More than 400 million patients suffer from rare diseases worldwide, while the majority of rare diseases currently still do not have effective treatment. Lack of public awareness, infrastructure, and technologies makes the diagnosis of these diseases highly challenging. There is an urgent need to catalyse a systemic transformation in the area, with the goal of improving the quality of life of the people living with such diseases. We believe that developing diagnostics and treatments through cross-border and multidisciplinary research and innovation programmes involving relevant stakeholders is one of the ways of contributing towards new drug discovery and improvement of patients' lives and the lives of their families.

The webinar **"Slovenia's Contribution to the Research of Rare Diseases**" is being organized by **Innovation Lighthouse Japan** and **supported by the Embassy of the Republic of Slovenia in Japan.** This webinar is an unrivalled opportunity to learn more about research and development on intractable and rare diseases in Slovenia.

The goal of the webinar is to unlock the opportunities in the fields of research and diagnostics of intractable and rare diseases and open a discussion with all relevant stakeholders in Japan and our keynote speaker, professor Borut Peterlin from the Clinical Institute for Genomic Medicine in Slovenia how to enhance and foster innovation and knowledge-sharing between Slovenia and Japan.
Join us on March 30th from 4:00-5:00 PM to take part in discussions on how to build together a collaborative ecosystem for rare disease services and support joint research between Slovenia and Japan.

Time and Date: March 30th 2022 from 4:00 – 5:.00 JST.
Attendance: free.
Language: English
This event will be held online.
Registration: https://zoom.us/webinar/register/WN_UBH1NF7UQQOUXYHRxyGPZw

The webinar is aimed at pharmaceutical companies, bio ventures, representatives of research organizations, academia, scientists, clinician-scientists and doctors.

The program of the webinar focuses on the following topics

- **Innovative technologies that can improve the diagnosis and treatment of rare diseases - Innovation and latest genomic technologies implemented in the Slovenian healthcare system**
- **Rare Diseases in Slovenia and health data**
- **Activities and implementation of precision medicine and development of “Public Health Genomics" concept in Slovenia**
- **Slovenian Contribution to Development of Orphan Drugs**
- **How to establish more joint health-related cooperation projects that benefit both Japan and Slovenia, both in research and in business**
- **Revealing the Concrete areas of cross-cutting themes for collaboration between Slovenia and Japan in the scope of co-creating scalable solutions for rare diseases and potential drug discovery**

Our aim is to inspire researchers and create strategic transdisciplinary networks to promote world-class rare disease developments, joint research, innovation and engagement between Japan and Slovenia.

The Program

• Opening Remarks
• Welcome words of the Ambassador of the Republic of Slovenia to Japan, H.E.Ana Polak Petrič
• ILJ Introduction & Introduction of Keynote Speaker Introduction, Ivana Ohbayashi, Innovation Lighthouse Japan, CEO
• Keynote Lecture: Professor Borut Peterlin, M.D., PhD
• Discussion
• Q&A Session
• Closing Remarks

With vast experience in the rare disease space, Innovation Lighthouse Japan holds a great honour to introduce for the first time to the Japanese audience, Slovenian researcher and genetic scientist, **professor Borut Peterlin M.D, PhD.**

Borut Peterlin graduated at the Medical Faculty, University of Ljubljana in 1987 and got PhD in medical genetics in 1993. He received Certificat de Genetique Humaine at the University Rene Descartes Paris in 1990 and licence as specialist in Neurology in 1995 and in Clinical Genetics in 2009.

He is employed at the Clinical Institute of Medical Genetics, University Medical Center Ljubljana from 1988, from 1998 as the Head of the institute.

Currently he is president-elect and member of Executive committee of European Society of Human Genetics, a member of the Board of Member States for European Reference Networks, European Comission, member of the 1+MG Group (Towards access to at least 1 million sequenced genomes in the European Union by 2022), member of the Scientific panel for Neurogenetics at European Association of Neurology and member of the Task-group for genetics at the European Reference Network for Neuromuscular Diseases and Board member of Section of Medical Genetics at UEMS (European Union of Medical Specialists). He is member of Professional Council of Slovene Medical Association.

He is past member of Public and Professional Policy Committee and past board member of European Society of Human Genetics and member of the Advisory council of the European Cytogenetics Association. He is also past member of EUCERD (European Union Committee of Experts on Rare Diseases), and SCHER (Scientific Committee for Health and Environmental Risks) at DG Sanco, EU Commission.
He was leading the Task-group that prepared the Slovene National plan and action plan for rare diseases at the Ministry of Health. He was member of the working group that prepared Recommendations on the impact of genetics on the organisation of health care services and training of health professionals at the Council of Europe.

His research is focused in discovery of new genes and mechanisms of human disorders, role of pathologic and normal genetic variability for public health and personalized medicine and translation of new, innovative genomic technologies in mainstream medicine. His group has in collaboration with international partners participated in discovery of 11 new genes for human disorders (ASCC3, NEMF, H3F3A, TUBGC5, SOX6, DNAH, SCN3A, SLC25A24, NLRP1, C2ORF72, FLCN)and description of new genetic disease in humans (Heart-Hand Syndrome – Slovenian type).

Borut Peterlin is full professor of Human genetics at the Medical faculty Ljubljana from 2007 and visiting professor at Universities Belgrade (Serbia), Osijek and Rijeka (Croatia).

He published more than 270 papers indexed in Pubmed and mentored 15 PhD and 13 MSc theses.

He coordinated FP6 project GENEPARK (Genomic biomarkers for Parkinson disease) and Interreg project SIGN (Slovenian Italian Genetic Network). He was national coordinator of 5 FP and DG Sanco projects and coordinated one program and 5 national research projects in the area of human genetics. Currently he is coordinator of national program and project as well as national coordinator of a DG Sanco project.

He served as evaluator for FP6, FP7 and Horizon 2020 programs as well as research projects for Austrian, French, Spanish, Swiss, Italian, Israeli, Bolgarian, Croatian and Serbian national science foundations.

Borut Peterlin is member of editorial boards for Public Health Genomics and Balkan Journal of Medical Genetics.

Ambassador Ana Polak Petrič, PhD Embassy of the Republic of Slovenia to Japan

Her Excellency, Ms. Petrič holds the position of the Ambassador of the Republic of Slovenia to Japan from 2019. Ambassador Petrič has extensive experience in international law and human rights law. She authored several publications and articles on the topics of international and European law, human rights law, and the succession of states. Moreover, Ambassador Petrič has been an assistant professor and lecturer of international law, international relations and European Law, an active member of the Slovenian branch of the International Law Association and a member of the UN Association of Slovenia and the Pan-European movement.

Ivana Ohbayashi, Innovation Lighthouse Japan, Founder and CEO

In 2021 Ms.Ohbayashi founded Innovation Lighthouse Japan, a community-based consultancy in Tokyo to foster and promote innovation between Japanese companies and startups, scaleups, SMEs, academia and research institutions originating from the Baltics, Central Europe, Southeastern Europe and the Middle East. She established herself as an entrepreneur and woman leader both in Europe and Japan, passionate about innovation and enhancing ties with the EU and Japan. Ms.Ohbayashi graduated with a Master's degree in International Relations from Waseda University.