

Curriculum Vitae

Personal information **Maja Bartoszewicz-Moritz**

Work experience

Rare Disease Project Manager (02.2025 – Present)

FH EUROPE FOUNDATION

- Leading rare disease projects to enhance patient advocacy and policy influence.
- Supporting initiatives that improve access to care and cross-border collaboration.

Patient Advocate & Caregiver (2009 – Present) Poland, Sweden

- Advocate for **MEF2C haploinsufficiency** awareness, .
- Work closely with medical experts to **improve diagnostic pathways** and patient care.

Cross-Border Assessment Coordinator- Patient representative (2024 – Present) Poland

- Collaborating on the creation of a **preclinical in-person assessment framework** between **Boston Children's Hospital (USA)** and **University Clinical Hospital in Gdańsk, Poland**.
- Exploring the possibility of establishing a **European Data Center for MEF2C patients** to improve research and data collection.

Rare Disease Advocate & Volunteer (2023 – 2025)

Lelek's Foundation, Poland

- Organizing **Rare Disease Day** and **Disability Day** events.
- Engaging with stakeholders, healthcare providers, and policymakers to address rare disease challenges.

Lecturer & Community Awareness Coordinator ,Poland (2024-Present)

- Conducting **radio lectures** to educate the public about rare diseases.
- Leading **local initiatives** to improve awareness and support for rare disease patients.

Business Owner (2013 – 2016)

- Managed daily operations, sales, and customer service.
- Developed marketing strategies and established brand identity.

Elderly Care/Patient Representative & Supervisor (2016 – 2020)

OMSORGSFAMILJEN H.E.M VÅRD & OMSORG, Sweden

- Advocated for elderly patients, particularly in **dementia care**.
- Worked with healthcare professionals to improve patient outcomes.

Department Manager / Store Assistant Manager (2004 – 2009)

Inditex 2004-2008(Ireland), Ted Baker2008-2009 (Ireland),

- Led HR and sales teams, implemented training programs, and optimized store performance.

Education and training

- **HTA Extended In-Person Training Certificate** ,Austria, 24.02.2025 – 27.02.2025
- **Person-Centred Value-Based Health Care (PCVBHC),Ongoing 14-week Training,Certificate, March 2025-June 2025**
- **EURORDIS Open Academy - Scientific Innovation & Translational Research Certificate 2024**
- **EURORDIS Open Academy - Medicines Research and Development (Ongoing)February 2025-June 2025**
- **EUCAPA - Fast Track Training on Health Technology Assessment (HTA) Certificate,September 2024**

Additional information

[Publications](#)

[Projects](#)

[Memberships](#)

Other Relevant Information

Languages:

Polish – **Native**

English – **C1/C2**

Swedish – **B3**

Italian – **B3**

Speaker RE(ACT) CONGRESS AND IRDiRC CONFERENCE, January 2021

Project- Awarded documentary 'Journey of Hope' international creation to represent diagnostic odyssey and meaning of diagnosis.2019

RAREfest Cambridge- Cambridge Rare Disease Network 2020