

Curriculum Vitae

Personal information Leire Solis Garate

Work experience

1. Employer: International Patient Organisation for Primary Immunodeficiencies (IPOPI)
 - Start date: 01/2014
 - End date: to date
 - Position:
 - Public Health and Advocacy Director (2025 - to date)
 - Public Health and Advocacy Senior Manager (2018 - 2024);
 - Public health and advocacy manager (2014-2017)
 - Activities:
 - Managing advocacy and awareness campaigns and programmes at international, EU and national level.
 - Monitoring health policy environment affecting PID community
 - Representing PID patients in collaboration with policy decision makers and stakeholders.
 - Country: Belgium
2. Employer: Rohde Public Policy
 - Start date: 05/2010
 - End date: 10/2013
 - Position: Senior Consultant
 - Activities:
 - Public affairs consulting for global companies, patient organisations and scientific organisations.
 - Developing and implementing advocacy programmes for clients.
 - Monitoring European and national legislative and policy developments.
 - Country: Belgium
3. Employer: South West UK Brussels Office
 - Start date: 09/2009
 - End date: 02/2010
 - Position: Assistant policy officer
 - Activities:
 - Monitoring EU policy and legislative developments.
 - Information to partnership of regional and local administrations.
 - Country: United Kingdom
4. Employer: Committee of the Regions
 - Start date: 02/2009
 - End date: 07/2009
 - Position: Intern
 - Activities: Support the preparation of committees and plenary sessions of group members.
 - Country: Belgium
5. Employer: Basque Regional Government
 - Start date: 09/2007
 - End date: 09/2008
 - Position: Assistant European Affairs
 - Activities: Organise Basque Government's participation at the Committee of the Regions (including coordination of amendments, drafting position papers, analysis of policy texts).
 - Country: Spain

Education and training

1. Fellow of the European Patients' Academy :
 - Start date: 10/2014
 - End date: 12/2015
 - Organisation: European Patients' Academy on Therapeutic Innovation (EUPATI)
2. Master in International Relations
 - Start date: 09/2004
 - End date: 07/2005
 - Organisation: Universidad San Pablo CEU (Spain)
3. Bachelor degree in Sociology
 - Start date: 09/2000
 - End date: 07/2004
 - Organisation: Universidad de Deusto (Spain) & University of Louvain-la-Neuve (Belgium)

Additional information

Publications

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

Chan CM, Mahlaoui N, Sánchez Ramón S, Pergent M, Solis L, Prevot J, Ali A. Primary immunodeficiencies (PID) Life Index in Southeast Asia: A comparative analysis of PID Principles of Care (PoC). *Front Immunol.* 2023 Mar 30;14:1151335. doi: 10.3389/fimmu.2023.1151335. PMID: 37063889; PMCID: PMC10097921.

Solís, L., Nordin, J., Prevot, J. et al. The PID Life Index: an interactive tool to measure the status of the PID healthcare environment in any given country. *Orphanet J Rare Dis* 17, 11 (2022). <https://doi.org/10.1186/s13023-021-02161-0>

Nordin, J., Solís, L., Prevot, J., Mahlaoui, N., Chapel, H., Sánchez-Ramón, S., Ali A., Seymour, J.W., Pergent, M. (2021) The PID Principles of Care: Where Are We Now? A Global Status Report Based on the PID Life Index. *Front Immunol*, November 2021, <https://doi.org/10.3389/fimmu.2021.780140>

Jones, G., Brown Hajdukova, E., Hanna, E., Duncan, R., Gough, B., Hughes, J., Ashworth, F., Prevot, J., Drabwell, J., Solís, L., Mahlaoui, N., Shrimpton, A. (2021) It's long-term, well it's for life basically: Understanding and exploring the burden of immunoglobulin treatment in patients with primary immunodeficiency disorders. *Qualitative Research in Medicine and Healthcare*, 4 (3). pp. 117_131. ISSN 2532_2044

Jones GL, Williams K, Edmondson Jones M, Prevot J, Drabwell J, Solís L, Shrimpton A, Mahlaoui N. The Development of a New Questionnaire to Measure the Burden of Immunoglobulin Treatment in Patients with Primary Immunodeficiencies: The IgBoT_35. *Patient Prefer Adherence*. 2020 Sep 3;14:1567_1584. doi: 10.2147/PPA.S234669. PMID: 32982185; PMCID: PMC7490431.

Chapel H, Prevot J, Gaspar HB, Español T, Bonilla FA, Solís L, Drabwell J and The Editorial Board for Working Party on Principles of Care at IPOPI (2014) Primary immune deficiencies – principles of care. *Front. Immunol*. 5:627. doi:10.3389/fimmu.2014.00627

Projects

SCIDNET (Developing Genetic medicines for Severe Combined Immunodeficiency (SCID)), a Horizon2020 research project

RECOMB (Stem-cell based gene therapy for recombination deficient SCID), a Horizon2020 research project

Memberships

Member of the Critical Medicines Alliance.

Alternate member of the European Medicines Agency (EMA) Patients' and Consumers' Working Party.

Alternate IPOPI representative at the EU HTA Stakeholders Network.

Other Relevant Information

I am a patient representative