

## Curriculum Vitae

Personal information **Patricia Durao**

### Work experience

---

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

*Co-founder and Executive Director*

**I**

**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