

## PISANA FERRARI

### Patient advocacy positions 2020-2025

- President, Italian Pulmonary Hypertension Association (AIPI OdV)
- Secretary General, Alliance for Pulmonary Hypertension (AfPH)
- Consultant as "Expert Patient" for scientific advice procedures, European Medicines Agency (EMA)
- Honorary Co-Chair of the European Society for Organ Transplant (ESOT) Congress 2023
- Member of the European Society for Organ Transplant (ESOT) Extended Education Committee (2020-2025)
- Member of the Jury for the ESOT Hackathon, a competition to identify tools serving the transplant patient community
- Member of the European Society for Organ Transplant (ESOT) European Transplant Patient Organization (ETPO) Alliance Steering Committee
- Member of the European Reference Network for Rare Lung Diseases (ERN-Lung) PH Patient Advisory Group
- Member of the European Respiratory Society (ERS) Task Force on Gender
- Member of the European Respiratory Society (ERS) Lung Transplant Task Force
- Member of the European Lung Foundation (ELF) Patient Advisory Group (PAG) on pulmonary hypertension
- Member of the European Lung Foundation (ELF) working group for the creation of a lung transplant web page
- Member of the European Society for Cardiology (ESC) Patient Forum
- Member of the European Society for Cardiology workstream on emotional wellbeing
- Member of the World Symposium on Pulmonary Hypertension (WSPH) 2024 Task Force on Patient Perspectives
- Member of the Innovative Drug Development Initiative (IDDI) workstream on Patient Engagement and Empowerment of the Pulmonary Vascular Research Institute (PVRI)
- Member of the Innovative Drug Development Initiative (IDDI) workstream on Transplantation of the Pulmonary Vascular Research Institute (PVRI)

### Speaking engagements 2020-2025

- Uncertainty from the patient's perspective, European Society for Organ Transplant (ESOT) Transplant Journey webinar (2020)
- The main concerns of transplant patients: results from a European survey, panel member, TLJ 2.0 Learning Workstream, European Society for Organ Transplant (ESOT) (2020)
- The experience of transplant from a patient's point of view - European Society for Organ Transplant (ESOT) HESPERIS course for transplant professionals Rome (2021)
- Impact of COVID-19 on pulmonary hypertension patients, 13<sup>th</sup> European Pulmonary Hypertension Meeting, Vienna (2021)
- Living with rare respiratory diseases through the COVID-19 pandemic - European Respiratory Society (ERS) panel (2021)
- Strategies to master the risks of being an organ recipient - European Society for Organ Transplant (ESOT) Congress Milan (2021)
- European Society for Organ Transplant (ESOT) TV Live studio session on the ESOT Patient Inclusion Initiative, panel member (2021)

