



# ANNUAL REPORT

2025



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## 1. Letter to the EupALS community

Dear EupALS community,

2025 could be defined as 'the year of HTA'.

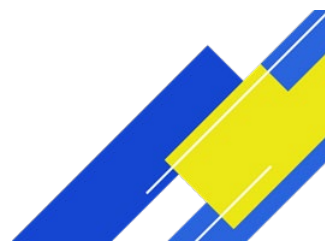
HTA is the acronym for Health Technology Assessment. HTA considers effectiveness, safety, economic impact and ethical implications of a new therapy. This should ultimately lead to negotiations on pricing and reimbursement.

After the phantastic news in February 2024 that the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency (EMA) adopted a positive opinion recommending marketing authorization under exceptional circumstances for Tofersen/Qalsody clinically developed by Biogen for the treatment of adults with amyotrophic lateral sclerosis (ALS), associated with a mutation in the superoxide dismutase (*SOD1*) gene, this dossier ended up on the desks of the many different national authorities within the European Union. Indeed, despite a general recommendation for EU marketing authorization can be given by EMA, the 27 European member states retain full authority over the HTA procedure, including pricing and reimbursement in their respective countries.

Going through their HTA procedures for Tofersen/Qalsody, some EU countries took the lead by offering swift market access with reimbursement claims. However, HTA procedures in a significant number of countries proceeded less smooth, often demanding a second round of similar assessment, or referring to another national financing programme. As a result, EupALS received many reactions of incomprehension from Member Associations involved in delay or (temporary) rejection.

Let us not lose heart by such drawbacks in our efforts to bring a clinically proven therapy to the our pALS. Together we stand strong to fight this challenging condition!

Evvy Reviers  
Chairwoman EupALS



## 2. What is ALS?

ALS stands for Amyotrophic Lateral Sclerosis, an incurable and lethal neuromuscular disease characterized by progressive paralysis.

In Europe, ALS is also known as  
SLA, for Sclérose Latérale Amyotrophique (France and French-speaking Belgium)  
and for Sclerosi Laterale Amiotrofica (Italy)  
MND, for Motor Neuron Disease (UK, Ireland, Iceland)  
ELA, for Esclerosi Lateral Amiotrófica (Spain and Portugal)  
Maladie de Charcot (France and French-speaking Belgium): less used than SLA

In the US the illness is often called Lou Gehrig disease, named after a legendary baseball player who passed away from this disease in 1941.

### Symptoms of ALS

In brief, the following symptoms can be observed in patients with ALS. Not all symptoms occur in an individual ALS-patient.

- Weak and thin muscles, resulting in paralysis
- Joint and muscle pains; muscle contractions
- Fatigue, tiredness
- Reduced appetite resulting in weight loss
- Difficulty chewing, swallowing and speaking; drooling
- Problems with bowel movement
- Reduced lung vital capacity, resulting in difficult breathing
- Compulsive crying, laughing or yawning

### Occurrence and heredity of ALS

ALS is not as rare as often thought, as it affects 6 to 7 people out of every 100.000. It occurs all over the world. Most people are affected by ALS between the age of 50 and 75 but there are also teenagers with ALS.

The diagnosis can only be determined after all other neurologic conditions have been excluded. The course of the disease is progressive but the evolution varies from one person to another.

In Europe, ALS affects about 50.000 individuals of middle age, killing about 10.000 people on a European level each year. Worldwide 450.000 people suffer from ALS. Each year 120.000 people are diagnosed with ALS. This means that every day there are 328 new known cases, which equals 2 new diagnoses of ALS per 100.000. Every year 120.000 patients die from ALS worldwide.



In about 10% of the ALS cases there is a familial pattern. When it concerns the familial type, ALS is usually genetically dominant, which means that a child has a 50% chance of becoming ill. The symptoms of familial ALS are the same as those of the sporadic form. The only difference is that people with familial ALS are usually younger when the first symptoms arise.

