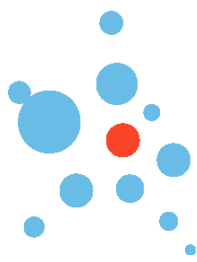


Formand Birthe Byskov Holm, Sjældne Diagnoser: Det europæiske og nordiske samarbejde i øvrigt





Det europæiske samarbejde - patienterne

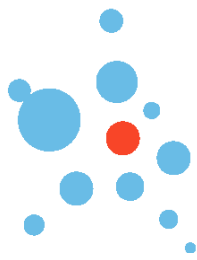


— Mere end:

- 600 patientorganisationer
- 4.000 diagnoser
- 50 lande

www.eurordis.org. Dansk deltagelse/Sjældne Diagnoser:

- Formandskab
- Bestyrelse
- Projekter
- Repræsentationer



Sjældne Diagnoser



Det europæiske samarbejde - myndighederne



<http://www.rd-action.eu/>

orphanet

<http://www.orpha.net/consor/cgi-bin/index.php?lng=EN>



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Orphanet website Denmark entry point



Denmark

- > Homepage
- > Team/Contact
- > Governance
- > Sponsors/Partners
- > Register your activity

Vælg sprog ▾

Leveret af Oversæt

NEWS

INTERNATIONAL NEWS

EVENTS

GENERAL INFORMATION

About Orphanet

About Rare Diseases

Orphanet international services

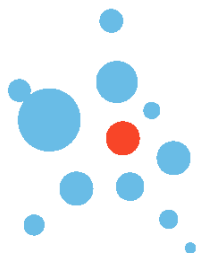
- o An inventory and classification of rare diseases
- o An encyclopaedia
- o A directory of services: clinics, laboratories, research projects, registries, clinical trials, patient organisations
- o An inventory of orphan drugs
- o Guidelines, reports
- o A newsletter

Access these services in: → **OK**

Welcome to the Danish entry point to Orphanet!

Please note that there is no active data collection on expert resources in this country. A national contact point is in charge of validating the already available national information and of the data submitted by national professionals through the online registration tool. If you wish to contact the national contact point for this country follow the link [here](#) and select the Orphanet country in the 'Contact the national Orphanet teams' section. If you wish to know more about the national contact point please check the Organisation chart of our latest activity report [here](#).





Sjældne Diagnoser



Det europæiske samarbejde - forskning

Globalt:

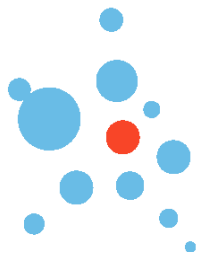


Europæisk:



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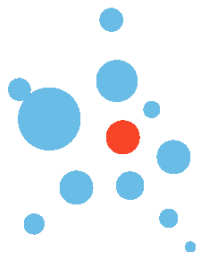




Det nordiske samarbejde

- Mindre struktureret end det europæiske samarbejde, omfatter bl.a.:
 - Patientsamarbejde understøttet af NVC
 - SBONN
 - Diagnosespecifikt
 - Samarbejde mellem fagpersoner omkring højt specialiserede ydelser
 - Rarelink – hjemmeside og konferencer
- Aktuelt: Nordic Network for Rare Diseases – anbefalinger på vej





Sjældne Diagnoser



Spørgsmål?
Kommentarer?



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