Curriculum Vitae

Personal information

Elizabeth Vroom

Work experience

1. Employer: Duchenne Parent Project
   - Start date: 012015
   - End date: 012024
   - Position: CEO
   - Activities: Raising Awareness Fundraising Funding Research Advocacy Improvement of Care Provide Information for families and professionals International collaboration
   - Country: Netherlands
2. Employer: E. Vroom BV
   - Start date: 081983
   - End date: 012015
   - Position: Owner
   - Activities: Dentist/Orthodontist
   - Country: Netherlands

Education and training

1. Subject:
   - Start date: 091971
   - End date: 051978
   - Qualification: Dentist
   - Organisation: RijksUniversiteit Groningen
   - Country: Netherlands
2. Subject:
   - Start date: 091979
   - End date: 091983
   - Qualification: Specialist Orthodontics and Maxillofacial Orthopedics
   - Organisation: Radboud University, Nijmegen
   - Country: Netherlands

Additional information

Publications

Publications since 2015

The FAIR journey of a patient-driven registry: Reflections and practical solutions from the Duchenne Data Platform FAIRification experience.

Lalout N, Wilkinson MD, Wandrei D, Tassoni A, Atalaia A, Prieto M, Camara A, Quemada E, Franken M, Jonker AH, Paliouras G, Siminiuc S, Carta C, Dos Santos Vieira B, Roos M, Kaliyaperumal R, Evangelista T, 't Hoen PAC, **Vroom E.**J Neuromuscul Dis. 2025 Oct 1:22143602251382969. doi: 10.1177/22143602251382969.

Development of the accredited duchenne centers program, a global program to achieve uniform and up-to-date care for all people living with duchenne muscular dystrophy.

de Groot IJM, Podolská K, Goemans N, Bakker SA, Lalout N, Jansen M, **Vroom E.**Orphanet J Rare Dis. 2025 Jul 2;20(1):335. doi: 10.1186/s13023-025-03843-9.PMID: 40604877

Factors affecting desired participation in transition to an adult life with Duchenne muscular dystrophy (DMD).

Merkenhof LJ, Veenhuizen Y, **Vroom E**, Sterenberg G, Hesseling WC, Groothuis JT, Cup EH, Houwen-van Opstal SL.J Neuromuscul Dis. 2025 May;12(3):353-363. doi: 10.1177/22143602251324847.

A matrix tool to foster patient engagement in children, adolescents and young adults: report from a multistakeholder workshop.

Cavaller-Bellaubi M, Degraeuwe E, Vande Walle J, Gasthuys E, Prytula A; expert group.Res Involv Engagem. 2024 Nov 27;10(1):125. doi: 10.1186/s40900-024-00658-

Towards harmonization of clinical tools for assessing Brain Involvement in Dystrophinopathies (BIND): report of four expert workshops: Newcastle, Leiden, Rome, Paris.

Hendriksen J, Weerkamp P, Miranda R, Kolesnik A, Chieffo D, Skuse D, **Vroom E**, Geagan C, Muntoni F, Mercuri E; BIND WP5 working group.Neuromuscul Disord. 2024 Oct 4;44:104452. doi: 10.1016/j.nmd.2024.104452. Online ahead of print.PMID: 39383638

The Dutch Dystrophinopathy Database: A National Registry with Standardized Patient and Clinician Reported Real-World Data.

van de Velde NM, Krom YD, Bongers J, Hoek RJA, Ikelaar NA, van der Holst M, Naarding KJ, van den Bergen JC, **Vroom E**, Horemans A, Hendriksen JGM, de Groot IJM, Houwen-van Opstal SLS, Verschuuren JJGM, van Duyvenvoorde HA, Snijder RR, Niks EH.J Neuromuscul Dis. 2024;11(5):1095-1109. doi: 10.3233/JND-240061.PMID: 39031379

EURO-NMD registry: federated FAIR infrastructure, innovative technologies and concepts of a patient-centred registry for rare neuromuscular disorders.

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, Kirschner 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, Silani V, Gyenge M, Reviers E, Hamroun D, **Vroom E**, Wilkinson MD, Lochmuller H, Evangelista T.Orphanet J Rare Dis. 2024 Feb 14;19(1):66. doi: 10.1186/s13023-024-03059-3.PMID: 38355534 **F**

Moving Beyond the 2018 Minimum International Care Considerations for Osteoporosis Management in **Duchenne** Muscular Dystrophy (DMD): Meeting Report from the 3rd International Muscle-Bone Interactions Meeting 7th and 14th November 2022.

