

## Curriculum Vitae

Personal information Jose Daniel de Vicente Corbeira

### Work experience

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1. Employer:
  - Start date: September, 2020
  - End date: present
  - Position: Freelance Consultant
  - Advocacy360 Consulting. [www.advocacy360.es](http://www.advocacy360.es)
  - Activities: Consulting in management, strategic planning, and health projects for patient organizations. RWE/RWD, PROMS/PREMS, development of patient registries, expert patient programs, patient journey
- Country: Spain
2. Employer:
  - Start date: January, 2001
  - End date: September 2020
  - Position: Associate Pharmacist
  - Employer's name: Farmacia El Plantío - LCG
  - Activities:
    - Responsible for team management
    - Dispensing and pharmaceutical care
    - Management of medicine purchases and stock management
- Country: Spain

### Education and training

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1. Subject:
  - Start Date: March, 2022
  - End Date: May, 2022
  - Qualification: Scientific Innovation & Translational Research
  - Organisation: Eurordis School
  - Country: France
2. Subject:
  - Start date: Nov, 2020
  - End date: June, 2021
  - Qualification: Postgraduate in Project Management for Patient Organizations. Strategic Planning and Leadership.
  - Organisation: European University
  - Country: Spain
3. Subject:
  - Start Date: Nov, 2019
  - End Date: March, 2020
  - Qualification: Public Health Technical Degree
  - Organisation: Colegio Oficial de Farmacéuticos de Madrid
  - Country: Spain
4. Subject:
  - Start Date: Oct, 1994
  - End Date: July, 1999
  - Qualification: Degree in Pharmacy
  - Organisation: University of San Pablo CEU
  - Country: Spain

### Additional information

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#### Publications

Geberhiwot, T., Wasserstein, M., Wanninayake, S., Bolton, S. C., Dardis, A., Lehman, A., ... & Schuchman, E. (2023). Consensus clinical management guidelines for acid sphingomyelinase deficiency (Niemann–Pick disease types A, B and A/B). Orphanet Journal of Rare Diseases, 18(1), 85.

Villarrubia, Morales Conejo, de Vicente et al. ASMD Care: Design of PROMs and PREMs questionnaire. Poster WODC 2024 BCN

Faye, F., Crocione, C., Anido de Peña, R. et al. Time to diagnosis and

determinants of diagnostic delays of people living with a rare disease:  
results of a Rare Barometer retrospective patient survey. *Eur J Hum Genet*  
32, 1116–1126 (2024).

## Projects

I have participate in olipudase alfa clinical trial as patient.

## Memberships

### Current titles:

President. *ASMD Spain Patient Association*  
Board Member. *FEDER (Spanish Federation of Rare Diseases)*  
Board Member. *EURORDIS (Rare Diseases Europe)*

### Workin groups/Committees:

Integrated Care Plan for Rare Disease Patients in the Autonomus Community of Madrid. (*FEDER/Health Departament Madrid*)  
Citizen participation commission IMPACT (*Instituto de Salud Carlos III. ISCIII*)  
Member of CMA EC (*Critical Medicines Alliance European Commission*)  
Research Liaison Officer. *INPDA (International Niemann-Pick Alliance)*  
INPDR (International Niemann-Pick Disease Registry) Working Group  
DITA (Drug Information, Transparency and Access) Task Force Member. *EURORDIS*  
Clinical Management Guidelines for ASMD. International Development Working Group. *INPDA/INPDR*  
Screen4Care. Newborn Screening Working Group. *EURORDIS*  
Rare Barometer Voices Working Group. *EURORDIS*

### Speaker/presentations:

The Rare Disease Action Plan. Where are we and how to integrate this from a European to a national level for real impact. *World Orphan Drug Congress 2024*  
Strategic Evidence Generation. *World Orphan Drug Congress 2024*  
The impact of ASMD in patients and families QoL. *ISPOR 2024, Atlanta*.  
III Post Degree in Lysosomal Diseases. *University of Santiago de Compostela*  
Orphan Drugs, Beyond the Cost. *68th SEFH Congress*  
Pharmaceutical Law: Patient Rights and Access Difficulties  
Diagnosis Problems and Treatment Access in Rare Disease Patients  
Patient Participation in R&D of Orphan Drugs  
Humanization of Healthcare for Rare Disease Patients  
The Importance of Patient Registries in Rare Diseases  
European Pharmaceutical Strategy  
European Comprehensive Care Plan for People with Rare Diseases  
RWE and RWD Impact on New Treatment Evaluation  
Social and Healthcare Needs of Rare Disease Patients  
"ASMD Patient Journey"  
Socio-educational Project "Expert Patient, Empowered Patient"  
International Advocacy and Patient Engagement Programme  
World Rare Disease Day Campaigns. *EURORDIS/FEDER*

## Other Relevant Information

After working for more than 20 years as a community pharmacist, combining this with patient projects development for patient organizations I finally decided to focus my education and career on this path.  
I develop expert patient programs that promote the active participation of empowered patients in decision making and relationships with all stakeholders, PROMs, PREMs and RWE/RWD projects.