

SBONN hybrid workshop – Save the date!

What is SBONN?

SBONN! SBONN is the Sallsynta BrukerOrganisationers Nordiske Netværk – the Nordic Network of rare disease patient organisations. For more information: https://sjaeldnediagnoser.dk/wp-content/uploads/2020/02/SBONN-Nordisk-poster_1184x841_2020.pdf.

A hybrid workshop?

Yes! We have much to learn from each other. The Agenda:

- Half a day with politics and strategics (Saturday): The Nordic landscape of rare diseases, national plans for rare diseases and patient representation in European Reference Networks.
- Half a day of networking and leaning from each other (Sunday). You might meet others with the same diagnosis as yours or with the same challenges. We will also discuss what to do for people living with ultra rare diagnoses who have no diagnosis specific organization to go to

We hope for up to 30 participants at the venue and many more online.

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)

How to attend?

Participation on Venue:

Members of SBONN organisations can participate at the following rates:

- Travel: at own planning and expense
- Accommodation and catering (excl. drinks) at Venue (Saturday – Sunday): 2.500 DKK
- Extra night (Friday – Saturday), Accommodation only: 950 DKK
- Participation in the program: free of charge

Please note, that the hybrid workshop is for non-profit – the rates cover the actual costs. Do you want to start a collaboration with your Nordic sister organisations? Contact your national SBONN member to learn about potential financial support.

Participation online:

- Members of SBONN organisations may participate online free of charge

Want to learn more about the hybrid workshop?

Contact your national SBONN member to learn more. Or write to Rare Diseases Denmark and get the full program – mail@sjaeldnediagnoser.dk.

Deadline for registration on Venue: august 2., 2022. Deadline for registration inline: august 25.

- Denmark: Sjældne Diagnoser: mail@sjaeldnediagnoser.dk
- Finland: Harso: sihteeri@harso.fi; Harvinaiset-verkosto: harvinaiset@harvinaiset.fi
- Norway: Funksjonshemmedes Fellesorganisasjon: post@ffo.no
- Iceland: Einstök bör börn-stuðningsfélag: einstokborn@einstokborn.is
- Sweden: Sällsynta Diagnoser: info@sallsyntadiagnoser.se