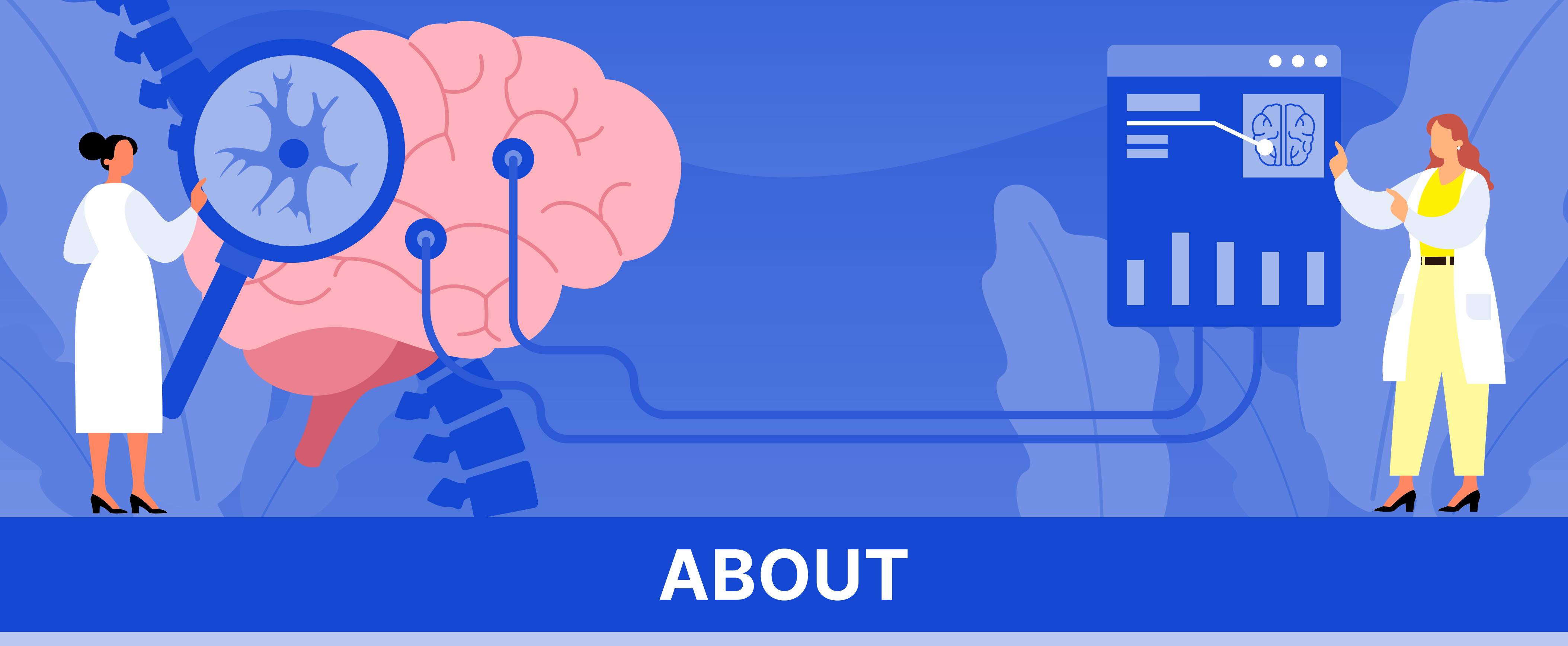
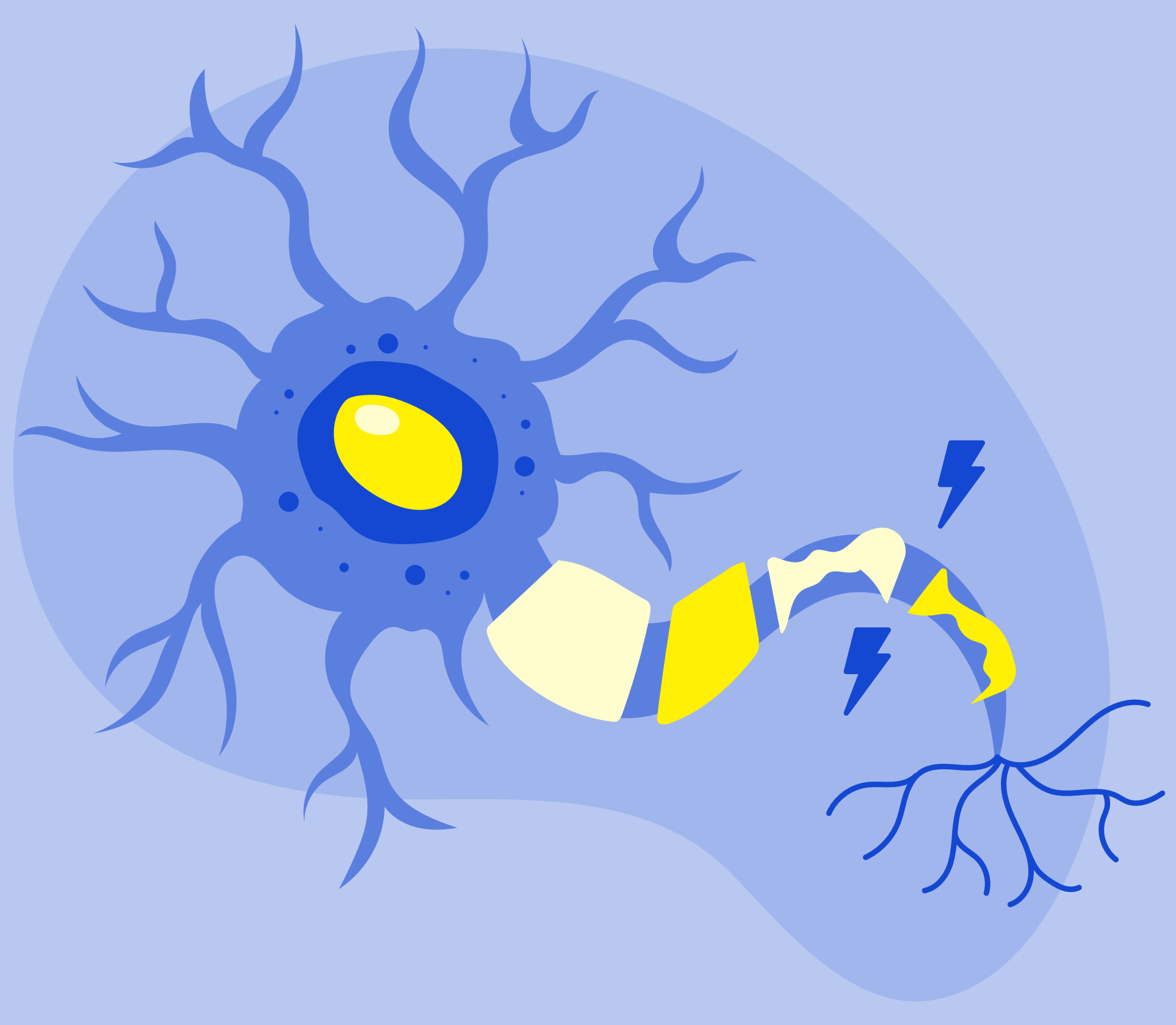
Amyotrophic Lateral Sclerosis (ALS)

