

INVITATION TO EVENING TALKS „LIVING WITH A RARE DISEASE“

RARE DISEASE DAY 2023

Date: February 28th, 2023

Time: 5 p.m. to 8 p.m.

Venue: Billrothhaus, Frankgasse 8, 1090 Vienna



RARE DISEASE DAY®

From 4.30 p.m. Admission

5.00 p.m. Opening: Moderation **Mag. Sabine Nikolay**

„The long road to diagnosis“

Peter Löffelhardt, President Global MPN Scientific Foundation

„Why is psychosocial support important especially for patients with Rare Diseases?“

Dr. Maria Resch, clinical and health psychologist

„Psychosocial support from the patient's point of view“

Eva Otter, Vice President PH Austria & President PHA Europe

„Challenges in study design for Rare Diseases“

Prof. Tanja Stamm, Institute for Outcomes Research, MedUni Vienna

„Research for Rare Diseases“

Dr. Martin Steinhart, CEO AOP Orphan Pharmaceuticals GmbH

6.00 p.m.

Panel discussion

„Rare Diseases: status and potential“

Participants:

Dr. Elena Greschner, President MPN Austria Selbsthilfegruppe

Peter Löffelhardt, President Global MPN Scientific Foundation

Eva Otter, Vice President PH Austria & President of PHA Europe

Dr. Maria Resch, Clinical and Health Psychologist

Prof. Tanja Stamm, Institute for Outcomes Research, MedUni Vienna

Dr. Martin Steinhart, CEO AOP Orphan Pharmaceuticals GmbH

Moderation **Mag. Sabine Nikolay**

7.00 p.m.

Get-together

LIVE-STREAM

**LANGUAGES: ENGLISH, GERMAN
SPANISH, ITALIAN**

WE LOOK FORWARD TO YOUR PARTICIPATION!

For online participation please
use the following link:

[REGISTER HERE](#)