### 3. About EupALS

#### 3.1. Mission

EupALS is the European association that takes the interests of European people with ALS (pALS) to heart. We want to obtain equal rights for all European pALS and provide them better access to clinical research and information about it.

#### 3.2. Vision

Our organization aims to fight against ALS in Europe and make everybody aware of this terrible disease. This is why we unite all the European ALS/MND associations: to fight harder together on a European scale.

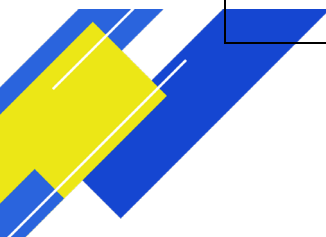
#### 3.3. Objectives

- Stand up for the rights of all European people with ALS
- Create awareness about ALS on a European scale
- Improve access to and information about ALS research and clinical trials
- Obtain the same rules for ALS research and clinical trials across Europe



## 4. EupALS Board of Directors

|                                                                                                                                                                                             |                                                                                                                                                                                                            |                                                                                                                                                                     |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  <p>Evy Reviers<br/><i>Chairwoman</i><br/>CEO ALS Liga Belgium</p>                                         |  <p>Sabine Turgeman<br/><i>Director</i><br/>CEO ARSLA France</p>                                                          |  <p>Prof. Christian Lunetta<br/><i>Director</i><br/>Expert Neurologist Italy</p> |
|  <p>Joaquin de la Herrán<br/><i>Director</i><br/>Executive Committee member<br/>Fundación Luzón Spain</p> |  <p>Dr. Aylin Yaman<br/><i>Director</i><br/>Antalya Branch of ALS/MND<br/>Association Turkey</p>                         |  <p>Guðjón Sigurðsson<br/><i>Secretary</i><br/>Chairman MND Iceland</p>         |
|  <p>Limore Noach<br/><i>Treasurer</i><br/>CEO Stichting ALS The<br/>Netherlands</p>                      | <p>EupALS Board of Directors meetings in 2025</p> <ul style="list-style-type: none"> <li>• March 19 (web meeting)</li> <li>• June 3 (Turin; hybrid meeting)</li> <li>• November 5 (web meeting)</li> </ul> |                                                                                                                                                                     |





## 5. EupALS Patients and Carers Expert Board (PCEB)

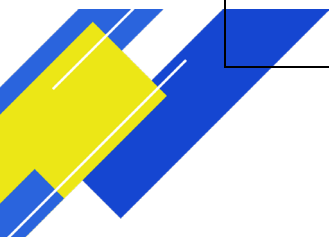
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|-------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|
|  <p>Alper Kaya<br/><i>ALS/MND Association Turkey</i></p>             |  <p>Mia Möllberg<br/><i>ALS Sweden</i></p>                                                                                                                                                                                                                                                |  <p>Conny van de Meijden<br/><i>ALS Patiëntenvereniging</i></p> |
|  <p>Valérie Berlaimont<br/><i>ALS Liga Belgium</i></p>               |  <p>Josefina Garcia Pastor<br/><i>Fundació Miquel Valls Spain</i></p>                                                                                                                                                                                                                     |  <p>Ywan Dierick<br/><i>ALS Liga Belgium</i></p>                |
|  <p>Louise Gunning-Schepers<br/><i>ALS Patiëntenvereniging</i></p> |  <p>Giampaolo Merlini<br/><i>conSLancio Italy</i></p>                                                                                                                                                                                                                                   |                                                                                                                                                    |
| <p>Major activities 2025 of the EupALS PCEB</p>                                                                                                       | <ul style="list-style-type: none"> <li>• Input from patient perspective provided for clinical trial protocols of several Industry Partners (from fist-in-human to Phase 3), and for the masterprotocol of an academic partner.</li> <li>• Active participation in Roundtable on 'Patient Reported Outcomes in ALS clinical trials', June 2 2025, Turin (Italy).</li> </ul> |                                                                                                                                                    |

