



## Curriculum Vitae

### Personal information Tomasz Grybek

#### Work experience

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All below mentioned roles are **fully voluntary**:

1. EURORDIS – Rare Disease Europe, France, Member of the Board of Directors, May 2023 – present. Voluntary position.
2. ERN ITHACA, France, Member of the Patient Advisory Board, December 2023 – present. Voluntary position
3. MetabERN, Italy, Member of the Patient Board and NBS WG, July 2020 - present. Voluntary position
4. ERN-RND, Germany, Member of the Patient Board, Nov 2025 - present. Voluntary position
5. Fundacja Bohatera Borysa, Poland, CEO, April 2019 – present. Voluntary position.

#### Education and training

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Education:

1. Doctoral School of Humanities & Social Science of University of Gdansk, 2020 – 2024, Doctor of Philosophy (PhD) in social sciences (quality and management).
2. University of Gdansk, Faculty of Management, Postgraduate studies in project management, 2010 – 2011.
3. University of Gdansk, Faculty of Economics, Master's degree in economics, 2002 - 2007.

Training:

1. Open Academy School on Scientific Innovation & Translational Research (2021).
2. Open Academy School on Medicines Research & Development (2020).
3. ISO 9001 Lead Auditor, ISO 14001 & ISO 45001 Auditor, IFS/BRCGS/HACCP Auditor.

#### Additional information

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##### Publications

1. Klein Haneveld, M. J., Świczekowska, K., **Grybek, T.**, Labunets, K., van Amelsvoort, Thérèse A. M. J., Bedeschi, Maria F., Behan, C., Dufke, A., Dupont, J., Gaasterland, C. M. W., Garavelli, L., Helverschou, Sissel B., McAnallen, S., Milska-Musa, K., Van Staa, A., Streață, I., Stumpel, Connie T. R. M., Tamburrino, F., Vasseghi, M., i in. (2026). Transition From Children's to Adults» Healthcare for Youth With (Genetic) Intellectual Disabilities: An ERN - ITHACA Guideline. Journal of Intellectual Disability Research, 70, Article 1. <https://doi.org/10.1111/jir.70049>
2. Klein Haneveld, M., Vyshka, K., Gaasterland, C. ., **Grybek, T.**, Świczekowska, K., , Van Staa, A. and Van Eeghen, A. (2025), "Mind the Gap"—A Survey on Care Gaps and Priorities for the Transition to Adult Healthcare According to Caregivers of Young People With Rare Conditions Associated With Intellectual Disability. Journal of Intellectual Disability Research. <https://doi.org/10.1111/jir.13229>
3. Mazurkiewicz-Beldzińska, M., Pietruszka, M., **Grybek, T.** (2024), "Clinical picture of a patient with metachromatic leukodystrophy" [in:] Doroszuk, J. (ed.) *Education of children with rare diseases. About Gdańsk's practices of making the system more flexible*, Difin, Warszawa, pp. 27-31, [https://ksiegarnia.difin.pl/upl/edukacja\\_dzieci\\_z\\_chorobami\\_rzadkimi\\_ebook.pdf](https://ksiegarnia.difin.pl/upl/edukacja_dzieci_z_chorobami_rzadkimi_ebook.pdf)
4. **Grybek, T.** (2024), "Parent of a child with a rare disease as a partner in the process of making the education system more flexible - from engagement to shared leadership" [in:] Doroszuk, J. (ed.) *Education of children with rare diseases. About Gdańsk's practices of making the system more flexible*, Difin, Warszawa, pp. 163-175, [https://ksiegarnia.difin.pl/upl/edukacja\\_dzieci\\_z\\_chorobami\\_rzadkimi\\_ebook.pdf](https://ksiegarnia.difin.pl/upl/edukacja_dzieci_z_chorobami_rzadkimi_ebook.pdf)
5. Wiśniewska, M.Z., Czerynszewicz, E., **Grybek, T.** (2023) „Food Safety Culture Assessment. SARS-CoV-2 perspective”, International Journal for Quality Research, 17(2), pp. 485-500 <https://doi.org/10.24874/IJQR17.02-12>
6. Wiśniewska, M.Z. and **Grybek, T.** (2023), "Do SARS-CoV-2 hazards influence stakeholders? Evidence from a Polish seafood company", Central European Management Journal, Vol. 31 No. 1, pp. 64-81. <https://doi.org/10.1108/CEMJ-03-2022-0037>
7. Wiśniewska, M.Z., Majerowska, E., **Grybek, T.** (2023), "Just culture assessment tool and its verification in a small seafood organization", Journal of Modern Science, Vol. 53, No. 4, pp. 752-772. <https://doi.org/10.13166/jms/176328>
8. Wiśniewska, M.Z. and **Grybek, T.** (2023), "SMETA standard as a tool to support sustainable development goals and food safety. A case study", European Journal of Transformation Studies, Vol. 11, No. 1, pp. 139-152, [https://www.journal-transformation.org/docs/issues/EJTS\\_2023\\_Vol\\_11\\_No\\_1/EJTS\\_2023\\_Vol\\_11\\_No\\_1.pdf](https://www.journal-transformation.org/docs/issues/EJTS_2023_Vol_11_No_1/EJTS_2023_Vol_11_No_1.pdf)
9. Wiśniewska, M.Z., **Grybek, T.**, Szymańska-Brałkowska, M. (2022), „Environmental Failure Mode and Effect Analysis and Its Application in a Seafood Company”, Krakow Review of Economics and Management, No. 4(998), pp. 73-86. <https://doi.org/10.15678/ZNUJK.2022.0998.0404>
10. Doroszuk, J. and **Grybek, T.** (2022), "Parents of a child with a rare disease as stakeholders of his education process", Disability. Discourses of special education, No. 45-46/2022, pp. 123-139. <https://czasopisma.bg.ug.edu.pl/index.php/niepelnosprawnosci/article/view/7354/6543>
11. Wiśniewska, M.Z., **Grybek, T.**, Grudowski, P. (2022), "The protective measures against SARS-CoV-2 infection in the seafood company from the perspective of the employees", Scientific Papers of Silesian University of Technology - Organization And Management Series, No. 157, pp. 631-648. <http://dx.doi.org/10.29119/1641-3466.2022.157.41>
12. Wiśniewska, M.Z. and **Grybek, T.** (2021), "Food safety culture in the light of standards recognized by GFSI", Problems of Quality, Vol. 53, No. 1, pp. 4-11. <http://dx.doi.org/10.15199/46.2021.1.1>

