via a memorandum to the Flemish and federal governments, to create a framework that allows an employee of its organisation to attend the multidisciplinary patient consultation of the seven different neuromuscular reference centres (NMRC) at UZ Leuven, UZ Antwerpen, UZ Gent, UZ Brussel, UCL Saint-Luc, Erasme Bruxelles and rehabilitation hospital Inkendaal. This way, the expertise of both parties can be combined to create an optimal and efficient care framework. This seemed best possible to us by creating an additional function within the ALS Liga Belgium that could be flexibly deployed according to the NMRC's planning and the patients' needs. Creating this function, we felt, would contribute enormously to the quality of life of patients with ALS and their loved ones.

In 2021, the ALS League also applied to the King Baudouin Foundation and the Marianne and Jean Mechelynck Fund under the project call 'Support for professionals and volunteers in communicating and talking to patients and their relatives around palliative care'. We are proud to announce that our project application titled 'Making end-of-life and palliative care negotiable among ALS patients and their loved ones: a bilingual e-learning for all caregivers supporting ALS patients.' was accepted. The aim is to make healthcare providers aware to engage in early conversation around palliative care. To this end, we focus on knowledge acquisition and attitude building, using a patient-centered and experience-based approach. This project will be set up in cooperation with all neuromuscular reference centers in Belgium and will be officially launched in 2022, running until May 2023.

## INFORMATION AND SUPPORT FOR PATIENTS AND THEIR LOVED ONES

### ➤ Providing information

Our website [www.ALS.be](http://www.ALS.be) provides the most up-to-date information about our operations.

Everyone can find comprehensive information there about ALS disease, the care needs of pALS, the support offered by the ALS Liga Belgium and the government, the state-of-the-art of scientific research on ALS and clinical trials of potential ALS drugs, etc.

The importance of our website in our organization continues to grow. In 2021, our website [www.ALS.be](http://www.ALS.be) had over 316,602 page views.

In addition, the ALS Liga Belgium is very active on social media like Facebook and Twitter. By this, we keep in touch with pALS, their families, caregivers and all our other stakeholders on a daily basis.