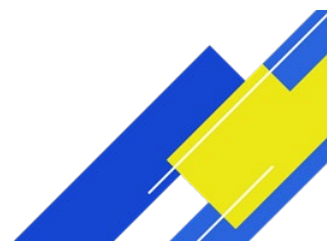




## 6. EUpALS Scientific Expert Board (SEB)

|                                                                                                                                                                   |                                                                                                                                                                        |                                                                                                                                                                                                                                   |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  <p>Prof. Philip Van Damme<br/><i>UZ Leuven, Belgium</i></p>                     |  <p>Prof. Leonard van den Berg<br/><i>UMC Utrecht, The Netherlands</i></p>           |  <p>Prof. Philippe Corcia<br/><i>CHRU Tours, France</i></p>                                                                                    |
|  <p>Prof. Caroline Ingre<br/><i>Karolinska Institutet Stockholm, Sweden</i></p> |  <p>Prof. Adriano Chiò<br/><i>University of Torino, Italy</i></p>                    |  <p>Prof. Ammar Al-Chalabi<br/><i>Kings College London, UK</i></p>                                                                            |
|  <p>Prof. Orla Hardiman<br/><i>Trinity College Dublin, Ireland</i></p>         |  <p>Prof. Monica Povedano<br/><i>IDIBELL Barcelona, Spain</i></p>                  |  <p>Prof. Markus Weber<br/><i>ALS Clinic, Kantonsspital St.Gallen, Switzerland. Professor of Neurology. Neuromuscular Diseases unit/</i></p> |
| <p>Major activities 2025 of the EUpALS SEB</p>                                                                                                                    | <ul style="list-style-type: none"> <li>Active participation in Roundtable on 'Patient Reported Outcomes in ALS clinical trials', June 2 2026, Turin (Italy)</li> </ul> | <ul style="list-style-type: none"> <li>Input in drafting position paper on 'Patient Reported Outcomes in ALS clinical trials'.</li> </ul>                                                                                         |





## 7. EupALS Member Associations 2025

Uniting 30 ALS/MND Associations from 22 European countries

|                                                                                                                                                    |                                                                                                                                                           |                                                                                                                                                                         |
|----------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  <p>ASSOCIAZIONE ITALIANA<br/>SCLEROSI LATERALE AMIOTROFICA</p>   |  <p>VEREIN <b>ALS<br/>SLA</b><br/>Schweiz Suisse Svizzera Svizra</p>    |  <p><b>ALS SLA</b><br/>ALS LIGA – LIGUESLA</p>                                       |
|  <p><b>ALS-mobil e.V.</b></p>                                     |  <p><b>ALS<br/>patiënten<br/>vereniging</b></p>                         |  <p><b>ALS MNH<br/>DERNEĞİ</b></p>                                                   |
|  <p><b>ALStuttu</b><br/>ALS-tutkimuksen tuki ry</p>              |  <p><b>alsa.</b></p>                                                    |  <p><b>apela</b><br/>associação portuguesa<br/>de esclerose lateral amiotrófica</p> |
|  <p><b>MND<br/>Association</b></p>                              |                                                                        |  <p><b>MOTUS VITA</b><br/>Association of people with special needs</p>             |
|  <p><b>ARSLA</b></p>                                            |                                                                        |  <p><b>ALS</b><br/>Stichting ALS Nederland</p>                                     |
|  <p>MIQUEL VALLS<br/><b>FUNDACIÓ<br/>CATALANA<br/>D'ELA</b></p> |  <p><b>Irish<br/>Motor<br/>Neurone<br/>Disease<br/>Association</b></p> |  <p>UDRUŽENJE OBOLJELIH<br/>OD AMIOTROFIČNE<br/>LATERALNE SKLEROZE (ALS)</p>       |



