

RARE DISEASES FORUM 2024



February 29, 2024
9 a.m. to 4:45 p.m.



Riga Stradins University,
16 Dzirciema Str., Riga

Program

Moderated by: Ieva Plume un Reinis Rekis

8.00 – 8.55

Registration

THE 1ST AUDIENCE

9.00 – 9.30

Opening

The representative of the Ministry of Health

Chairman of the Board of Children Clinical
University Hospital Valts Abols

Rector of Riga Stradins University Aigars Petersons

Chairman of the Board of Latvian Alliance of
Rare Diseases Juris Beikmanis

9.30 – 9.50

Inspiration

Musical greeting

Opening of the Scientific part of the Forum with
Dr. med. Madara Auzenbaha.

9.50 – 13.00

Scientific Part

9.50

Anja Helm, EURORDIS Senior Manager of Relations
with Patient Organisations / EURORDIS - organization
representing people living with rare diseases.

10.00

Dr. med. Madara Auzenbaha / ORPHA codes: what are they?

10.20

Dr. med. Andris Skride / Rare – that's a lot!

10.40

Dr. med. Viktorija Kenina / Center for Rare Neurological
Diseases - from research to care.

11.00 – 11.30

Coffee break

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- 11.30 Dr. med. Baiba Lace / Patient odyssey.
- 11.50 Dr. Ieva Micule / Are all mistakes equally unacceptable?
How to understand genetic variants?
- 12.10 Dita Raiska / The role of the nurse in the care of patients
with rare diseases.
- 12.20 Dr. iur., advocate Juris Beikmanis / Patient rights and
obligations: the perspective of medical practitioners.
- 12.50 Information on the parallel discussions.
- 13.00 – 14.00 Lunch time

14.00 – 15.20

Parallel Discussions

THE 1ST AUDIENCE

- 14.00 – 15.20 Doctor, nurse and family member - professional or
emotionally attached?
Discussion moderators: Dr.med. Madara Auzenbaha,
Mg.psych. Gunita Skaldere-Darmudasa.

THE 2ND AUDIENCE

- 14.00 – 15.20 The role of primary care in the journey of a patient
with rare disease.
Discussion moderators: Marta Augucevica, Dr. med.
Viktorija Kenina.

THE 3RD AUDIENCE

- 14.00 – 15.20 At the Crossroads: Rare Diseases Plan 2023 - 2025.
Discussion moderators: Dr. Renate Snipe, Juris Beikmanis.
- 15.20 – 16.00 Coffee break

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16.00 – 16.45

Workshops

THE 3RD AUDIENCE

16.00 – 16.45

Dance and movement therapy / Certified Dance and Movement Therapist Una Reke, Diana Semerova.

THE 2ND AUDIENCE

16.00 – 16.45

Drama therapy / Certified Drama Therapist Anna Steina, Anastasija Rekuta-Dzordzevica.

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Organizers



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fonds

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Supporters

