

Curriculum Vitae

Personal information **Martine Pergent**

Work experience

1. As patient advocate

1.1 International Primary Immunodeficiency Patient Organisation (IPOPI)

- **President** (2018 – Present)
- **Vice Chair** (2012 – 2018)
- **Board Member** (2004 – Present)
- Leads global advocacy efforts for PID patients, ensuring access to diagnosis, treatment, and care.
- Develops and strengthens partnerships with healthcare professionals, policymakers, and researchers.
- Chairs the Organising Committee of IPIC (International Primary Immunodeficiency Congress).
- Oversees IPOPI's strategic direction, policy engagement, and expansion of patient organisations worldwide.
- Chairs the IPOPI Global Patient Meeting (global gathering of delegates coming from the 75 national member organisations)

1.2 IRIS (French Association for PIDs)

- **Co-Founder** (1998)
- **Strategic Adviser** (1998 – 2025)
- **Honorary Member** (Since 2012)
- **Board Member** (Present)
- Played a key role in the foundation and growth of IRIS, advocating for PID patients in France.
- Provided strategic direction to enhance patient support, awareness, and policy engagement. (Strategic planning, Patient surveys, Newborn screening activities, Releasing- writing IRIS newsletter, magazines and leaflets)
- Committee member of CEREDIH (the French Centre of reference for Primary immunodeficiencies)
- Member of the French steering committee for Newborn screening

2. As a professional

Martine is now retired since December 31, 2023

Her career began as a teacher (1978), then a consultant in strategic communication communication (working first for different communication agencies in Paris, then by McDonald's France, then as self employed as internal communication and change management specialist), she also used to be a lecturer at Paris Sorbonne University for the 15 last years of a career.

Education and training

1979 French Teaching diploma

1991 Master degree in Education sciences

Many different training sessions alongside her career, last one to become sprint facilitator (2021).

Additional information

Publications

Most recent publications

The PID Odyssey 2030: outlooks, unmet needs, hurdles, and opportunities — proceedings from the IPOPI global multi-stakeholders' summit - Tadros S, Pre' vot J, Meyts I, Sanchez-Ramon S, Erwa NH, Fischer A, Lefevre G, Hotchko M, Jaworski PM, Leavis H, Boersma C, Drabwell J, van Hagen M, Van Coillie S, Pergent M, Burns SO and Mahlaoui N (2023) Front. Immunol. 14:1245718. doi: 10.3389/fimmu.2023.1245718

Primary immunodeficiencies (PID) Life Index in Southeast Asia: A comparative analysis of PID Principles of Care - Chan CM, Mahlaoui N, Sanchez-Ramon S, Pergent M, Solis L, Prevot J and Ali A (2023) - Front. Immunol. 14:1151335. doi: 10.3389/fimmu.2023.1151335

COVID-19 vaccination in patients with primary immunodeficiencies: an international survey on patient vaccine hesitancy and self-reported adverse events - Pergent M, Haerynck F, Hoste L and Gardulf A (2023) Front. Immunol. 14:1166198. doi: 10.3389/fimmu.2023.1166198

Newborn Screening Today and Tomorrow: A Brief Report from the International Primary Immunodeficiencies Congress Solis, L.; Van Coillie, S.; Bonham, J.R.; Hauck, F.; Hammarstr.m, L.; Staal, F.J.T.; Lim, B.; Pergent, M.; Prévot, J. Newborn Screening - Int. J. Neonatal Screen. 2024, 10, 30. <https://doi.org/10.3390/ijns10020030>

Charting a course for global progress in PIDs by 2030 — proceedings from the IPOPI global multi-stakeholders' summit - Van Coillie S, Pre' vot J, Sa' nchez-Ramo'n S, Lowe DM, Borg M, Autran B, Segundo G, Pecoraro A, Garcelon N, Boersma C, Silva SL, Drabwell J, Quinti I, Meyts I, Ali A, Burns SO, van Hagen M, Pergent M and Mahlaoui N (2024). Front. Immunol. 15:1430678. doi: 10.3389/fimmu.2024.1430678

Immunoglobulin solutions for patients with primary immunodeficiency - Comments on Burnouf et al.'s 'Stepwise options for preparing therapeutic plasma proteins from domestic plasma in low- and middle-income countries' Martine Pergent, Johan Prevot, Leire Solis, Albert Farrugia – Vox Sanguinis June 2024 DOI: 10.1111/vox.13696

2 pending publications on:

- Post COVID-19 in PIDs,
- How can Artificial Intelligence benefit to PID Patients

Projects

Martine Pergent is a dedicated volunteer patient advocate representing people with primary immune deficiencies (PIDs) worldwide. She has extensive experience in patient rights advocacy, global health initiatives, and fostering collaboration between patient organisations, healthcare professionals, and policymakers. Since October 2018, she has served as President of IPOPI (International Primary Immunodeficiency Patient Organisation), where she works to enhance access to early diagnosis, personalised treatments, and innovative healthcare solutions.

Her expertise includes establishing new patient organisations, particularly in low- and middle-income countries, and promoting advancements in medical and social sciences, innovative treatments, artificial intelligence, and health data collection. She is actively engaged in international networks, ensuring patient representation in key medical and research initiatives.

She promotes patient participation in any project that concerns them. Martine believes that cooperation with all the players in the healthcare ecosystem, first and foremost physicians and healthcare professionals, is essential.

- Patient Advocacy & Rights : access to timely diagnosis and personalized treatment (PID forum at EU Parliament, Patients representatives training, ...)
- Primary Immunodeficiencies, associated diseases among Rare Diseases (newborn screening as a case for rare diseases, educational material: Webinars, mini documentaries, leaflets, ...)
- Medical & Social Science Innovation
- Artificial Intelligence in Healthcare (Learning expedition on Artificial intelligence, article)
- Health Data Collection & Utilisation - PREMs and PROMs (PID life index, patient surveys, ...)
- Stakeholder Engagement & Collaboration (Global stakeholders' summit, Work with IPOPI mediacy advisory panel, network of experts, ...)
- Patient journey (addressing all ages with focus on transitioning and aging)
- Patient engagement (webchats with the global PID community, national, regional, and global patient meetings)

Memberships

Current affiliations on behalf of IPOPI

- **ERN RITA (European Reference Network for Immunological Conditions)** – Responsible for the Patient Journey Taskforce
- **ESID (European Society for Immunodeficiencies)** – Member of the Extended Registry Committee & Clinical Committee
- **Transform Alliance for ATMPs** – Member of the steering committee, representing patients advocacy groups
- **3D GATA-2 research project-** *How GATA2 Deficiency affects development and disease (EJP programme)*

Current affiliations on behalf of IRIS

- **Member of the steering committee of CEREDIH** (French national reference centre for PIDs - part of national Rare diseases plan)
- **Member of the steering committee for Newborn screening** for SCID in France

Other Relevant Information

Immunoglobulin therapy is a very important treatment for the PID community and has become a major subject of concern.

- It addresses a majority of patients with PIDs
- These patients have no alternative treatment
- The global need for Ig is growing
- Other conditions like secondary hypogammaglobulinemias are also in need