Phung K, Crabtree N, Connolly AM, Furlong P, Hoffman EP, Jackowski SA, Jayash SN, Johnson A, Koujok K, Munns CF, Niks E, Rauch F, Schrader R, Turner C, **Vroom E**, Weber DR, Wong BL, Guglieri M, Ward LM, Wong SC.J Neuromuscul Dis. 2024;11(1):233-252. doi: 10.3233/JND-230176.PMID: 37980681

269th ENMC international workshop: 10 years of clinical trials in **Duchenne**muscular dystrophy - What have we learned? 9-11 December 2022, Hoofddorp, The Netherlands.

Naarding KJ, Stimpson G, Ward SJ, Goemans N, McDonald C, Mercuri E, Muntoni F; 269th ENMC workshop participants.Neuromuscul Disord. 2023 Nov;33(11):897-910. doi: 10.1016/j.nmd.2023.10.003. Epub 2023 Oct 11.PMID: 37926638

Harmonization of outcomes in epidermolysis bullosa: report of the Core Outcome Sets for Epidermolysis Bullosa (COSEB) kick-off meeting.

Korte EWH, Spuls PI, van den Akker PC, Kiritsi D, Laimer M, Pasmooij AMG, Riedl R, **Vroom E**, Wally V, Welponer T, Bolling MC.Br J Dermatol. 2024 Jan 23;190(2):268-270. doi: 10.1093/bjd/ljad361.PMID: 37792735

Patient reported outcome measure for upper limb in **Duchenne** muscular dystrophy: correlation with PUL2.0.

Cicala G, Pane M, Coratti G, Brogna C, Fanelli L, Norcia G, Forcina N, Mazzone E, Stanca G, Ferrante R, Vento A, Ferraroli E, Ricci M, Capasso A, Leone D, Palermo C, Berti B, Cutrona C, Mahyew A, Duong T, Goemans N, **Vroom E**, Mercuri E.Neuromuscul Disord. 2023 Sep;33(9):69-73. doi: 10.1016/j.nmd.2023.07.003. Epub 2023 Jul 22.PMID: 37612177

> The Dilemma of Choice for Duchenne Patients Eligible for Exon 51 Skipping The European Experience.
*Aartsma-Rus A, De Waele L, Houwen-Opstal S, Kirschner J, Krom YD, Mercuri E, Niks EH, Straub V, van Duyvenvoorde HA, **Vroom E.** J Neuromuscul Dis. 2023;10(3):315-325. doi: 10.3233/JND-221648.PMID: 36911945*

> 263rd ENMC International Workshop: Focus on female carriers of dystrophinopathy: refining recommendations for prevention, diagnosis, surveillance, and treatment. Hoofddorp, The Netherlands, 13-15 May 2022.
Sarkozy A, Quinlivan R, Bourke JP, Ferlini A; ENMC 263rd Workshop Study Group.Neuromuscul Disord. 2023 Mar;33(3):274-284. doi: 10.1016/j.nmd.2023.01.003. Epub 2023 Jan 12.PMID: 36804616

> A Comparison of Caregiver and Patient Preferences for Treating Duchenne Muscular Dystrophy.
*Crossnohere NL, Fischer R, **Vroom E**, Furlong P, Bridges JFP.Patient. 2022 Sep;15(5):577-588. doi: 10.1007/s40271-022-00574-y. Epub 2022 Mar 4.PMID: 35243571*

> The Role of Patient Involvement When Developing Therapies.
*Aartsma-Rus A, **Vroom E**, O'Reilly D.Nucleic Acid Ther. 2022 Apr;32(2):118-122. doi: 10.1089/nat.2021.0048. Epub 2021 Oct 1.PMID: 34597188 Free PMC article.*

> 263rd ENMC International Workshop: Focus on female carriers of dystrophinopathy: refining recommendations for prevention, diagnosis, surveillance, and treatment. Hoofddorp, The Netherlands, 13-15 May 2022. Sarkozy A, Quinlivan R, Bourke JP, Ferlini A; ENMC 263rd Workshop Study Group.Neuromuscul Disord. 2023 Jan 12;33(3):274-284. doi: 10.1016/j.nmd.2023.01.003. Online ahead of print.PMID: 36804616

