EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Curriculum Vitae

Personal information

Mencia de Lemus Belmonte

Work experience

July 2022-present: alternate member at the Committee for Advanced Therapies (CAT), European Medicines Agency: Patient representative for ATMPs; CAT representative at the PCWP. Co-author of Reflection paper on Patient Experience Data. CAT representative for Study on SMA Registries as a tool for regulatory decisions. Speaker at Strategic Learning Meetings (EMA) and at national medicines agencies (AIFA, INFARMED).

February 2013-present: patient advocate at SMA Europe, Head of Regulatory, Real World Evidence; Patient Relevant Outcomes. Executive-President (2018-2020). Vicepresident (2015-2017). Member of Advisory Boards for Clinical Trial design and roll out (Novartis, Biogen, Roche, Avexis). Appointed patient representative at SAWP; SAG, Protocol Advices. Chair, Co-chair, keynote speaker, speaker at Conferences, Scientific Congresses, Workshops, Symposia, Masterclasses (EMA, EFPIA, European Parliament, ESCGT..).

January 2012- present: trustee at FundAME. Executive-President (2016-2021). Executive-Vicepresident (2013-2015). Head of stakeholder engagement (national regulator, HTA, healthcare practitioners, researchers, pharmaceutical industry). Leader of regulatory and reimbursement activity. Led creation of national patient registry including development of Patient Relevant Outcome Measures (PROMs). Led creation of National Clinical Registry. Led creation of healthcare practitioners national network.

Education and training

2020: University of Tirol UMIT: Course on Health Economics and HTAs.

1999 – 2000: Post university studies on international politics and international relations (**diplomacy training**). Madrid (Spain).

1993 – 1998: **UNIVERSITÉ CATOLIQUE DE LOUVAIN – U.P. COMILLAS (ICADE):** MA Law. (Louvain La Neuve (Belgium), Madrid (Spain).

1993- 1998: **UNIVERSIDAD PONTIFICIA COMILLAS (ICADE):** BA Business. (Madrid, Spain).

Additional information

Publications

RegistrAME: the Spanish self-reported patient registry of spinal muscular atrophy. Cattinari MG, **de Lemus M**, Tizzano E.Orphanet J Rare Dis. 2024 Feb 19;19(1):76. doi: 10.1186/s13023-024-03071-7.PMID: 38373977

Understanding European patient expectations towards current therapeutic development in spinal muscular atrophy. Gusset N, Stalens C, Stumpe E, Klouvi L, Mejat A, Ouillade MC, **de Lemus M.**Neuromuscul Disord. 2021 May;31(5):419-430. doi: 10.1016/j.nmd.2021.01.012. Epub 2021 Feb 4.PMID: 33752935

264th ENMC International Workshop: Multi-system involvement in spinal muscular atrophy Hoofddorp, the Netherlands, November 19th - 21st 2021. Detering NT, Zambon A, Hensel N, Kothary R, Swoboda K, Gillingwater TH, Baranello G; Workshop participants; Industry participants. Neuromuscul Disord. 2022 Aug;32(8):697-705. doi: 10.1016/j.nmd.2022.06.005. Epub 2022 Jun 17.PMID: 35794048

A Decision for Life - Treatment decisions in newly diagnosed families with spinal muscular atrophy (SMA). Gusset N, Erbas Y, Germanenko O, Rucinski K, Stumpe E, **de Lemus M.**Eur J Paediatr Neurol. 2021 Jan;30:105-107. doi: 10.1016/j.ejpn.2020.11.003. Epub 2020 Dec 14.PMID: 33353801.

244th ENMC international workshop: Newborn screening in spinal muscular atrophy May 10-12, 2019, Hoofdorp, The Netherlands. Dangouloff T, Burghes A, Tizzano EF, Servais L; NBS SMA Study Group.Neuromuscul Disord. 2020 Jan;30(1):93-103. doi: 10.1016/j.nmd.2019.11.002. Epub 2019 Nov 9.PMID: 31882184

Correction to: Understanding the relationship between the 32-item motor function measure and daily activities from an individual with spinal muscular atrophy and their caregivers' perspective: a two-part study. Duong T, Braid J, Staunton H, Barriere A, Petridis F, Reithinger J, Cruz R, Jarecki J, **De Lemus M**, Gusset N, Broekgaarden R, Randhawa S, Flynn J, Arbuckle R, Reif S, Yang L, De Martini A, Vuillerot C.BMC Neurol. 2021 Sep 13;21(1):354. doi: 10.1186/s12883-021-02307-4.

Understanding the relationship between the 32-item motor function measure and daily activities from an individual with spinal muscular atrophy and their caregivers' perspective: a two-part study. Duong T, Braid J, Staunton H, Barriere A, Petridis F, Reithinger J, Cruz R, Jarecki J, **De Lemus M**, Gusset N, Broekgaarden R, Randhawa S, Flynn J, Arbuckle R, Reif S, Yang L, De Martini A, Vuillerot C.BMC Neurol. 2021 Mar 31;21(1):143. doi: 10.1186/s12883-021-02166-z.

