

The National Alliance "Rare Diseases Bulgaria"

The National Alliance "Rare Diseases Bulgaria" unites the efforts of numerous patient organizations working for the common goal - improving the lives of people with rare diseases in Bulgaria.

The National Alliance "Rare Diseases Bulgaria" is an Association for Public Benefit, registered in April 2023. as an association of non-profit legal entities. It is composed of organizations led by patients with different types of rare diseases. Detailed information about the mission, vision, values and activities of the Alliance can be found on the official website of "Rare Diseases Bulgaria" <https://rare.bg/>

.The National Alliance "Rare Diseases Bulgaria" is the representative organization of people with rare diseases from Bulgaria in EURORDIS– Rare Diseases Europe www.eurordis.org, and is represented through EURORDIS before European authorities and stakeholders.

By decision of the Board of Directors of EURORDIS, dated July 2023. "Rare Diseases Bulgaria" is a member of the Council of National Alliances of EURORDIS - the governing body of the network of national alliances - and actively participates in the activities of the Council by planning and coordinating its pan-European and national actions and campaigns, including activities related to the work of patient representatives (ePAG) in the European National Reference Networks (ERNs), the work on the Joint Action of the European Union on the Integration of European Reference Networks into National Health Systems JARDIN, the work in the European Research Alliances for Rare Diseases ERDERA, the participation of patients in the Health Technology Assessment (HTA) process, etc.

The current main organizations - members of "Rare Diseases Bulgaria" can be seen at <https://rare.bg/chlenove/>

The activities of individual organizations and ways to support patients from these communities can be seen on the websites of the organizations themselves, which are available on the website of the National Alliance "Rare Diseases Bulgaria".

The representatives of patient organizations from Bulgaria – members of the European Patient Advocacy Groups (ePAG) of the European Reference Networks (ERNs) can be seen at

<https://rare.bg/%D0%BF%D1%80%D0%B5%D0%B4%D1%81%D1%82%D0%B0%D0%B2%D0%B8%D1%82%D0%B5%D0%BB%D0%B8-%D0%BD%D0%B0-%D0%BF%D0%B0%D1%86%D0%B8%D0%B5%D0%BD%D1%82%D0%B8%D1%82%D0%B5-%D0%BE%D1%82-%D0%B1%D1%8A%D0%BB%D0%B3%D0%B0/>