Rare Diseases and Nordic Countries – Present and Future Prospects

Webinar 12 November 2021
11.00 – 15.00 (UTC+2)

Registration by 7 November 2021:
https://link.webropolsurveys.com/S/8E48657CAF9C46CE

Finnish Institute for Health and Welfare
PL / PB / P.O. Box 30 • FI-00271 Helsinki, Finland
www.thl.fi

Welcome and Introduction

11.00-11.10

Ritva Halila, Ministry of Social Affairs and Health, Finland

Satu Wedenoja, Finnish Institute for Health and Welfare

FIRST SESSION (11.10 – 13.00)

European Reference Networks (ERNs), Orphanet and Nordic Cooperation

Chair: Helena Kääriäinen, Finnish Institute for Health and Welfare

11.10-11.40

Role of small countries and collaboration between ERN members

Birute Tumiene, Vilnius University Hospital Santaros Klinikos, Lithuania

11.40-12.10

Integration of ERNs to healthcare in Nordic countries: can we learn from each other?

Mikko Seppänen, Rare Disease Center, Helsinki University Hospital, Finland

12.10-12.15

ERNs and patient perspective

Saija Ristolainen-Kotimäki, Finnish Huntington Association, European Huntington Association

12.15-12.30

Can we reach RD patients from national registries with ICD-10?

Satu Wedenoja, Finnish Institute for Health and Welfare

12.30 -12.50

ORPHAcodes in Norway

Stein Are Aksnes and Linn Björnstad, Oslo University Hospital, Norway

12.50-13.00

Discussion

BREAK

SECOND SESSION (13.30 – 15.00)

Knowledge Sharing and Inclusion in Nordic Countries

Chair: Birthe Byskov Holm, Rare Diseases Denmark

13.30 -14.10

Supporting inclusion in the Nordic context

Rebecca Tvedt Skarberg, The Rare2030 Panel of Experts, Norway

14.10 -14.40

Crosstalk between Nordic countries – how to find best practices together

Introduction by Carita Åkerblom, The Finnish Network for Rare Diseases
Panel discussion
Stein Are Aksnes, Oslo University Hospital, Norway
Katri Asikainen, Harso ry, Finland
Stephanie Juran, Rare Diseases Sweden
Helena Kääriäinen, Finnish Institute for Health and Welfare

14.40-14.55

National coordination and the support of inclusion

Satu Wedenoja, Finnish Institute for Health and Welfare

Conclusions

14.55-15.00

Satu Wedenoja, Finnish Institute for Health and Welfare

Registration and Webinar Link

Open for clinicians, patients, authorities, and all who are interested in rare diseases.

Register at: https://link.webropolsurveys.com/S/8E48657CAF9C46CE

Webinar link will be sent via e-mail to those registered on 8 November.