

National groups: Denmark

- National groups talking about the bigger picture. mission and vision.
 - What is the National purpose?
 - What business are HSP patient groups in?
 - What is the preferred future for people with HSP?
 - What does success look like?
 - Common interests: the values by which patient groups work.
Future: Realistic collaborations and working relationships

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The purpose of the Danish association is:

Arrange social and informative events for our members.

Provide information about:

- the newest research results - national and international -.
- treatments - options and methods - both medical and therapeutically.
- aids (e.g. walkers) and public subsidies.

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Our business:

We are a national patient association, and the BoD are all volunteers.

We are a member of Rare Diseases Denmark, which is an umbrella organization for RD associations.

We are a member of Euro-HSP and a member of EURORDIS.

The preferred future:

For our association: We hope to get many members and be able to arrange activities for both children, young people and adults.

For people with HSP: We hope to get quicker diagnosing, patient registries and possibility for participation in clinical trials.

Success:

For our association: Getting as many HSP diagnosed people as possible to join our association and making the members feel, that a membership is worthwhile and profitable. The more members the more possibilities for activities, as all members pay a small annual fee.

Common interests:

We depend on membership fees and fundraising - private as well as public.
E.g., each Rare Disease association gets money from the public fund "Tips&Lotto" through Rare Diseases Denmark.

Future:

A stronger Scandinavian (Nordic) network of HSP associations - so far only Norway and Denmark have HSP associations. Sweden has an HSP Facebook group. In Finland, HSP people are members of MS associations.

Denmark/Foreningen for Ataksi / HSP - Dorthe