



Curriculum Vitae

Personal information **Evy Reviere**

Work experience

1. Employer: ALS Liga Belgium
 - Start date: 13-09-2007
 - End date:
 - Position: CEO and Chairwoman
 - Activities: General management of patient organisation ALS Liga Belgium. Focus on patient advocacy at governmental agencies and institutions at the Belgian, European and international level. I am responsible for patient contact, providing information and support. I establish partnerships to the benefit of ALS patients, such as collaborations with university hospitals.
 - Country: Belgium
2. Chairwoman EUpALS 'European organisation for professionals and people with ALS'
Start date: December 2017

Education and training

1. Subject:
 - Start date:
 - End date:
 - Qualification: Marketing, Management and Communication
 - Organisation: All aspects involved, including financial and human resources.
 - Country: Belgium

Additional information

Publications

Van Damme P, Al-Chalabi A, Andersen PM, Chio A, Couratier P, De Carvalho M, Hardiman O, Kuzma-Kozakiewicz M, Ludolph A, McDermott CJ, Mora JS, Petri S, Probyn K, Reviere E, Salachas F, Silani V, Tysnes OB, van den Berg LH, Villanueva G, Weber M (2024): European Academy of Neurology (EAN) guideline on the management of amyotrophic lateral sclerosis in collaboration with the European Reference Network for Neuromuscular Diseases (ERN EURO-NMD). *Eur J Neurol*. DOI 10.1111/ene.16264

Atalaia A, Wandrei D, Lalout N, Thompson R, Tassoni A, 't Hoen PAC, Athanasiou D, Baker SA, Sakellariou P, Paliouras G, D'Angelo C, Horvath R, Mancuso M, van der Beek N, Kornblum C, Kirshner J, Pareyson D, Bassez G, Blacas L, Jacoupy M, Eng C, Lamy F, Plançon JP, Haberlova J, Brusse E, Hoeijmakers JGJ, de Visser M, Claeys KG, Paradas C, Toscano A, Silvano V, Gyenge M, Reviere E, Hamroun D, Vroom E, Wilkinson MD, Lochmuller H, Evangelista T (2024): EURO-NMD registry: Federated FAIR infrastructure, innovative technologies, and concepts of a patient-centred registry for rare neuromuscular disorders. *Orphanet J. Rare Dis*. DOI 10.1186/s13023-024-0305-3.

Ludolph AC, Grandjean H, Reviere E, De Micheli V, Bianchi C, Cardoso L, Russ H, Silani V (2023): The preferences of people with amyotrophic lateral sclerosis on riluzole treatment in Europe. *Sci Rep*. DOI 10.1038/s41598-023-49424-3.

Willems SW, Roes KCB, Van Damme P, Hardiman O, Ingre C, Povedano M, Wray NR, Gijzen M, de Pagter MS, Demaege KC, Janse AFC, Vink RG, Sleutjes BTHM, Chio A, Corcia P, Reviere E, Al-Chalabi A, Kiernan MC, van den Berg LH, Van Es MA, van Eijk RPA (2022): Lithium carbonate in amyotrophic lateral sclerosis patients homozygous for the C-allele at SNP rs12608932 in UNC13A: protocol for a confirmatory, randomized, group-sequential, event-driven, double-blind, placebo-controlled trial. *Trials*. DOI 10.1186/s13063-022-06906-5.

Tessa Kliet, Ruben P.A. van Eijk, Ammar Al-Chalabi, Alberto Albanese, Peter M. Andersen, Geir Bråthen, Veronique Brunaud_Danel, Lev Brylev, William Camu, Mamede De Carvalho, Cristina Cereda, Hakan Cetin, Delia Chaverrri, Adriano Chio, Philippe Corcia, Philippe Couratier, Fabiola De Marchi, Claude Desnuelle, Michael A. van Es, Jesus Estaban, Massimiliano Filosto, Alberto Garcia Redondo, Julian Grosskreutz, Clemens O. Hanemann, Trygve Holmøy, Helle Hoyer, Caroline Ingre, Blaz Koritnik, Magdalena Kuzma_Kozakiewicz, Thomas Lambert, Peter N. Leigh, Christian Lunetta, Jessica Mandrioli, Christopher J. McDermott, Thomas Meyer, Jesus S. Mora, Susanne Petri, Mónica Povedano, Evy Reviere, Nilo Riva, Kit C.B. Roes, Miguel A Rubio, François Salachas, Stayko Sarafov, Gianni Sorarù, Zorica Stevic, Kirsten Svenstrup, Anette Torvin Møller, Martin R. Turner, Philip Van Damme, Lucie A.G. Van Leeuwen, Luis Varona, Juan F. Vázquez Costa, Markus Weber, Orla Hardiman, Leonard H. Van Den Berg (2022): Clinical trials in paediatric ALS: a TRICALS feasibility study. *Lateral Sclerosis and Frontotemporal Degeneration*. DOI 10.1080/21678421.2021.2024856.