> A Comparison of Caregiver and Patient Preferences for Treating Duchenne Muscular Dystrophy. Crossnohere NL, Fischer R, Vroom E, Furlong P, Bridges JFP.Patient. 2022 Sep;15(5):577-588. doi: 10.1007/s40271-022-00574-y. Epub 2022 Mar 4.PMID: 35243571

> The Role of Patient Involvement When Developing Therapies. Aartsma-Rus A, Vroom E, O'Reilly D.Nucleic Acid Ther. 2022 Apr;32(2):118-122. doi:10.1089/nat.2021.0048. Epub 2021 Oct 1.PMID: 34597188

> How Patient Organizations Can Drive FAIR Data Efforts to Facilitate Research and Health Care: A Report of the Virtual Second International Meeting on Duchenne Data Sharing, March 3, 2021. van Lin N, Paliouras G, Vroom E, 't Hoen PAC, Roos M.J Neuromuscul Dis. 2021;8(6):1097-1108. doi: 10.3233/JND-210721.PMID: 34334415

> 249th ENMC International Workshop: The role of brain dystrophin in muscular dystrophy: Implications for clinical care and translational research, Hoofddorp, The Netherlands, November 29th-December 1st 2019. Hendriksen JGM, Thangarajh M, Kan HE, Muntoni F; ENMC 249th workshop study group.Neuromuscul Disord. 2020 Sep;30(9):782-794. doi: 10.1016/j.nmd.2020.08.357. Epub 2020 Aug 15.PMID: 32912717

> Safety issues and harmful pharmacological interactions of nutritional supplements in Duchenne muscular dystrophy: considerations for Standard of Care and emerging virus outbreaks. Boccanegra B, Verhaart IEC, Cappellari O, Vroom E, De Luca A.Pharmacol Res. 2020 Aug;158:104917. doi: 10.1016/j.phrs.2020.104917. Epub 2020 May 30.PMID: 32485610 Review.

> The evolution of patient-focused drug development and Duchenne muscular dystrophy. Crossnohere NL, Fischer R, Crossley E, Vroom E, Bridges JF.Expert Rev Pharmacoecon Outcomes Res. 2020 Feb;20(1):57-68. doi: 10.1080/14737167.2020.1734454. Epub 2020 Mar 6.PMID: 32098551 Review.

> Meeting on data sharing for Duchenne 21-22 March 2019 Amsterdam, the Netherlands. Verhaart IEC, 't Hoen PAC, Roos M, Vroom E; Workshop Participants.Neuromuscul Disord. 2019 Oct;29(10):800-810. doi: 10.1016/j.nmd.2019.08.010. Epub 2019 Aug 28.PMID: 31548100 Review. No abstract available.

> 2nd Workshop on upper-extremity assistive technology for people with Duchenne: Effectiveness and usability of

arm supports Irvine, USA, 22nd-23rd January 2018. Janssen MMHP, Lobo-Prat J, Bergsma A, Vroom E; workshop participants.Neuromuscul Disord. 2019 Aug;29(8):651-656. doi: 10.1016/j.nmd.2019.07.005. Epub 2019 Jul 25.PMID: 31443952 No abstract available.

> 238th ENMC International Workshop: Updating management recommendations of cardiac dystrophinopathyHoofddorp, The Netherlands, 30 November - 2 December 2018. Bourke JP, Guglieri M, Duboc D; ENMC 238th Workshop Study Group.Neuromuscul Disord. 2019 Aug;29(8):634-643. doi: 10.1016/j.nmd.2019.06.598. Epub 2019 Jul 1.PMID: 31402197 No abstract available.

> Muscle biopsies in clinical trials for Duchenne muscular dystrophy - Patients' andcaregivers' perspective. Verhaart IEC, Johnson A, Thakrar S, Vroom E, De Angelis F, Muntoni F, Aartsma-RusAM, Niks EH.Neuromuscul Disord. 2019 Aug;29(8):576-584. doi: 10.1016/j.nmd.2019.06.004. Epub 2019 Jun 12.PMID: 31378431

> "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.PMID: 31174585

> 236th ENMC International Workshop Bone protective therapy in Duchenne muscular dystrophy: Determining the feasibility and standards of clinical trials Hoofddorp, The Netherlands, 1-3 June 2018. Wong SC, Straub V, Ward LM, Quinlivan R; 236th ENMC workshop participants.Neuromuscul Disord. 2019 Mar;29(3):251-259. doi: 10.1016/j.nmd.2019.01.002. Epub 2019 Jan 12.PMID: 30803852 No abstract available.