- Connecting people who had a transplant and health care professionals: examples of participation and co-production, European Society for Organ Transplant (ESOT) Congress Milan (2021)
- What is good communication from the patient's perspective? European Society for Organ Transplant (ESOT) ACADEMIA course for transplant professionals, Rome (2022)
- The transplant patient's experience, European Society for Organ Transplant (ESOT) HESPERIS course for transplant professionals (2022)
- Workshop on improving patient-health care provider communication with Alessandra Agnese Grossi, European Society for Organ Transplant (ESOT) ACADEMIA Course Rome (2022)
- How to adapt trial design and endpoints to PAH groups, the patient viewpoint - 19th Global Cardiovascular Clinical Trialists Forum (CVCT), remote (2022)
- What's new in the diagnosis and treatment of pulmonary hypertension. Part 2, The patient's perspective, World Symposium on Pulmonary Hypertension Updates, Bologna (2022)
- Inequality in organ transplantation in Europe, European Society for Organ Transplant Action Day (2022)
- Welcome address as Honorary Co-Chair, European Society for Organ Transplant (ESOT) Congress Athens (2023)
- Taking my life back after a lung transplant, European Society for Organ Transplant (ESOT) Congress Athens (2023)
- Round Table on immunosuppression, European Society for Organ Transplantation (ESOT) congress Athens (2023)
- My experience with rehabilitation post-lung transplant, European Society for Organ Transplant (ESOT) Professional Course (2023)
- Partnering with patients and shared decision making: a new paradigm for pulmonary hypertension care? Alliance for Pulmonary Hypertension (AfPH) webinar (2023)
- La comunicazione medico-paziente dalla prospettiva del paziente, Campus Transplantation, Ospedale di Verona (2024 and 2025)
- Patient education and shared decision making, European Society for Organ Transplant (ESOT) CMV Management Course (2024)
- Evolution of the pulmonary hypertension care landscape in the past 30 years, Hellenic Pulmonary Hypertension Symposium, remote (2024)
- Patient perspectives Task Force 1, World Symposium on Pulmonary Hypertension (WSPH), Bologna (2024)
- Balancing life and health: pulmonary hypertension, women and family planning, Alliance for Pulmonary Hypertension webinar (2024)
- The inclusion of the patient perspective in new trials in pulmonary hypertension, European Society of Cardiology (ESC) Congress, London (2024)
- Teaching the transplant teachers, member of panel, The Transplantation Society (TTS), Istanbul (2024)
- La partecipazione dei rappresentanti delle associazioni dei pazienti alla stesura delle linee guida ESC 2022: tra indicazioni certe e gap, ancora da colmare, VI Congresso Triveneto, Università degli Studi di Udine (2024)
- Quality of care in post-transplant infectious disease, European Society for Organ Transplant (ESOT) course (2024)
- The voice of the patient with Pulmonary Arterial Hypertension (PAH): Progress in treatment and its impact on patients, European Respiratory Society (ERS), Vienna (2024)
- The patient's journey around immunomodulation and Rejection, moderator, European Society for Organ Transplant (ESOT) (2024)
- Pulmonary Arterial Hypertension (PAH): The Patient perspective, video for Medscape Cardiology Decision point (2024)

- Introducing the European Society of Cardiology (ESC) quality indicators for adult pulmonary arterial hypertension care, European Reference Network for rare respiratory diseases (ERN-LUNG) webinar (2024)
- Rare Diseases among Older Adults, panel member, World Orphan Drug Congress, Barcelona (2024)
- Person-centered care and rehabilitation before and after solid organ transplant, European Society for Organ Transplant (ESOT), Rehabilitation after Solid Organ Transplantation course (2025)
- Fostering European Collaboration in Pulmonary Hypertension, Lung Failure and Transplantation Symposium, Medical University of Vienna, Vienna (2025)
- Patient empowerment in pulmonary hypertension and PROMS, the patient perspective, WSPH updates, Bologna, remote (2025)

### **Publications (author and/or co-author) 2020-25**

- Prevalence of Mental Disorders and Impact on Quality of Life in Patients with Pulmonary Arterial Hypertension (co-author), *Frontiers in Psychiatry* (2021)
- European Society of Cardiology (ESC) and European Respiratory Society (ERS) Guidelines for the diagnosis and treatment of pulmonary hypertension (co-author), *European Heart Journal* (2022)
- Why patient empowerment should be at the heart of organ transplantation: a personal perspective (author), *Hospital Health Care Europe* (2022)
- European Society of Cardiology quality indicators for the care and outcomes of adults with pulmonary arterial hypertension (co-author), *European Journal of Heart Failure* (2022)
- European Society of Organ Transplantation (ESOT) Consensus Statement on Prehabilitation for Solid Organ Transplantation (co-author), *Transplant International* (2023)
- Navigating the Journey of Chronic Thromboembolic Pulmonary Hypertension: Insights, Challenges, and Aspirations (author), *RHU Destination* (2023)
- Exploring the patient perspective in pulmonary hypertension (co-author), *European Respiratory Journal* (2024)
- The patient perspective in lung transplantation, co-author of chapter for "Pulmonary Hypertension and Lung Transplantation", a collaboration between researchers at Stanford Usa and the University of Genova, Nova Science Publishers (2024)
- The Pulmonary Hypertension Global Patient Survey: understanding the experiences and perspectives of patients (co-author), *European Respiratory Journal Open Research* (2025)
- How to engage patients in shared decision-making for cardiovascular prevention, co-author) *European Society of Cardiology CVD Prevention Toolbox* (2025)

### **Awards**

Premio "Segno Donna" Friuli-Venezia Giulia per l'impegno nel volontariato, Fondazione Friuli (2024)