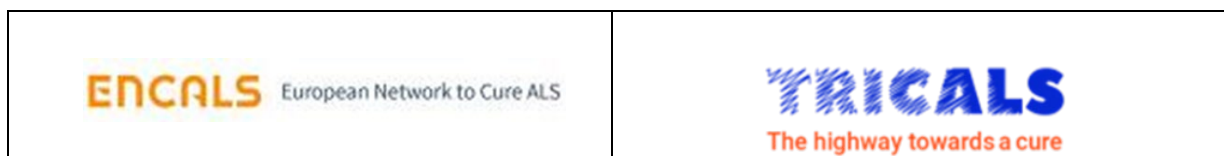
|                                                                                                                                            |                                                                                                                                                                                                                                      |                                                                                                                                                                       |
|--------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  <p><b>MUSKELSVINDFONDEN</b><br/>plads til forskelle!</p> |  <p><b>POST FATA RESURGO</b><br/>VINCERE LA SLA PER RITORNARE A VIVERE<br/><a href="http://www.postfataresurgo.org">www.postfataresurgo.org</a></p> |  <p>FUNDACIÓN<br/><b>L U Z Ó N</b><br/>UNIDOS CONTRA LA ELA</p>                    |
|  <p><b>ALS-FONDEN</b></p>                                 |  <p>Research Motor Neurone</p>                                                                                                                      |  <p><b>MDA</b> ΕΜΑΑ<br/>ΣΩΜΑΤΕΟ ΣΠΟΝΔΙΛΙΑΣ ΑΤΡΟΦΙΑΣ ΜΕ ΝΕΥΡΟΜΥΣΙΚΕΣ ΠΑΘΗΣΕΙΣ</p>   |
|  <p><b>MUSCULAR DYSTROPHY ASSOCIATION OF SLOVENIA</b></p> |                                                                                                                                                     | <p><b>eamda</b><br/>European Alliance of Neuromuscular Disorders Associations</p>  |
| <p>ALLT OM<br/><b>ALS</b></p>                            |  <p><b>ALS</b><br/>2024 HELLENIC ALS ASSOCIATION</p>                                                                                               |  <p><b>LIVE NOW</b><br/>RUSSIA</p>                                                |



## 8. EupALS Industry Partners 2025



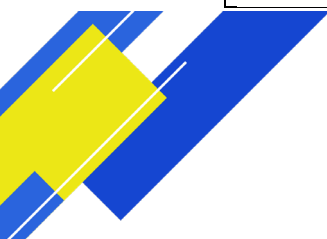
## 9. EupALS Academic Partners 2025



## 10. EupALS General Partner 2025



## 11. EupALS European Projects 2025





## 12. EupALS Activities 2025 - Overview

|               |                                                                                                                  |
|---------------|------------------------------------------------------------------------------------------------------------------|
| February 6    | Meeting EU Horizon project Hereditary in Barcelona                                                               |
| February 20   | TRICALS Masterclass in Amsterdam                                                                                 |
| March 6       | RNA Leaders Europe Congress in Basel                                                                             |
| March 21      | Visit of prof. Ammar Al-Chalabi to EupALS office                                                                 |
| April 4       | EupALS Newsletter Spring edition                                                                                 |
| May 21        | Consortium Meeting EU Horizon Project Real4Reg in Lisbon                                                         |
| June 2        | EupALS Roundtable on 'Patient Reported Outcomes in ALS clinical trials', Turin (Italy), satellite to ENCALS 2025 |
| June 3        | EupALS Annual General Meeting 2025, Turin (Italy), satellite to ENCALS 2025                                      |
| July 15       | EupALS Newsletter Summer edition                                                                                 |
| September 25  | EupALS Newsletter Autumn edition                                                                                 |
| October 8     | ALS/MND Fundamental Rights Survey                                                                                |
| October 14    | EURORDIS-Rare Diseases Europe Round Table                                                                        |
| October 15-16 | Brain Innovation Days, Brussels (Belgium)                                                                        |
| December 23   | EupALS Newsletter Winter edition                                                                                 |

## 13. EupALS activities 2025 - highlights

### 13.1. Annual consortium meeting EU Horizon project HEREDITARY

On February 6 2025, EupALS participated in the annual consortium of EU Horizon project **HEREDITARY** in Barcelona (Spain).

