



Curriculum Vitae

Personal information **Patricia Durao**

Work experience

June 2011 – Present Cure & Action for Tay-Sachs (CATS) Foundation

Co-founder and Executive Director

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March 2012 – Present European Tay-Sachs Charity Consortium (ETSCC)

Advocacy representative

March 2011 – December 2017 Full-time carer

Full-time carer

October 2014 – October 2015 Consultancy

Freelance Consultant

July 2012 – October 2014 AlexandAlexa

Production Manager

July 2010 – July 2012 Marie Chantal

Wholesale Manager

March 2009 – July 2010 Consultancy

Freelance Consultant

June 2002 – March 2009 Caramel Baby & Child

Wholesale & Production Manager

Education and training

Qualifications

2021-online EURORDIS- Rare Diseases Europe

Leadership School on Healthcare and Research

2021-online EURORDIS- Rare Diseases Europe

Open Academy School on Scientific Innovation & Translational Research

2020-online EURORDIS- Rare Diseases Europe

Digital School on Social and Digital Media

2020-online EURORDIS- Rare Diseases Europe

Open Academy School on Medicines Research and Development

2020-online Innovative Medicines Initiative Conect4Children (IMI c4c)

Patient and Public Involvement in Paediatric Clinical Research

2020 Media Trust

Digital Summer School

Education

September 2003 – King's College London

July 2004 MBA

September 2001 – King's College London

July 2003 BSc (Hons) in Business and Managerial Economics

September 1999 – Faculdade de Economia do Porto _ Universidade do Porto

July 2001 BSc (Hons) in Business and Managerial Economics

September 1996 – Escola Secundária Aurélia de Sousa

July 1999 Diploma de Ensino Secundário, Ciências Socioeconómicas

September 1987 – Colégio de Nossa Senhora da Paz

July 1996 Primeiro e Segundo Ciclo

Languages

Portuguese 5 – Native

English 5 – Bilingual Proficiency

French 3 – Professional Working Proficiency

Spanish 3 – Professional Working Proficiency

Additional information

Publications

Lewi, D., Durao, P., Stokes, L., MacKillop, I., & Wiltshire, M. (2024). Empowering the GM2 gangliosidosis community: Developing a single clinical toolkit for clinicians, patients and caregivers in the UK. *Molecular Genetics and Metabolism*, 141(2), 107938. <https://doi.org/10.1016/j.ymgme.2023.107938>

Lewi, D., & Durao, P. (2018). How to get research done on your rare disease. 9th European Conference on Rare Diseases & Orphan Products (ECRD Vienna 2018). *Orphanet Journal of Rare Diseases*, 13(2), 167. <https://doi.org/10.1186/s13023-018-0895-2>

Lewi, D., & Durao, P. (2016). The eAcademy for Tay-Sachs & Sandhoff disease app. 8th European Conference on Rare Diseases & Orphan Products (ECRD 2016). *Orphanet Journal of Rare Diseases*, 11(1), 143. <https://doi.org/10.1186/s13023-016-0515-y>

Projects

Memberships

Other Relevant Information I am a patient representative