> The patient's view on rare disease trial design - a qualitative study. Gaasterland CMW, van der Weide MCJ, du Prie-Olthof MJ, Donk M, Kaatee MM, Kaczmarek R, Lavery C, Leeson-Beevers K, O'Neill N, Timmis O, van Nederveen V, Vroom E, van der Lee JH.Orphanet J Rare Dis. 2019 Feb 7;14(1):31. doi: 10.1186/s13023-019-1002-z.PMID: 30732630

> A Transition Toolkit for Duchenne Muscular Dystrophy. Trout CJ, Case LE, Clemens PR, McArthur A, Noritz G, Ritzo M, Wagner KR, Vroom E, Kennedy A.Pediatrics. 2018 Oct;142(Suppl 2):S110-S117. doi: 10.1542/peds.2018-0333M.PMID: 30275255

> Primary Care and Emergency Department Management of the Patient With Duchenne Muscular Dystrophy. Noritz G, Naprawa J, Apkon SD, Kinnett K, Racca F, Vroom E, Birnkrant DJ.Pediatrics. 2018 Oct;142(Suppl 2):S90-S98. doi: 10.1542/peds.2018-0333K.PMID: 30275253

> The POWER-tool: Recommendations for involving patient representatives in choosing relevant outcome measures during rare disease clinical trial design. Gaasterland CMW, Jansen-van der Weide MC, Vroom E, Leeson-Beevers K, Kaatee M, Kaczmarek R, Bartels B, van der Pol WL, Roes KCB, van der Lee JH.Health Policy. 2018 Dec;122(12):1287-1294. doi: 10.1016/j.healthpol.2018.09.011. Epub 2018 Sep 21.PMID: 30274934

> Report on the workshop: Meaningful outcome measures for Duchenne muscular dystrophy, London, UK, 30-31 January 2017. Straub V, Mercuri E; DMD outcome measure study group.Neuromuscul Disord. 2018 ug;28(8):690-701. doi: 10.1016/j.nmd.2018.05.013. Epub 2018 Jun 6.PMID: 30033203 No abstract available.

> Nutrition in Duchenne muscular dystrophy 16-18 March 2018, Zaandam, the Netherlands. Verhaart IEC, van den Engel-Hoek L, Fiorotto ML, Franken-Verbeek M, Vroom E; workshop participants.Neuromuscul Disord. 2018 Aug;28(8):680-689. doi:10.1016/j.nmd.2018.05.004. Epub 2018 May 16.PMID: 29910096 No abstractavailable.

> Meeting report of the "Regulatory Exchange Matters" session at the 5th International TREAT-NMD Conference:: Lessons in communication: How an early dialogue between patients, regulators and academics can further therapy development for neuromuscular disorders Freiburg, Germany, 27-29 November 2017.

> Aartsma-Rus A, Mercuri E, Vroom E, Balabanov P.Neuromuscul Disord. 2018 Jul;28(7):619-623. doi: 10.1016/j.nmd.2018.04.009. Epub 2018 Apr 20.PMID: 29778308 No abstract available.

> 227th ENMC International Workshop:: Finalizing a plan to guarantee quality in translational research for neuromuscular diseases Heemskerk, Netherlands, 10-11 February 2017. Willmann R, Buccella F, De Luca A, Grounds MD; 227th ENMC workshop study group.Neuromuscul Disord. 2018 Feb;28(2):185-192. doi: 10.1016/j.nmd.2017.11.002. Epub 2017 Nov 15.PMID: 29361397 No abstract available.

> 226th ENMC International Workshop:: Towards validated and qualified biomarkers for therapy development for Duchenne muscular dystrophy 20-22 January 2017, Heemskerk, The Netherlands. Aartsma-Rus A, Ferlini A, McNally EM, Spitali P, Sweeney HL; workshop participants.Neuromuscul Disord. 2018 Jan;28(1):77-86. doi:10.1016/j.nmd.2017.10.002. Epub 2017 Oct 26.PMID: 29203356 No abstract available.