The infrastructure for federated multimodal data sharing is getting into place, ready to analyze the data for the ALS use case.





### 13.2. TRICALS Masterclass 2025

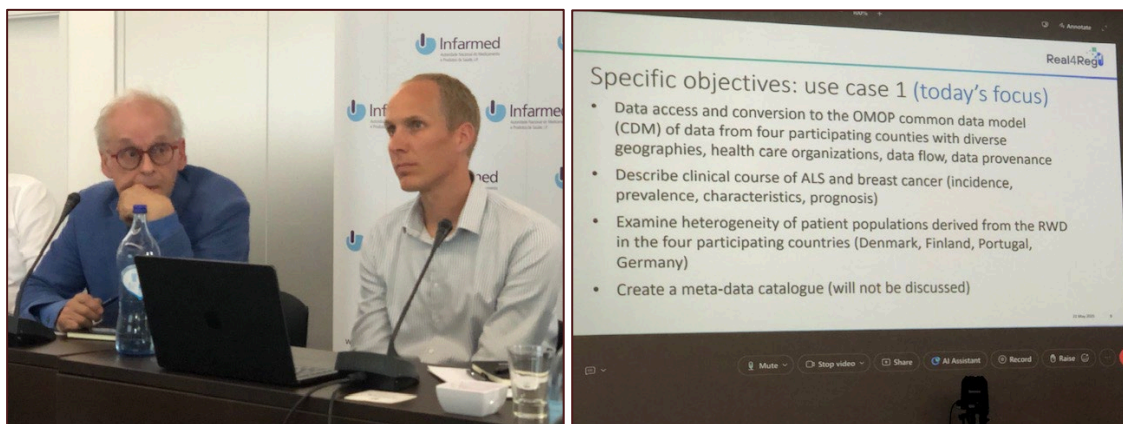
On February 19-21, EUpALS actively participated in the TRICALS Masterclass 2025 in Amsterdam (The Netherlands). In particular, our Chairwoman Evy Reviérs represented the patient perspective in the panel discussing ‘what evidence is needed from a Phase 3 ALS trial?’.



### 13.3. Annual consortium meeting EU Horizon project Real4Reg

On May 21 2025, EUpALS attended the consortium meeting of EU Horizon project **Real4Reg** in Lisbon (Portugal).

Results of AI analysis of population based registries from specific European countries to determine the heterogeneity of ALS populations were presented to the ALS experts Prof. Mamede de Carvalho (Portugal) and to Associate Prof. Ruben van Eijk (The Netherlands), who provided valuable feedback.





### 13.4. EupALS Roundtable 2025

On June 2, EupALS organized its roundtable 2025 on 'Patient Reported Outcomes in ALS clinical trials' in Turin (Italy), satellite to ENCALS 2025.

Representatives of EupALS Industry Partners, EupALS Member Associations, EupALS Patients and Carers Expert Board and the EupALS Scientific Expert Board participated in an interactive discussion on this important topic to the benefit of people with ALS.

Special thanks to Dr. Syed Raza (argenx), Prof. Christian Lunetta (Istituti Clinici Scientifici Maugeri IRCCS Milan (Italy)), pALS Ywan and pALS Stéphane for having set the stage from industry, academic and patient perspective.





### 13.5. EUpALS Annual General Meeting 2025

On June 3, EUpALS organized its **Annual General Meeting 2025** in Turin (Italy), satellite to ENCALS 2025.

We informed our stakeholders about EUpALS activities, governance, and EUpALS partnership in EU Horizon projects real4reg and hereditary.

But even as important, we learned a lot of the inspiring initiatives taken by the many EUpALS Member Associations and Industry Partners.