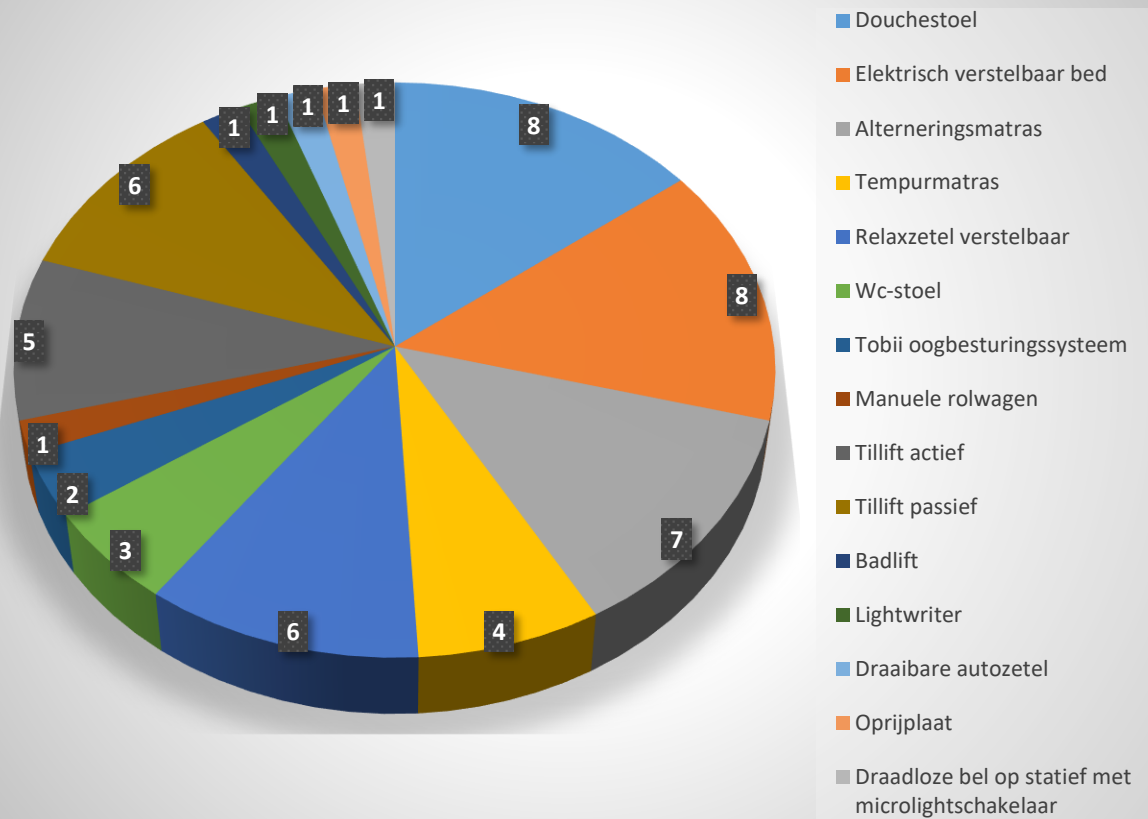
### ➤ Patients are invited to register

pALS are invited to join the ALS Liga Belgium for free. This can be done through our web application. Family members or friends can also sign up for free.

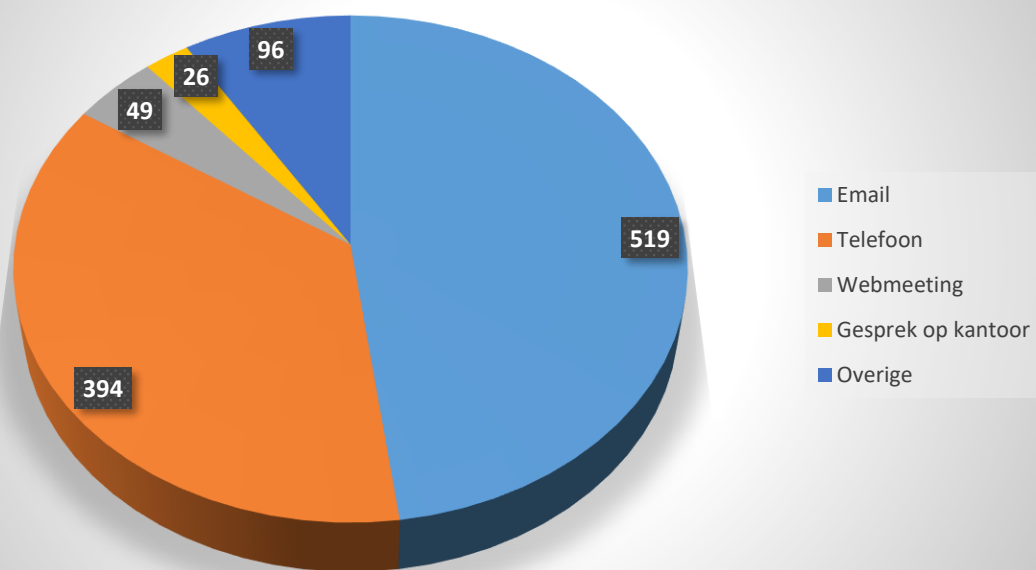
All pALS are invited to the ALS Liga Belgium secretariat at least once. On that occasion, they receive customized information of a general nature and also of a strictly individual nature. The latter mainly takes the form of answers to personal questions. During their visit, pALS learn about the possibilities of granting aids, their use or their possible replacement. Replacement of aids usually involves adapting the aid to the state of evolution of the pALS' state of health.

