

Who are we?

- [ERN-RND](#): 6 volunteer members representing different disease groups
- Patients or close relatives
- Active members of a national or European patient organisation

Purpose patient involvement

- Enhance patient focused services
- Share expertise
- Collaborate with clinicians
- Raise awareness

How can patient representatives help realize the ERN's objective:

Access to expertise and best knowledge-based care for all Rare Disease patients in Europe?

What do we do?

- Provide time & expertise
- Contribute to development of:
 - Diagnostic flow chart (Ataxia)
 - Clinical rating scale (HSP)
 - Patient registers
 - Care survey
- Raise awareness about ERN-RND in disease communities
- Advocate for the importance of ERN-RND to policy and decision makers
- Encourage clinics to active participation

How do we work?

- Regular teleconferences with ERN-RND project manager & Eurordis contact
- Attending the annual ERN-RND meeting
- Face-to-face ePAG meeting with project manager (January 2020)
- Participation in:
 - ERN-RND board meetings
 - ePAG conference (Eurordis)
 - ePAG steering committee meeting (Eurordis)

Success criteria

- Members commit sufficient time & expertise
- Good & regular communication with ERN-RND project manager and partners
- Financial support to cover necessary travel costs
- [Eurordis](#) support
- ePAGs are connected to their disease community
- ePAGs can be a point of communication in- and outside of the network

Goals for the next two years

- Implementation of ERN-RND partnership and activities into national health care plans
 - Diagnostic flow chart for all ERN-RND disease groups
- Care guidance documents for all ERN-RND disease groups by the end of 2020 and implementation into clinical practice