**HEREDITARY use case ALS**

Use Case 1: Neurodegenerative Diseases Phenotyping & Progression Evaluation

- Identify genetic variants associated with ALS and other neurodegenerative diseases.
- Investigate the role of these variants in disease progression and prognosis.
- Develop predictive models for disease progression and prognosis.
- Validate the models using real-world data.
- Implement the models in clinical practice.

**EUpALS Real4Reg**

**Real4Reg use case ALS : where are we?**

Extraction of ALS-patient profiles out of health claim databases

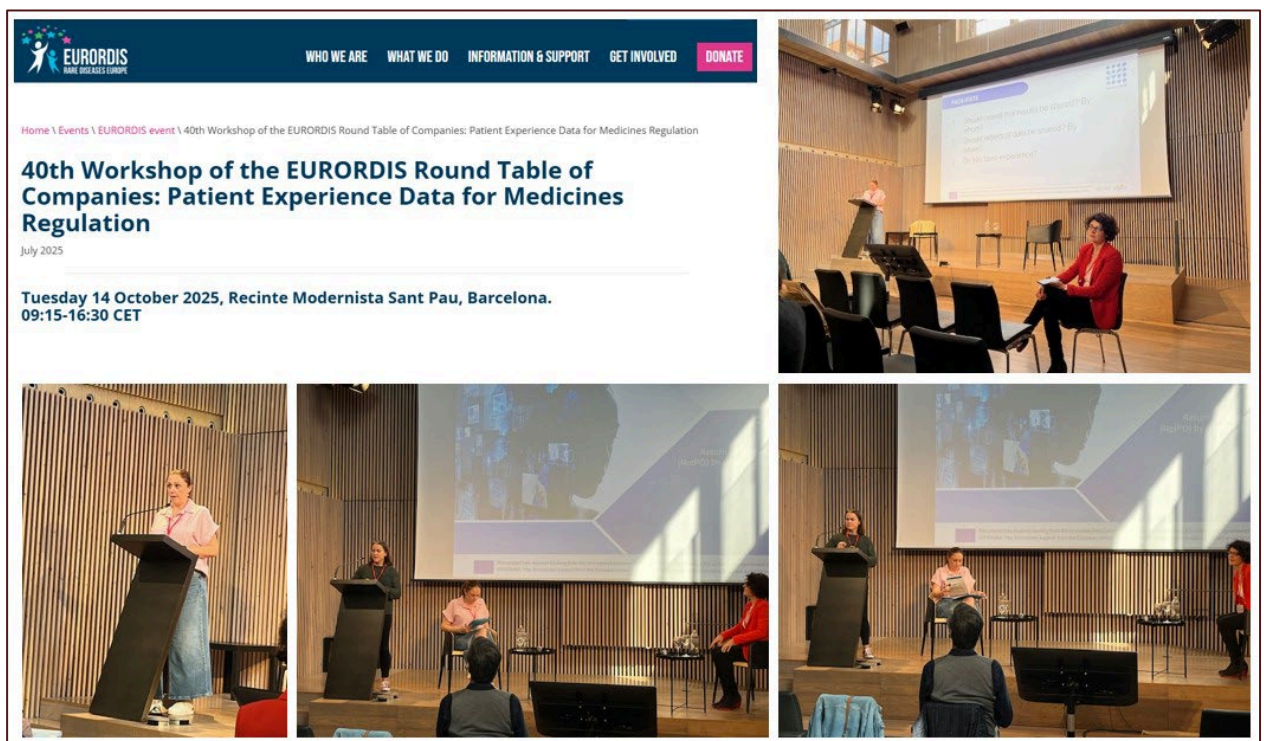
- EUpALS contributed to code books for the algorithm (ICD-10 and ATC classifications)
- Native AI analysis performed on databases of Finland, Denmark and Portugal
- Data presented to ALS Experts



### 13.6. EURORDIS- Rare Diseases Europe Roundtable 2025

On October 14, EupALS Chairwoman Evy Reijers chaired the panel session 'Brainstorming on future Public Private Partnership: Results from CTs and Real-World data studies. How to inform patients when their data are used, and which knowledge has been gained thanks to them sharing data?' at the EURORDIS-Rare Diseases Europe Roundtable of Companies: Patient Experience Data for Medicines Regulation, in Barcelona (Spain).

