



## Curriculum Vitae

Personal information **Simona Borroni**

### Work experience

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May 2023 - current: Board Member - currently Treasurer (volunteer) - Adajo APS  
December 2012 - current: Board Member - currently Deputy Chair (volunteer) - Gruppo Famiglie Dravet APS, Italy  
May 2014 - current : Board Member (volunteer) - currently Chair (volunteer) - Dravet syndrome European Federation, France  
April 2009 - March 2024: Board Member (volunteer) - Italian Federation for Epilepsy  
October 2007 - December 2015: accountant - Studio Vaelntini, Italy  
December 1982 - September 1999: Audit manager - PriceWaterHouseCoopers, Italy

### Education and training

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2020-2021 Master II level – CMU2 “Patient Advocacy Management”, Università Cattolica del Sacro Cuore, Rome, I

2018-2019 Master “Patient Engagement in Research and Development of Innovative Therapies” EUPATI Italy

April 2019 Organizing and maximizing rare diseases biological sample data in biobanks” EJP-RD Training workshop

1981 Diploma in Accountancy and Business Studies Istituto Tecnico Statale Commerciale e per Geometri Enrico Mattei, Rho (MI), Italy

### Additional information

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#### Publications

Ianes PG, Martini R, Frazzetta S, Bertholom Y, Montecchi MG, De Luca V, Di Lisa S, Cutrona C, Moriconi F, Quintiliani M, **Borroni S**, Rega FR, Chieffo DPR, Battaglia DI. Cognitive Orientation to daily Occupational Performance Approach using telerehabilitation with parents to improve performance issues in children/adolescents with Dravet Syndrome. *Epilepsy Behav.* 2026 Mar;176:110803. doi: 10.1016/j.yebeh.2025.110803. Epub 2026 Jan 23. PMID: 41579788.

Camp R, **Borroni S**, DeKeyser H, Hees M, Leijenhof A, Nasrulloeva M, Trigoso D, Houyez F. Evaluation of the methodology of independent Community Advisory Boards in health products research and development: a mixed-methods cross-sectional survey study. *Res Involv Engagem.* 2026 Mar 20. doi: 10.1186/s40900-026-00866-9. Epub ahead of print. PMID: 41863016.

Konrad, C., **Borroni S**, Budak, S. *et al.* More than epilepsy—a parent-initiated collaborative analysis of the research landscape and research needs in Dravet syndrome. *Clin Epileptol* (2025). <https://doi.org/10.1007/s10309-025-00785-x>

Ianes PG, Martini R, Bertholom Y, Montecchi MG, Salvatore G, Cutrona C, Moriconi F, Quintiliani M, **Borroni S**, Rega FR, Rosaria Chieffo DP, Battaglia DI. Cognitive Orientation to daily Occupational Performance Approach with children with Dravet syndrome using a telerehabilitation format: A single subject study. *Epilepsy Behav.* 2025 Nov;172:110548. doi: 10.1016/j.yebeh.2025.110548. Epub 2025 Jun 24. PMID: 40561845.

Porto C, Perulli M, Arpaia C, Villa M, Arcangeli V, Quintiliani M, Gambardella ML, Brando C, Contaldo I, Veredice C, Zaghi V, Canepa G, Borroni S, Chieffo DPR, Battaglia DI. Survey of rehabilitation approaches and plans for individuals with dravet syndrome (RAPIDS) in Italy: Current practices and strategies to progress. *Epilepsy Behav.* 2024 Aug;157:109888. doi: 10.1016/j.yebeh.2024.109888. Epub 2024 Jul 10. PMID: 38991471.

Benvenuti S, Wang CM, **Borroni S**. Perspectives, Expectations, and Concerns of European Patient Advocates on Advanced Therapy Medicinal Products. *Front Med (Lausanne).* 2021 Nov 23;8:728529. doi: 10.3389/fmed.2021.728529. PMID: 34888320; PMCID: PMC8649896.

Porto C, Perulli M, Arpaia C, Villa M, Arcangeli V, Quintiliani M, Gambardella ML, Brando C, Contaldo I, Veredice C, Zaghi V, Canepa G, **Borroni S**, Chieffo DPR, Battaglia DI. Survey of rehabilitation approaches and plans for individuals with dravet syndrome (RAPIDS) in Italy: Current practices and strategies to progress. *Epilepsy Behav.* 2024 Aug;157:109888. doi: 10.1016/j.yebeh.2024.109888. Epub 2024 Jul 10. PMID: 38991471.

Enia G, Giussani G, Bianchi E, Mecarelli O, Beghi E; EPINEEDS Study Group. The management of epilepsy in clinical practice: Do the timing and severity of the disease influence the priorities of patients and the caring physicians? Data from the EPINEEDS study. *Epilepsy Behav.* 2021 Jan;114(Pt A):107201. doi: 10.1016/j.yebeh.2020.107201. Epub 2020 Jul 29. PMID: 32739237.

## Projects

1. June 2022 – April 2024 – Project Manager for the RINGS project Neonatal genome sequencing: feasibility and clinical, ethical, psychological and economic implications, coordinated by the Telethon ETS Foundation and co-funded by the Lombardy Region, Italy
2. June 2021 – December 2021 – Member of the Expert Panel – International consensus on the diagnosis and management of Dravet syndrome
3. October 2021 to September 2024 – Participation as a Partner Organisation in the collaborative EUROPEAN – SCN1A-UP! project, funded by EJPRD - European Joint Project on Rare Disease
4. March – August 2021 – "Position paper on patients' views on advanced therapies by patient advocates". Collaboration with the Telethon Foundation RTS to conduct interviews with European patient experts on ATMPs as part of the Restore project.
5. July – September 2019 – ERA PER MED – lay reviewer for projects under the JOINT TRANSNATIONAL CALL FOR PROPOSALS (2019)
6. March 2017 – September 2018 – Member of the Scientific Board of the "White Paper on Epilepsy in Italy"

## Memberships

### Other Relevant Information

I am a patient representative. As the parent of a 30-year-old with Dravet syndrome, it is my ambition and desire to get involved and offer my expertise in support of causes aimed at improving the quality of life for this community, with a particular focus on diagnosis, treatment and care pathways. I have been volunteering in the non-profit associations, since 2009 in the areas of epilepsy and rare diseases, both nationally and internationally. Specifically, currently I am Deputy-President of the Dravet Families Group APS and President of the European Federation for Dravet Syndrome.

Until 1999, I gained more than ten years' experience as auditor at the multinational firm PriceWaterhouseCoopers, developing team working and project management skills.

I attended the Eupati Patient Academy course obtaining the Expert Patient certificate in 2019 and the master in Patient Advocacy Management at ALTEMS, the Catholic University, Rome.

Significant experiences: Project management, including research funding calls, within the scope of reference association activities; participation in the Technical Board of the Epilepsy White Paper in Italy; participation in PDTA (Diagnostic, Therapeutic and Care Pathways) drafting working groups; participation in ELSI working groups of BBMRI Italian node of the European Research Infrastructure of Biobanks and BioMolecular Resources; lay reviewer in scientific project evaluation processes both in the association and in the Era PerMed Call; participation as Patient Expert in Advisory Boards and Conferences; collaboration with Telethon Foundation, Italy in the Horizon 2020 project "RESTORE Health by Advanced Therapies" and in the "RINGS - Newborn genome sequencing: feasibility and clinical, ethical, psychological and economic implications" project funded by the Lombardy Region, Italy.