



EURORDIS  
Rare Diseases Europe

# PATIENT VOICE



# Patient Advisory Council

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Sigurður Jóhannesson, Alternating Hemiplegia association of Iceland (AHCAI)/AHCFE Europe



# PAC TERMS OF REFERENCE

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- The Rare Disease Patient Advisory Council (PAC) will act to inform partners from RD-Connect, EUrenOmics and NeurOmics of issues important to patients.
- To ensure that all project activities have a patient-centric approach throughout, EURORDIS will coordinate activities in relevant projects with the PAC as well as invite its patient representatives to meetings and discussions.
- Feedback from the PAC will be centralised by EURORDIS and shared with the project coordinators.
- Two way communication flow will be promoted by EURORDIS to ensure that recommendations from PAC members are taken into consideration by the given RD-Connect Work Packages.



# PAC Feedback

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- Clearer communication of WPs' activities on how they affect patients
- Involvement of patients in addressing ethics issues
  - maximise use of the PEC to consider impact of new technological development and data sharing challenges
- The success of the project is crucial for the patients
  - Increase impact of the PAC
  - More clearly define its tasks



# Next steps

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- Two patient representatives should be included in each WP in order for the PAC to better address and pre-empt relevant issues
- Embedding patients within WPs will improve collaborative decision making amongst all stakeholders
- Ensure that the patient perspective is reflected in the outcomes in a transparent and accountable way
- PAC should be integral in the communication of project outcomes which is then shared with patients' communities
- Patient specific area on RD Connect website managed by the PAC



# Thank you

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