Posters:

1. Walkowiak, D., Grybek, T., Śledzińska, K., Lemska, A., Domaradzki, J., "A study on caregiver burden and quality of life of informal caregivers of children with metachromatic leukodystrophy in Poland", EuroNDD 2026, 09-10.04.2026, Warsaw.
2. Doroszuk, J. and Grybek, T., "Parents of a child with a rare neurological as stakeholders of his social and education process - a case study analysis", First European Workshop for a multidisciplinary view on rare genetic neurodevelopmental disorders (EuroNDD 2023), 20-21.04.2023, Amsterdam.
3. Miłska-Musa, K., Labunets, K., Grybek, T., Śledzińska, K., Wierzbą, J., "The transition of care from the biomedical perspective the state of play and outlook for the future. A lesson learned from Poland". 4th European Symposium on Transition: from principles to practice, 2023, 21-22.09.2023, Rotterdam.

Projects

Member of Poland Aid project team "Strengthening the institutional capacity of public administration in Moldova in the preparation of strategic documents and development projects", 2012-2013.

Memberships

Member of the Coordinating group of the European network of paediatric research at the European Medicines Agency (Enpr-EMA), 2025-2027.

Speaker at conferences (RAPS Europe, DIA Europe, ECRD, EESC Conferences, International Congress on RD & OD and others)

Trainer at Open Academy 2024, 2025; EJP RD Workshop; Co-Chair of the 37th, 41st ERTC Workshop, EMM 2025 Workshop.

Adjunct Professor at Medical University of Gdańsk (MUG) at the Faculty of Health Science, Department of Public Health and Social Science.

Other Relevant Information

I am a patient representative. I am parent of child living with rare disease.