In total, we had about 1,100 face-to-face interventions and numerous telephone and virtual contacts in 2021. At the secretariat, we welcomed over 100 pALS. To comply with the measures of Covid19 and teleworking, web meetings were added to the contact offer. Thus, during the six-month period when the ALS Liga Belgium switched to telecommunication, around 50 intake meetings were organised via web meeting. At each visit, information is provided and, if necessary, tools are lent out. As far as mobile aids are concerned, from 2019 input from the ALS Liga Belgium in Flanders was reduced to a minimum, as the new regulation via VSB provides for the renting of mobile aid goods (rollator, scooter, power wheelchair or manual wheelchair) for all persons with disabilities. Of course, the ALS Liga Belgium is still ready to step in in case of need and for our Walloon pALS. Furthermore, 44 pALS were supported with aid goods, either because they were no longer eligible for government support given their age, or pALS wishing to bridge the waiting period of their subsidised aid goods.

### Hulpmiddelen uitgeleend M&D 2021



### Ondersteuning patiënten



## A visit from our Liaison

Since the end of May 2014, the ALS Liga Belgium has an external ALS Liaison. This project, into which convention hospitals have also entered, is funded by the federal government in collaboration with the NIHDI.

The Liaison function aims to provide pALS who are in an acute home situation with the tools and helplines to remain as self-reliant as possible. After the pALS' context and help request is clear, tailor-made advice is given and the patient is supported with information.

This procedure runs as follows:

In a first phase, pALS and informal carers are invited for an exploratory interview in order to identify their specific need. Every pALS who applies to the ALS League will be invited for an interview at the secretariat. That way, we hope to reach as many pALS as possible. In acute situations, a home visit is of course scheduled.

In a second phase, a roundtable is organised with all parties involved, possibly including caregivers, to work out a solution. After both personal input, and possibly professional input has been given, the most optimal situation for the pALS is outlined.

In the final phase, a personal care plan is drawn that, through counselling, strives for an optimal home situation.



The ALS League offers a free, tailor-made service to support the individual and specific needs and requirements of patients:

- register for free with the ALS League (via our website);
- make an appointment at the secretariat;
- in case of emergency, the Liaison can come to you;
- a solution will be sought that works for you, your care givers , and informal carers;
- we provide creative solutions without the need for too big changes.

ALS Liaison

[liaison@ALS.be](mailto:liaison@ALS.be)

016/23.95.82

## OUR ACTIONS AND ACTIVITIES – WE FIGHT AGAINST ALS!

Throughout the year, both on the initiative of the ALS Liga Belgium and on the initiative of a very large group of pALS, family members and friends, relatives or other sympathizers, various actions are launched to raise funds for the ALS Liga Belgium. Unfortunately, the Covid-19 virus also meant that many activities could not take place in 2021.

We thank all the organizers for their commitment and perseverance especially in this difficult year. An overview of all activities can be found on our Facebook page and our webpage.

### ➤ Global ALS Day

June 21 has been declared Global ALS Day. The ALS Liga Belgium tries to bring ALS to the attention of governments and the wider public on this day. The ALS Liga Belgium does this by organizing activities, actions by our ambassadors as well as media campaigns.

In 2021, ALS ambassador Simon Mignolet created a video message to raise awareness of ALS patients.



### ➤ BEFORE summer weekend - juni 2021

At the end of June 2021, the ALS Liga Belgium organised its second BEFORE summer weekend with patients and informal carers at care hotel Middelpunt in Middelkerke.

The easing of the corona measures allowed us to host 27 pALS with their companion. It was nice to see familiar faces again and to welcome new ones.

The theme of this edition was hot Mexico. Special thanks go to our financial sponsor the National Lottery and its players and partywear365.be for sponsoring the party items. Of course, we also thank the Middelpunt staff and our fantastic volunteers.



## ➤ AFTER summer weekend - september 2021

Also in September 2021, pALS met at care hotel Middelpunt for the AFTER summer weekend. During the weekend, we imagined ourselves in Austria, the land of lederhosen, Mozartkugeln and Edelweiss.

On Saturday, the whole group took a nice walk on the dyke and visited the FC De Kampioenen sand sculpture festival in Middelkerke. That same day we ended with a fun karaoke evening.