In particular, EupALS knowledge and expertise gained by our partnerships in Real World Data oriented EU Horizon projects Real4Reg and Hereditary Project were highlighted.



### 14. ALS Research News

- January 07, 2025 - Topline Results Denali Therapeutics eIF2B Agonist DNL343
- January 09, 2025 - Topline Results Abbvie - Calico eIF2B Activator Fosigotifator
- January 31, 2025 - uniQure Announces Recommendation Independent Data Monitoring Committee for its EPISOD1 Clinical Trial of AMT-162 for Treatment of SOD1-ALS
- April 01, 2025 - Results Cytokinetics COURAGE-ALS trial with Reldesemtiv
- April 15, 2025 - Lighthouse II study terminated after interim analysis
- April 28, 2025 - Prilenia and Ferrer collaboration on pridopidine in Europe
- May 06, 2025 - Results MIROCALS clinical trial with low-dose IL-2 in ALS - The Lancet
- June 10, 2025 - Corcept Presents Results from Phase 2 Study of Dazucorilant in Patients with Amyotrophic Lateral Sclerosis (ALS) at ENCALs 2025 Annual Meeting
- August 12, 2025 - IONIS ALS community statement on completion of enrollment of FUSION clinical trial of ulefnersen
- August 28, 2025 - Collaborative Partnership between IQVIA and TRICALS
- November 24, 2025 - NeuroSense Receives FDA Clearance to Initiate Pivotal Phase 3 Trial for Primec in ALS

- December 05, 2025 - VectorY Therapeutics Receives FDA Clearance of IND to Proceed with the PIONEER-ALS Phase 1/2 Trial of VTX-002, a First-in-Class Vectorized Antibody Targeting TDP-43 Pathology in ALS

## 15. EupALS Authorship in Scientific Journals

> [Health Res Policy Syst.](#) 2025 Feb 27;23(1):27. doi: 10.1186/s12961-025-01287-y.

### The EU project Real4Reg: unlocking real-world data with AI

Jonas Peltner <sup>1</sup>, Cornelia Becker <sup>2</sup>, Julia Wicherski <sup>2</sup>, Silja Wortberg <sup>2</sup>, Mohamed Aborageh <sup>3</sup>, Inês Costa <sup>4</sup>, Vera Ehrenstein <sup>5</sup>, Joana Fernandes <sup>6</sup>, Steffen Heß <sup>7</sup>, Erzsébet Horváth-Puhó <sup>5</sup>, Monika Roberta Korcinska Handest <sup>8</sup>, Manuel Lentzen <sup>3</sup>, Peggy Maguire <sup>9</sup>, Niels Henrik Meedom <sup>8</sup>, Rebecca Moore <sup>9</sup>, Vanessa Moore <sup>9</sup>, Dávid Nagy <sup>5</sup>, Hillary McNamara <sup>9</sup>, Anne Paakinaho <sup>10</sup>, Kerstin Pfeifer <sup>2</sup>, Liisa Pylkkänen <sup>11</sup>, Blair Rajamaki <sup>10</sup>, Evy Reviers <sup>12</sup>, Christoph Röthlein <sup>2</sup>, Martin Russek <sup>2</sup>, Célia Silva <sup>6</sup>, Dirk De Valck <sup>12</sup>, Thuan Vo <sup>10</sup>, Elvira Bräuner <sup>8</sup>, Holger Fröhlich <sup>3</sup> <sup>13</sup>, Cláudia Furtado <sup>6</sup> <sup>14</sup>, Sirpa Hartikainen <sup>10</sup>, Aleksi Kallio <sup>15</sup>, Anna-Maija Tolppanen <sup>10</sup>, Britta Haenisch <sup>16</sup> <sup>17</sup> <sup>18</sup>

Affiliations + expand

PMID: 40016823 PMID: [PMC11869640](#) DOI: [10.1186/s12961-025-01287-y](#)

> [Clin Transl Sci.](#) 2025 Dec;18(12):e70454. doi: 10.1111/cts.70454.

