



EURORDIS Template email for Patient Organisations to share with members

Subject: Register to join Rare Barometer Voices

EURORDIS, the European Organisation for Rare Diseases is launching a new project called Rare Barometer Voices. This initiative aims to strengthen the voice of rare disease patients in Europe. By transforming your opinions and experiences into facts and figures that can be shared with European level policy makers and other influential figures, they will be made aware of the actions that need to be taken for the rare disease community in Europe and make changes that directly affect you. It will also help us in our work to raise awareness about the impact of living with a rare disease.

To add your opinions and experiences to the voice of rare disease patients [register to Rare Barometer Voices](#). After registration you will be send an email to request your participation in each new survey related to subjects that concern you. You are free to decide which surveys you want to participate in.

Please note that the responses to these surveys are completely confidential, owned by EURORDIS, a non-profit organization, and will not be used for commercial purposes.

Kind regards,