



Curriculum Vitae

Personal information Baiba Ziemele

Work experience

- President of Latvia Hemophilia Society November 2009 – up to now
- Board member at Latvia Hemophilia Society May 2005 – up to now
- Board member at World Federation of Hemophilia October 2020 – May 2022
- Chair of Latvian Network of Patient Organizations September 2022 – up to now
- Building network of patient organizations in Latvia June 2018 – up to now
- President of Latvian Alliance of Rare Diseases March 2016 – October 2022
- Board member at Latvian Alliance of Rare Diseases October 2014 – April 2023

Education and training

- Doctor degree (**PhD**) from Riga Stradins University (joined 2023, degree expected in 2027)
- Master of Business Administration (**MBA**) from Riga Business School (in cooperation with State University of New York at Buffalo, USA and University of Ottawa, Canada, 2006)
- Bachelor degree of **Social Sciences in Sociology** from Riga Stradins University (2004)

Informal education:

- Riga Tech Girls: Humanly about technologies in health care (2023)
- EURORDIS Leadership Academy (2020, 60h)
- WordPress Academy "Website development" (2019, 8h)
- Stockholm School of Economics in Riga "Contemporary Business Management Research" (2018-2019, 160h, 4KP)
- University of Latvia "Introduction to lecturer's work" (2017-2018, 64h, 4KP)
- EUPATI – European Patients Academy training (2016, 250h+, www.eupati.eu)
- COST ACTION CA15105 Training school I&II Medicines shortages (2017, 70h)
- 4th International Summer School & 3rd Rome-BYOD in the RD-Connect (2016, 40h)
- Health Technology Assessment, European Hemophilia Consortium (2014)
- Advocacy in Action I&II, World Federation of Hemophilia (2010 & 2014)
- Professional project management, Frankley Covey Co. (2008)
- Lean Six Sigma/Green belt, Facilitation Training, GE (2007)

Additional information

Publications

ORCID: 0000-0003-0817-9693

D.Coffin, Y.Collé, R.Kulkarni, et al. "Key Findings From the World Federation of Haemophilia National Member Organization Survey on Women and Girls With Bleeding Disorders." *Haemophilia*32, no. 2 (2026): 561–567. <https://doi.org/10.1111/hae.70213>

"Findings from the WFH NMO survey on women and girls with bleeding disorders": <https://onlinelibrary.wiley.com/doi/full/10.1111/hae.14973>

O'Sullivan, J., Tootochian, E, Ziemele, B, Makris, M, Federici, A.B., Khayat Djamas, C., El Ekiaby, M., Rotellini, D., Sidonio, R.F., Iorio, A, Coffin, D., Pierce, G.F., Stonebraker, J., James, P.D., Lavin, M. 2023. Von Willebrand disease: Gaining a global perspective. *Haemophilia*. <https://doi.org/10.1111/hae.14804>

Durante L, Sedmina M, Vaskova A, Ziemele B, Tollwe A. Raising awareness globally for women with inherited bleeding disorders: World Federation of Hemophilia Symposium. *Proceedings of the First European Conference on Women and Bleeding Disorders*. *J Haem Pract* 2019; 6(1 suppl 2): S16-S21. <https://doi.org/10.17225/jhp00140>

Ziemele B. (2019) *Patient Perspective: Reporting on Medicines Shortages—Hemophilia A Case in Latvia*. In: Barbosa-Povoa A., Jenzer H., de Miranda J. (eds) *Pharmaceutical Supply Chains - Medicines Shortages*. Lecture Notes in Logistics. Springer. https://doi.org/10.1007/978-3-030-15398-4_4

Projects

Active Citizen Fund project to set up Patient organization network in Latvia, various Public Integration fund projects to advocate for people with bleeding disorders and people with rare diseases in Latvia, World Federation of Hemophilia Development grant to improve von Willebrand disease care in Latvia, CSL Behring international LEAD project to set up bleeding assessment tool in Latvian, another state Public Integration fund project to improve patient advocacy framework in Latvia.

Memberships

Board member and chair of Latvia Hemophilia Society and Latvian Network of Patient Organizations. Previously member of European Haemophilia Consortium VWD Committee, member of World Federation of Hemophilia VWD

and Rare bleeding disorders committee, WFH Women and Girls with bleeding disorders committee. Various conference program committees, and others.

Other Relevant Information I am a patient representative