"My friends and family do not see the sickness, the ALS, they see me."
– Person from Sweden living with ALS



ABOUT

ALS is a deadly disease with no known cause or cure. There is no time to waste, people living with ALS need better and coordinated care now and further research to find a solution.



ALS is a progressive, debilitating, and fatal disease caused by the death of motor neurons in the brain and spinal cord.

ALS can affect anyone and in 90 % of cases is a sporadic disease. This means ALS mostly happens by random chance and only 10 % of cases run in a family.

It is estimated that 1 in 400 people will develop ALS in their life. Because it is a rapidly evolving disease, there is only a small total number of people living with ALS across the world each year, making it a rare disease.

IMPACT OF ALS

In just a few months, most people with ALS rapidly lose their ability to use their arms and legs, walk, and even speak. In a short time, ALS leads to losing the ability to breathe independently and death.

The life expectancy of someone diagnosed with ALS varies and can range from 2 to 5 years, though some people can live longer.

Eventually, the person with ALS becomes totally dependent on family members and caregivers to help with daily tasks.

ALS has debilitating effects on the lives of patients and their caregivers.

CARE & TREATMENTS

Despite the urgent need, only one medicine for ALS was approved in Europe in 1996, which may extend life by only some months.

There have been no new treatments approved for ALS in Europe in the last 27 years.

There is a shared commitment and responsibility of ALS patient groups, the wider ALS community, policymakers, payers, and pharmaceutical companies to work together as a community to transform treatment and care for people living with ALS.

WE NEED YOU

Every moment counts for people living with ALS and their families. Funding and accelerated pathways for further ALS research and multidisciplinary care are needed on the European level.

Europeans are united to face ALS

"My family and I have uncertainty about the disease progression and it's worrying that no one knows what the future brings."
– Person from the Netherlands living with ALS

Learn more and get in contact

RAREDISEASEDAY.ORG

EUpALS
European Organisation for Professionals and Patients with ALS

www.als.eu

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