

# SBONN Hybrid Workshop – invitation

## Date and venue

- Saturday, September 3., 12.00 – Sunday, September 4. 13.00, 2022
- Scandic Sydhavnen, Sydhavns Plads 15, 2450 Copenhagen, Denmark (3,7 kilometers from Main Railway Station – 10,2 kilometers from Copenhagen Airport Kastrup)
- Online via Zoom

## Program

### Saturday, September 3. 2022:

11.30 – 13.00: Arrival

12.00 – 13.00: Lunch

#### **13.00 – 14.00: Welcome and introductions, chair: Denmark**

- Welcome – introductions: The participants and the Nordic landscape for rare diseases

#### **14.00 – 16.15: National plans and strategies for rare diseases, chair: Sweden and all countries**

- The SBONN declaration – what all Nordic countries should do to offer good care for people living with rare diseases?, Sweden
- National status – how does the national plan for rare diseases look in your country?, all countries
  - Experiences - what is good, what not. What is needed to be successful?
  - What lacks in the countries without a national plan?

15.00 – 15.30: Coffee break

15.30 – 16.15: Action point: How to promote national plans and strategies at national, Nordic and EU level?

16.15 – 16.30: Break

#### **16.30 – 18.00: European Reference Networks – a European network of experts in rare diseases, chair: Denmark and all countries**

16.30 – 17.00: What is ERN – and what is ePAG? – presenter from EURORDIS

17.00 – 17.20: Experiences from a clinician (on video) and 2 ePAGs from Finland and Norway

17.20 – 17.50: Action points - a Nordic Roadmap from SBONN?

- How to promote national (Nordic?) participation in ERNs? NNRD as a driver?
- How to get more patient involvement into ERN?

17.50 – 18.00: Any Other Business

- Activities during the Swedish EU-Presidency 2023
- Other?

19.00: Dinner

### Sunday, September 4. 2022:

7.30 – 9.15: Breakfast at hotel, informal networking

### **9.15 – 12.15: Network across! Chair: Iceland and all countries**

9.15 – 10.00: Inspirational examples of Nordic cooperation between rare people

10.00 – 11.00: How do National alliances and others deal with ultra rare diseases?

11.00 – 11.20: Break

11.20 – 12.00: To be planned when participants list and suggestions are known, f.i.:

- 'Ultra Rare continued'
- 'Diagnosis specific and other networking online'
- How to apply for NVC-funds in order to create Nordic network
- More options may be added on the spot

12.00 – 12.15: That's it! Evaluation of the workshop

12.15 – 13.00: Lunch and departure.

## Practical information

### Deadline for registration

- Participation **on venue** – deadline for signing up: August 2., 2022 – [mail@sjaldnediagnoser.dk](mailto:mail@sjaldnediagnoser.dk)
- Participation **online** – deadline for signing up: August 25., 2022 – [mail@sjaldnediagnoser.dk](mailto:mail@sjaldnediagnoser.dk)

### Participation on venue:

- Each country can participate with 3 persons from SBONN / member organisations of SBONN free of charge, travel expenses covered
- More members of SBONN organisations can participate at the following rates:
  - Travel: at own planning and expense
  - Accommodation and catering at Venue (Saturday – Sunday): 2.500 DKK, extra night (Friday – Saturday), Accommodation only: 950 DKK – ask for free pass, if your organization can not cover the expenses
  - Participation in the program: free of charge

### Participation online:

- Members of SBONN organisations can participate in the workshop, participation online is free of charge. For more information, contact your national SBONN member (see below).

### Conditions

- Registration for participation on venue is binding per August 2., 2022. If a participant cancels after August 2., the full amount for accommodation and catering at the venue must be paid, if the registration is not used by another participant
- It is possible to make other arrangement for accommodation and catering and to participate on venue free of charge
- Insurance must be handled by each participant
- In need for accessible transportation from train station/airport to venue? Let us know and we will try to help – [mail@sjaldnediagnoser.dk](mailto:mail@sjaldnediagnoser.dk)

### Comments and questions?

- Comments and questions may be directed to your national SBONN members or to the secretariat at Rare Diseases Denmark, [mail@sjaldnediagnoser.dk](mailto:mail@sjaldnediagnoser.dk), phone: +45 3314 0010
- Contact info SBONN members:
  - Denmark: Sjældne Diagnoser: [mail@sjaldnediagnoser.dk](mailto:mail@sjaldnediagnoser.dk)
  - Finland: Harso: [sihteeri@harso.fi](mailto:sihteeri@harso.fi); Harvinaiset-verkosto: [harvinaiset@harvinaiset.fi](mailto:harvinaiset@harvinaiset.fi)
  - Norway: Funksjonshemmedes Fellesorganisasjon: [post@ffo.no](mailto:post@ffo.no)
  - Iceland: Einstök bör börn-stuðningsfélag: [einstokborn@einstokborn.is](mailto:einstokborn@einstokborn.is)
  - Sweden: Sällsynta Diagnoser: [info@sallsyntadiagnoser.se](mailto:info@sallsyntadiagnoser.se)