

## Curriculum Vitae

Personal information **Alessia Bernardi**

### Work experience

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#### WORK EXPERIENCE

20/06/2019 – CURRENT Nova Gorica, Slovenia - ZAVOD BV FOR  
Director of the non-profit organisation supporting patients with  
mitochondrial, neurological and neurometabolic diseases.  
Director of the national SLOMITO register for mitochondrial patients.  
Promotion of first aid activities.  
Member of Eurordis from 2020

01/02/2024 – PRESENT Milano, Italy - REGIONE LOMBARDIA -Territorial Ethics Committee LOMBARDIA 6  
Patient Representative (full member) of the Territorial Ethics Committee LOMBARDIA 6 by decree of Regione  
Lombardia on 12.02.2024.  
Work tasks: Clinical trial review and approval activities, compassionate uses of investigational drugs, ICF review for  
an estimated 1500 clinical trials per year.

17/06/2024 – PRESENT Milano, Italy - REGIONE LOMBARDIA - Vice Chair of Territoriale Ethics Committee  
LOMBARDIA 6

Activities required by the Rules of Operation of the Ethics Committees of the Lombardy Region for the function of  
vice chairperson  
I coordinate the work of the President's Core Group for the preliminary evaluation of observational studies.  
I took care of the investigation part, creating the preliminary checklists for the submission of studies (those not  
submitted according to EU regulation 536/2014).  
I check with the President and the scientific secretariat the preparation of the agenda for the plenary sessions.  
In addition to my role as Vice Chair, I continue to serve as a patient representative on the same committee.

### Education and training

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#### POSTGRADUATES COURSES

-01/11/2021 – 21/11/2022 Roma, Italy  
Website [www.unitelmasapienza.it](http://www.unitelmasapienza.it)

Expert Patient in digital health technologies- Unitelma Sapienza Università degli studi di Roma

-01/11/2021 – 25/10/2022 Utrecht, Netherlands  
Website <https://eupati.eu/>

Eupati Fellow The European patients' Academy on Therapeutic Innovation (EUPATI)

-01/10/2021 - 16/09/2022 - Rome, Italy Website: [www.accademiadeipazienti.it](http://www.accademiadeipazienti.it)

Patient Expert on Medicines Research and Development Accademia del Paziente Esperto Eupati Italia

-01/09/2021 – 01/09/2022 Boston, United States  
Address 25 Shattuck St, 02115, Boston, United States Website <https://onlinelearning.hms.harvard.edu/hmx/>

Certificate of Achievement - Genetic testing and sequencing technologies HMX Harvard Medical School

-01/11/2020 – 30/04/2021 Boston, United States  
Address 25 Shattuck St, 02115, Boston, United States Website <https://onlinelearning.hms.harvard.edu/hmx/>

Certificate of achievement, Genetics HMX Harvard Medical School

-01/12/2020 – 16/04/2021 Paris, France  
Address 96, rue Didot , 75014, Paris, France Website <https://www.eurordis.org>

Certificate of attendance The EURORDIS Winter School on Scientific Innovation and  
Translational Research

#### GRADUATED DEGREE

-01/11/2008 – 14/11/2013 Milano, Italy  
Website <https://www.unimi.it/>

Master's degree in economics and business management science - Università degli studi di  
Milano

### Additional information

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## Publications

### Projects

- 31/05/2022 to 31/05/2024 Policlinico Gemelli, Rome (Italy)

Research Grant - LANTERN PROJECT: LUNG CANCER MULTI-OMICS AVATARS FOR INTEGRATED PRECISION MEDICINE Policlinico Gemelli

### Memberships

Member of Eurordis since 2020

### Other Relevant Information

I am a patient representative and an expert patient.

Multidisciplinary background encompassing, economy, management, ethics, regulatory affairs, with focus on the EU and health.

I am a strong Europeanist who loves multicultural and international environments.

Expert patient, with specific expertise in rare diseases and technical knowledge in R&D and regulatory affairs.

My background starts with a degree in economics and business management science (UniMI, 2013) and subsequently, a series of postgraduate master's degree programs in R&D.

Enthusiast in Translational Research and Regulatory Science since my graduation at Eurordis School on Scientific Innovation & Translational Research (Paris, 2020-2021). Solid knowledge of clinical research, drug development processes and regulatory affairs of clinical trials (ICH-GCP, GLP, GMP, EudraLex) as trainee at the European Patients' Academy on Therapeutic Innovation (EUPATI, cohort 2021-2022).

For the past 15 years I have been actively engaged in patient advocacy in the field of rare diseases, particularly neurometabolic diseases, both in my country and abroad. Since 2019, my patient association has been a member of Eurordis and follows its activities.

As director of ZavodBV (starting in 2019), I have responsibility for ensuring the best possible path for the patient, taking care of developing and monitoring the detection of patient satisfaction. I am also the principal investigator of the SLOMITO registry, an epidemiological registry for mitochondrial diseases in Slovenia, started in 2020.

The position acquired allows me to complete the profile with the knowledge of the dynamics both from a patient and managerial point of view, the pathways of patients by pathology and the functioning of health processes at community, national and European level.

My focus on these issues was implemented by my postgraduate master's degree at La Sapienza University of Rome in 2022 as an expert in digital health technologies.

Since February 2024, I have been a member of the Lombardy 6 Ethics Committee, and since June 2024, I have been appointed vice-chair of the same Committee.