> Development of Exon Skipping Therapies for Duchenne Muscular Dystrophy: A Critical Review and a Perspective on the Outstanding Issues. Aartsma-Rus A, Straub V, Hemmings R, Haas M, Schlosser-Weber G, Stoyanova-Beninska V, Mercuri E, Muntoni F, Sepodes B, Vroom E, Balabanov P.Nucleic Acid Ther. 2017 Oct;27(5):251-259. doi: 10.1089/nat.2017.0682. Epub 2017 Aug 10.PMID: 28796573 Review.

Development of Exon Skipping Therapies for Duchenne Muscular Dystrophy: A Critical Review and a Perspective on the Outstanding Issues.

Aartsma-Rus A, Straub V, Hemmings R, Haas M, Schlosser-Weber G, Stoyanova-Beninska V, Mercuri E, Muntoni F, Sepodes B, **Vroom E**, Balabanov P.Nucleic Acid Ther. 2017 Oct;27(5):251-259. doi: 10.1089/nat.2017.0682.

Cite

Development of a patient-reported outcome measure for upper limb function in Duchenne muscular dystrophy: DMD Upper Limb PROM.

Klingels K, Mayhew AG, Mazzone ES, Duong T, Decostre V, Werlauff U, **Vroom E**, Mercuri E, Goemans NM; Upper Limb Clinical Outcome Group.Dev Med Child Neurol. 2017 Feb;59(2):224-231. doi: 10.1111/dmcn.13277.

Stakeholder cooperation to overcome challenges in orphan medicine development: the example of Duchenne muscular dystrophy.

Straub V, Balabanov P, Bushby K, Ensini M, Goemans N, De Luca A, Pereda A, Hemmings R, Campion G, Kaye E, Arechavala-Gomeza V, Goyenvalle A, Niks E, Veldhuizen O, Furlong P, Stoyanova-Beninska V, Wood MJ, Johnson A, Mercuri E, Muntoni F, Sepodes B, Haas M, **Vroom E**, Aartsma-Rus A.Lancet Neurol. 2016 Jul;15(8):882-890. doi: 10.1016/S1474-4422(16)30035-7.PMID: 27302365

1st Workshop on Upper-Extremity Assistive Technology for People with Duchenne: State of the art, emerging

avenues, and challenges: April 27th 2015, London, United Kingdom.

Bergsma A, Lobo-Prat J, **Vroom E**, Furlong P, Herder JL; Workshop Participants.Neuromuscul Disord. 2016 Jun;26(6):386-93. doi: 10.1016/j.nmd.2016.04.005.

Imperatives for DUCHENNE MD: a Simplified Guide to Comprehensive Care for Duchenne Muscular Dystrophy.

Kinnett K, Rodger S, **Vroom E**, Furlong P, Aartsma-Rus A, Bushby K.PLoS Curr. 2015 Aug 7;7:ecurrents.md.87770501e86f36f1c71e0a5882ed9ba1. doi: 10.1371/currents.md.87770501e86f36f1c71e0a5882ed9ba1.PMID: 26331093

Will the trilogue on the EU Data Protection Regulation recognise the importance of health research?

Coppen R, van Veen EB, Groenewegen PP, Hazes JM, de Jong JD, Kievit J, de Neeling JN, Reijneveld SA, Verheij RA, **Vroom E.**Eur J Public Health. 2015 Oct;25(5):757-8. doi: 10.1093/eurpub/ckv149. Epub 2015 Aug 10.PMID: 26265364

The TREAT-NMD advisory committee for therapeutics (TACT): an innovative de-risking model to foster orphan drug development.

Heslop E, Csimma C, Straub V, McCall J, Nagaraju K, Wagner KR, Caizergues D, Korinthenberg R, Flanigan KM, Kaufmann P, McNeil E, Mendell J, Hesterlee S, Wells DJ, Bushby K; TACT.Orphanet J Rare Dis. 2015 Apr 23;10:49. doi: 10.1186/s13023-015-0258-1.PMID: 25902795

[Re-use of medical data for research. What do the Dutch think of the requirement for explicit consent?].

Coppen R, Groenewegen PP, Hazes JM, de Jong JD, Kievit J, de Neeling JN, Reijneveld SA, Verheij RA, **Vroom E.**Ned Tijdschr Geneeskd. 2015;160:A9868.PMID: 27027208 Dutch.