Special thanks goes to our financial sponsor the National Lottery and its players, and to DK Rents for providing a bouncy castle and a large 4-Up-1 Row for the children free of charge. The contact weekends are also co-sponsored by the ALS Liga's MaMuze Fund.



The ALS League is always looking for new campaigns, activities or other sponsorship events. Publicise your activity in favour of the ALS Liga Belgium and we will be happy to help you with promotional material or, if desired, put you in touch with a pALS who would like to contribute to your campaign.

Companies wishing to sponsor the ALS Liga Belgium are also welcome to contact our PR & Events department.

Discover our website for registering actions !

ALS Liga PR & Events  
[events@ALS.be](mailto:events@ALS.be) - 016/23.95.82

## DE ALS LIGA AND THE REST OF THE WORLD

### National level

The ALS Liga Belgium is represented in several national umbrella patient organizations notably Onafhankelijk Leven (Independent Living), Vlaams Patiëntenplatform (VPP) and GRIP vzw. This commitment involves participation in the governing councils and general meetings, as well as support for any initiatives taken towards policy makers. During the board councils, the activities of the respective organizations are steered and evaluated.

ALS M&D is also represented in the Special Technical Commission (BTC) of the Flemish Social Protection (VSB), which evaluates applications for non-standard mobility aids.

### European level

At the European level, Evy Reviere, CEO of the ALS Liga Belgium, holds a number of key positions in European advisory bodies and patient representative bodies.

Since 2015, Evy Reviere is a patient representative in scientific advisory procedures for the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA) ([www.ema.europa.eu](http://www.ema.europa.eu)).

She is actively involved in the European Reference Network (ERN) EURO-NMD ([www.ern-euro-nmd.eu](http://www.ern-euro-nmd.eu)), as a member of the Patient Advocacy Group, the Executive Committee, and the Neuromuscular Special Working Group. In addition, she chairs the Ethics Committee. In February 2021, the article 'Survey on patients' organizations' knowledge and position paper on screening for inherited neuromuscular diseases in Europe' was published in the scientific journal *Orphanet Journal of Rare Diseases*, co-authored by ALS Liga (Evy Reviere) through the ERN EURO-NMD Patient Advocacy Group.

In 2016, Evy Reviere founded a new European ALS organization EUpALS - European Organization for Professionals and Patients with ALS ([www.ALS.eu](http://www.ALS.eu)) - with the aim of creating equal rights for all European ALS patients and, among other things, providing them with better information about and better access to ALS clinical trials. She also chairs this organization.

As of 31 December 2021, the EUpALS Board of Directors was composed as follows:

- ✓ Evy Reviere, ALS Liga Belgium, Chairwoman
- ✓ Gorrit-Jan Blonk, Stichting ALS The Netherlands, Treasurer
- ✓ Gudjon Sigurdsson, MND Association Iceland, Secretary
- ✓ Christian Lunetta, AISLA Italy, Director
- ✓ Joaquin de la Herran, Fundacion Luzon Spain, Director