Validation of a Set of Instruments to Assess Patient- and Caregiver-Oriented Measurements in Spinal Muscular Atrophy: Results of the SMA-TOOL Study. Vázquez-Costa JF, Branas-Pampillón M, Medina-Cantillo J, Povedano M, Pitarch-Castellano I, López-Lobato M, Fernández-Ramos JA, Lafuente-Hidalgo M, Rojas-García R, Caballero-Caballero JM, Málaga I, Eirís-Puñal J, **De Lemus M**, Cattinari MG, Cabello-Moruno R, Díaz-Abós P, Sánchez-Menéndez V, Rebollo P, Maurino J, Madruga-Garrido M.Neurol Ther. 2023 Feb;12(1):89-105. doi: 10.1007/s40120-022-00411-2. Epub 2022 Oct 21

Design of a Non-Interventional Study to Validate a Set of Patient- and Caregiver-Oriented Measurements to Assess Health Outcomes in Spinal Muscular Atrophy (SMA-TOOL Study). Madruga-Garrido M, Vázquez-Costa JF, Medina-Cantillo J, Brañas M, Cattinari MG, **de Lemus M**, Díaz-Abós P, Sánchez-Menéndez V, Terrancle Á, Rebollo P, Maurino J.Neurol Ther. 2021 Jun;10(1):361-373. doi: 10.1007/s40120-020-00229-w. Epub 2021 Jan 9.

"Be an ambassador for change that you would like to see": a call to action to all stakeholders for co-creation in healthcare and medical research to improve quality of life of people with a neuromuscular disease. Ambrosini A, Quinlivan R, Sansone VA, Meijer I, Schrijvers G, Tibben A, Padberg G, de Wit M, Sterrenburg E, Mejat A, Breukel A, Rataj M, Lochmüller H, Willmann R; 235th ENMC workshop study group.Orphanet J Rare Dis. 2019 Jun 7;14(1):126. doi: 10.1186/s13023-019-1103-8.

Position Statement: Sharing of Clinical Research Data in Spinal Muscular Atrophy to Accelerate Research and Improve Outcomes for Patients. Lochmüller H, Evans D, Farwell W, Finkel R, Goemans N, **de Lemus M**, Matyushenko V, Muntoni F, Ouillade MC, Schwersenz I, Wilson P.J Neuromuscul Dis. 2018;5(2):131-133. doi: 10.3233/JND-180325.

Patient and parent oriented tools to assess health-related quality of life, activity of daily living and caregiver burden in SMA. Rome, 13 July 2019. Mercuri E, Messina S, Montes J, Muntoni F, Sansone VA; all participants and the SMA PROM working group.Neuromuscul Disord. 2020 May;30(5):431-436. doi: 10.1016/j.nmd.2020.02.019. Epub 2020 Mar 7.

Identification of the most relevant aspects of spinal muscular atrophy (SMA) with impact on the quality of life of SMA patients and their caregivers: the PROfuture project, a qualitative study. **de Lemus M**, Cattinari MG, Pascual SI, Medina J, García M, Magallón A, Dumont M, Rebollo P.J Patient Rep Outcomes. 2024 Jul 24;8(1):78. doi: 10.1186/s41687-024-00758-0.

209th ENMC International Workshop: Outcome Measures and Clinical Trial Readiness in Spinal Muscular Atrophy 7-9 November 2014, Heemskerk, The Netherlands. Finkel R, Bertini E, Muntoni F, Mercuri E; ENMC SMA Workshop Study Group.Neuromuscul Disord. 2015 Jul;25(7):593-602. doi: 10.1016/j.nmd.2015.04.009. Epub 2015 Apr 28.

The Position of Neuromuscular Patients in Shared Decision Making. Report from the 235th ENMC Workshop: Milan, Italy, January 19-20, 2018.
Lochmüller H, Ambrosini A, van Engelen B, Hansson M, Tibben A, Breukel A, Sterrenburg E, Schrijvers G, Meijer I, Padberg G, Peay H, Monaco L, Snape M, Lennox A, Mazzone E, Bere N, **de Lemus M**, Landfeldt E, Willmann R; 235th ENMC workshop study group.J Neuromuscul Dis. 2019;6(1):161-172. doi: 10.3233/JND-180368.

Projects

- Led creation of a patient registry for Spinal Muscular Atrophy in Spain (2014-present)
- Led development of a PROM for Spinal Muscular Atrophy in Spain (2020-present)
- Contributed to the development of the International Standards of Care in SMA (2019)
- Co-author of Reflection paper on Patient Experience Data, EMA (2024)
- Led organisation of International Scientific Congress on SMA (2019)
- Participated as patient caregiver on 3 clinical trials
- Inputed in clinical trial protocols
- Inputed in HTA assessments for reimbursement of treatments.

Memberships

- Awarded with the Social Award for Patient Organisations (Spanish Society for Neurology, 2020 (SEN)).
- Awarded with the Spanish Rare Diseases Research Centers (CIBERER) award for best collaboration between healthcare professionals and patient organisations (2024).

Other Relevant Information

I am a patient representative