### Key Stakeholders' Knowledge, Opinions, and Interests on Real-World Evidence in the Regulatory Process—Results of an EU-Wide Survey

Frank Lucas Depner <sup>1</sup>, Martin Russek <sup>2</sup>, Christoph Röthlein <sup>2</sup>, Cornelia Becker <sup>2</sup>, Jonas Peltner <sup>1</sup> <sup>2</sup>, Kerstin Pfeifer <sup>2</sup>, Evy Reviers <sup>3</sup>, Dirk De Valck <sup>3</sup>, Julia Wicherski <sup>2</sup>, Sirpa Hartikainen <sup>4</sup>, Anna-Maija Tolppanen <sup>4</sup>, Britta Haenisch <sup>1</sup> <sup>2</sup> <sup>5</sup>

Affiliations + expand

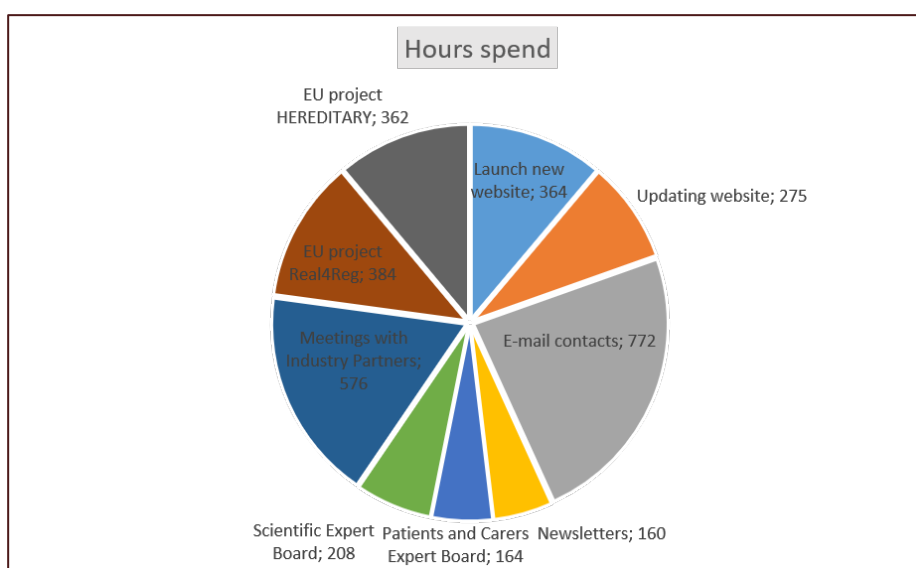
PMID: 41420643 PMID: [PMC12717853](#) DOI: [10.1111/cts.70454](#)



## 16. EUpALS 2025 in numbers

In 2025, EUpALS invested resources and time in

- Launching new EUpALS website, representing 364 hours
- updating EUpALS website, representing 275 hours
- Managing e-mail contacts, representing 772 hours
- Production of 4 Newsletters, representing 160 hours
- Activities Patients and Carers Expert Board, representing 164 hours
- Activities Scientific Expert Board, representing 208 hours
- Meetings with Industry Partners, representing 576 hours
- Managing partnership in EU project Real4Reg, representing 384 hours
- Managing partnership in EU project HEREDITARY, representing 362 hours



## 17. Contact

Address: EUpALS, vaartkom 17, B-3000 Leuven, Belgium

Enterprise number: BE0684.923.631

Phone number: +32 (0)16-23 95 82

RPR: Leuven

Website: ALS.eu

E-mail: info@als.eu

X/Facebook: @EUpALS