## Global level

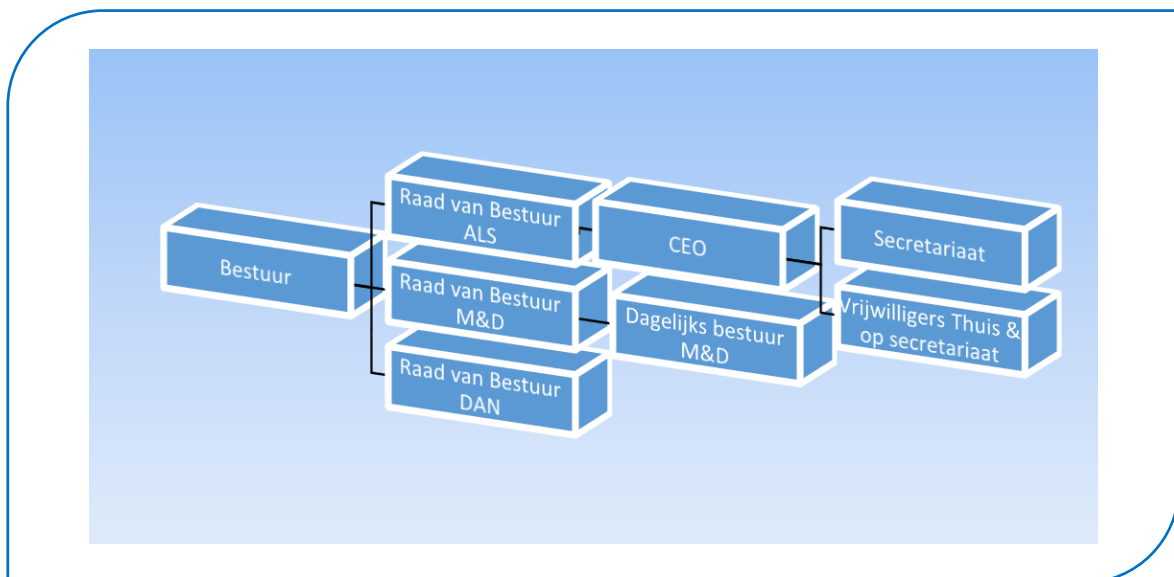
In addition to these national and European commitments, the ALS Liga Belgium aspires global responsibilities. The ALS Liga Belgium is a member of the International Alliance of ALS/MND Associations ([www.alsmndalliance.org](http://www.alsmndalliance.org)). ALS Liga Belgium CEO Evy Reviers completed a second 6-year term as a member of the Board of Directors on 4 December 2017, and also serves as Honorary Treasurer.

## ALS LIGA BELGIUM – OUR ORGANIZATION AND GOVERNANCE

### ➤ Our organization

The non-profit organization ALS Liga Belgium was founded in February 1995 (Belgian Official Gazette 15/06/1995). The ALS Liga Belgium is under the High Protection of Her Majesty the Queen of Belgium. The organization works closely with the non-profit organizations ALS Mobility & Digitalk (renting out free of charge adapted aid goods), ALS DAN (establishment and operation of the ALS Care Home in Middelkerke) and MyAssist vzw (assistance organization).

### ➤ Organigram



### ➤ Daily management and staff

The daily management is provided by the CEO of the ALS Liga Belgium together with the chairman of the Board of Directors as well as the treasurer.

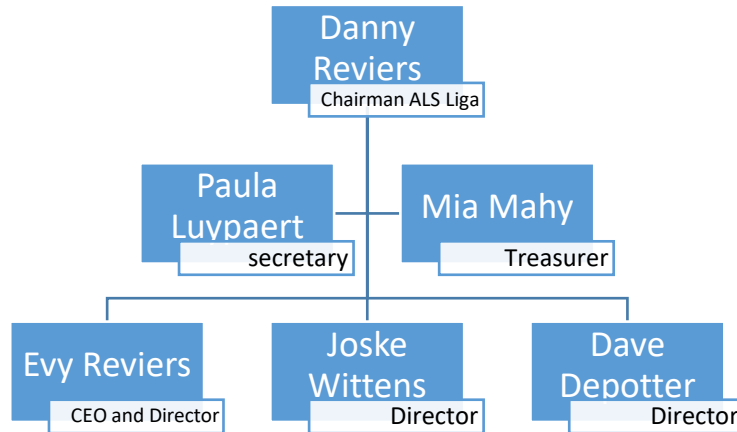
Together with the CEO, there is a team of four permanent staff members working at the ALS Liga Belgium:

- Management assistant and administrative officer
- PR & Events
- ALS Liaison
- Administration

Finally, our team is strengthened by an enthusiastic group of volunteers, some of whom support the secretariat on a more or less permanent basis. More information on our website.