Measuring clinical effectiveness of medicinal products for the treatment of Duchenne muscular dystrophy.

Lynn S, Aartsma-Rus A, Bushby K, Furlong P, Goemans N, De Luca A, Mayhew A, McDonald C, Mercuri E, Muntoni F, Pohlschmidt M, Verschuuren J, Voit T, **Vroom E**, Wells DJ, Straub V.Neuromuscul Disord. 2015 Jan;25(1):96-105. doi: 10.1016/j.nmd.2014.09.003. Epub 2014 Sep 11.PMID: 25307856

Translational and regulatory challenges for exon skipping therapies.

Aartsma-Rus A, Ferlini A, Goemans N, Pasmooij AM, Wells DJ, Bushby K, **Vroom E**, Balabanov P.Hum Gene Ther. 2014 Oct;25(10):885-92. doi:10.1089/hum.2014.086.PMID: 25184444 Review.

Biomarkers and surrogate endpoints in Duchenne: meeting report.

Aartsma-Rus A, Ferlini A, **Vroom E.**Neuromuscul Disord. 2014 Aug;24(8):743-5. doi: 10.1016/j.nmd.2014.03.006. Epub 2014 May 28.PMID: 24951452

Forty-Five Years of Duchenne Muscular Dystrophy in The Netherlands.

van den Bergen JC, Ginjaar HB, van Essen AJ, Pangalila R, de Groot IJ, Wijkstra PJ, Zijnen MP, Cobben NA, Kampelmacher MJ, Wokke BH, de Coo IF, Fock JM, Horemans AM, van Tol M, **Vroom E**, Rijlaarsdam ME, Straathof CS, Niks EH, Verschuuren JJ.J Neuromuscul Dis. 2014;1(1):99-109.PMID: 27858664

Development of the Performance of the Upper Limb module for Duchenne muscular dystrophy.

Mayhew A, Mazzone ES, Eagle M, Duong T, Ash M, Decostre V, Vandenhauwe M, Klingels K, Florence J, Main M, Bianco F, Henrikson E, Servais L, Campion G, **Vroom E**, Ricotti V, Goemans N, McDonald C, Mercuri E; Performance of the Upper Limb Working Group.Dev Med Child Neurol. 2013 Nov;55(11):1038-45. doi: 10.1111/dmcn.12213. 1.PMID: 23902233

195th ENMC International Workshop: Newborn screening for Duchenne muscular dystrophy 14-16th December, 2012, Naarden, The Netherlands.

Ellis JA, **Vroom E**, Muntoni F.Neuromuscul Disord. 2013 Aug;23(8):682-9. doi: 10.1016/j.nmd.2013.05.008. Epub 2013 Jun 20.PMID: 23791627

Guidance in social and ethical issues related to clinical, diagnostic care and novel therapies for hereditary neuromuscular rare diseases: "translating" the translational.

McCormack P, Woods S, Aartsma-Rus A, Hagger L, Herczegfalvi A, Heslop E, Irwin J, Kirschner J, Moeschen P, Muntoni F, Ouillade MC, Rahbek J, Rehmann-Sutter C, Rouault F, Sejersen T, **Vroom E**, Straub V, Bushby K, Ferlini A.PLoS Curr. 2013 Jan 10;5:ecurrents.md.f90b49429fa814bd26c5b22b13d773ec. doi: 10.1371/currents.md.f90b49429fa814bd26c5b22b13d773ec.PMID: 23330068

Projects

WDO/UPPMD was involved in 'Vision_DMD' a horizon2020 project http://cordis.europa.eu/project/rcn/199721_en.html Share4Rare This project has received funding from European Union's Horizon 2020 programme under Grant Agreement 780262

Recently WDO/UPPMD was involved in

Trials@home https://trialsathome.com IMI funded

BIND https://bindproject.eu Brain involvement in Dystrophinopathies H2020

BEAMER https://beamerproject.eu Improving Adherence Behavior IMI funded

ERDERA https://www.ejprarediseases.org/erdera/ Horizon Europe Funding

Memberships

Chair World Duchenne Organization (former UPPMD) www.worldduchenne.org

Member Advisory Board DARWIN EU https://darwin-eu.org/

Other Relevant Information

I am a patient representative