van Eijk RPA, Beelen A, Kruitwagen ET, Murray D, Radakovic R, Hobson E, Knox L, Helleman J, Burke T, Rubio Pérez MA, Reviere E, Genge A, Steyn FJ, Ngo S, Eaglesham J, Roes KCB, van den Berg LH, Hardiman O, McDermott CJ. (2021): A Roadmap for Remote Digital Health Technology for Motor Neuron Disease. *J Med Internet Res*. DOI 10.2196/28766.

Lamy F, Ferini A, ERN EURO_NMD Patient Advisory Board, Evangelista T. (2021): Survey on Patients' Organisations' knowledge and position paper on screening for inherited neuromuscular diseases in Europe. *Orphanet J Rare Dis*. DOI 10.1186/s13023_020_01670_8. Reviere E., Vanopdenbosch L., Van Den Bosch L., Van Damme P. (2021) Public Policy in ALS/MND Care: The Belgian Perspective. In: Blank R.H., Kurent J.E., Oliver D. (eds) *Public Policy in ALS/MND Care*. Palgrave Macmillan. DOI 10.1007/978_981_15_5840_5_3.

Ruben P.A. van Eijk, Tessa Kliet, Christopher J. McDermott, Kit C.B. Roes, Philip Van Damme, Adriano Chio, Markus Weber, Caroline Ingre, Philippe Corcia, Mónica Povedano, Evy Reviere, Michael A. van Es, Ammar

Al_Chalabi , Orla Hardiman & Leonard H. van den Berg (2020): TRICALS: creating a highway toward a cure. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, DOI: 10.1080/21678421.2020.1788092.

Please visit www.ALS.be for all other publications, information and communication on my professional activities at ALS Liga Belgium.

Projects

I established the non-profit umbrella organisation EUpALS : European Organisation for Professionals and People with ALS. EUpALS contributes to the quality of life of European ALS patients by patient advocacy and defending their rights at European governments, agencies and institutions. In particular, EUpALS aims at establishing globalised access for all European ALS patients to the same clinical trials and future medicines. For all information visit www.ALS.eu.

Coordinator of the funding campaign for the Belgian branch of Project MinE, the ground breaking international project to find the genetic cause of ALS. By the crowd funding campaign of ALS Liga Belgium, the Belgian branch of Project MinE was the first partner country that reached its financial goals.

Coordinator of the Flanders' Care demonstration project 'Proeftuin ALS Digtalk'. The project offered consecutive assistive communication devices to ALS patients with verbal and/or written communication problems to increase their quality of life by preventing social isolation and depression.

Coordinator of the innovative care project 'Helpdesk ALS Digtalk' of the Province Flemish_Brabant (Belgium). The project supported ALS patients with communication problems in using assistive devices.

Coordinator of the realisation of specialised care center Middelpunt (www.middelpunt.com).located at the Belgian coast. In this multifunctional and fully accessible centre, ALS patients can have holiday together with family and friends in an atmosphere that combines relaxation with care.

Coordinator of the realisation of a liaison function that visits ALS patients in their home situation to provide them all kinds of support.

Memberships

Chairwoman and member of the Board of EUpALS, the European Organisation for Professionals and People with ALS (December 2017 - current). For all information visit www.ALS.eu .

Member of the Board of Directors of the International Alliance of ALS/MND Associations (2010 - 31/12/2016 & 04/12/2017 - 31/12/2020 & 01/01/2021 - current). For all information visit www.alsmndalliance.org.

Member of the Executive Board of TRICALS.

Member of EURORDIS (Rare Diseases Organisation Europe), being a member of the EURORDIS Drug Information, Transparency and Access (DITA) Task Force.

Via EURORDIS: involved in the ERN EURO-NMD, being a member of the Patient Advocacy Group, its Executive Committee and special working groups such as the Ethics Committee and Neuromuscular. Besides this, I am also involved in the Community Engagement Task Force.

Member of Working Group on European Academy of Neurology (EAN) Guidelines on management of ALS.

Member of DIA (Drug Information Association).

Member of RadiOrg.(Rare Diseases Organisation Belgium).

Other Relevant Information

I am a patient representative