## ➤ Board of Directors

On December 31 2021, the Board of Directors of the ALS Liga Belgium was composed as follows:



## ➤ General Assembly

On December 31 2021, the General Assembly of ALS Liga Belgium was composed as follows: Danny Reviere (Chairman ALS Liga Belgium), Paula Luybaert (Secretary ALS Liga Belgium), Mia Mahy (Treasurer ALS Liga Belgium), Josephine (Joske) Wittens, Dave Depotter, Evy Reviere (CEO ALS Liga Belgium) and Dirk De Valck.

## ➤ Seat, offices and contact

Until May 2022, the ALS Liga Belgium had offices in:

Kapucijnenvoer 33/B1  
3000 Leuven.

From June 2022 onwards, we are located at:

Vaartkom 17  
3000 Leuven  
Tel. +32(0)16/23.95.82

[info@ALS.be](mailto:info@ALS.be)

[www.ALS.be](http://www.ALS.be)

OUR AMBASSADORS



Leah Thys

**Also they**

**fight**



Mong Rosseel



Marleen Merckx

**together with us**



Simon Mignolet



Marc Pinte



Brigitte Stolk



Herman Van Rompuy

and help

Katrien De Becker

Kate Ryan

ALS

Anouk Lepère

out of this world!

David Davidse

Erik Goris

## IN MEMORIAM

We dedicate our activities to all pALS and their family members and, in particular, we also want to take a moment to remember the many pALS we had to say goodbye this year. Our thoughts go out to all bereaved families, friends and acquaintances who lost a loved one to ALS. For them too, our door remains open.



## THANKS TO ALL OUR DONORS

Thanks to your generosity we are able to continue the fight against ALS in 2021 by funding research; supporting ALS patients and their loved ones psychosocially as well as with resources and representing the interests of ALS patients and all patients with a rapidly degenerating disease.

### ➤ Your generosity is a big support in our fight against ALS

The ALS Liga Belgium is not subsidized by public funds. All the initiatives, actions and research we support are only possible thanks to the support of our donors!

The funds we invest into the fight against ALS come entirely from gifts, legacies, actions and other forms of donations.

We therefore also insist on extending our heartfelt thanks to everyone who contributed in 2021. They made further research possible, supported pALS and their family members who joined the ALS Liga Belgium and made ALS more visible in the world.

### ➤ Also the business community provide strong support

Every year, it is clear that also companies and businesses want to contribute to the fight against ALS. Companies that are confronted with the disease because one of their employees was diagnosed with ALS or companies that are looking out for a charity that is a little less well known and could use a boost.

Corporate sponsorship has also proved to be of great importance at various activities and often made it possible to build the activity into a great success.

We especially thank our regular sponsors for their continued support.

### ➤ We keep on fighting like Lions!

There are more than 200 new ALS patients every year. Much research has already been done, but much research will still be needed before a conclusive drug comes to market. Thus, we have to keep fighting as Lions to raise more funds.

Funds for research, but also funds to assist pALS and their loved ones in their process, to support them psychosocially and with resources.

We therefore call on everyone to keep fighting with us!



➤ Fighting together with us? It's possible!

*as an individual you can*

Having the ALS Liga Belgium included in your will.

You can also make the choice to support a good cause through making a will or bequest.

**Donate money**

via our website or  
by bank transfer.

You can also arrange a direct debit or standing order with your bank.

**Organize an event to the benefit of ALS Liga Belgium**

Let us know if you would like to do organize an event to the benefit of the ALS Liga Belgium. We will be happy to help you with promotional material.

**Visit the ALS-shop**

Here you will find plenty of gadgets, t-shirts and books or small tools.



*as a company you can*

directly transfer  
funds to the ALS  
Liga Belgium  
account.

organise campaigns for  
your employees, the  
proceeds of which go to  
research and patient  
support.

become a permanent  
sponsor of the ALS Liga  
Belgium with your  
company or institution

as a company or public  
institution, are you interested  
in supporting the ALS Liga  
Belgium? Many have already  
preceded you. Will you join  
too?

Contact

Our service PR & Events