



**Application form for UDNI Members (Patient Organizations)**

**Date of Application:** \_\_\_\_\_

**Organization:** \_\_\_\_\_

**Main Contact Name:** \_\_\_\_\_

**Main Contact Email:** \_\_\_\_\_

**The specific goals of the UDNI are to:**

- (1) Improve the level of diagnosis and care for patients with undiagnosed diseases through the development of common protocols designed by a large community of investigators.
- (2) Facilitate research into the etiology of undiagnosed diseases, by collecting and sharing standardized, high-quality clinical and laboratory data, including genotyping, phenotyping, and documentation of environmental exposures.
- (3) Create an integrated and collaborative community across multiple clinical sites and among laboratory and clinical investigators prepared to investigate the pathophysiology of these newly recognized and rare diseases.

**The UDNI is open to Patient Organizations that adhere to the criteria for participation described below.**

**Requirements for Online Application**

Membership will be open to patient organizations from all countries who serve undiagnosed disease patients. To qualify, patient organizations must meet the following qualifications:

- An organizational mission that centers on, or substantially includes, increasing timely, equitable access to accurate diagnoses for undiagnosed individuals
- Non-profit 501(c)(3) status in the U.S. or the equivalent globally recognized tax-exempt status obtained through their respective country

- A board of directors (or equivalent) that is composed of a majority undiagnosed disease or rare disease patient advocates and representatives
- Proven activities that show a commitment to advocating for improving access to accurate diagnoses for undiagnosed disease patients

Once members, patient organizations within the UDNI shall:

- Advise the UDNI on the patient perspectives of individuals with undiagnosed diseases to ensure all UDNI deliberations are conducted, and decisions are made, with patient preferences in mind.
- Serve on the UDNI Patient Engagement Committee (if chosen by the full UDNI patient organization membership body).
- If chosen to serve as the Chair or Vice-Chair of the UDNI Patient Engagement Committee, attend the periodic meetings of the full UDNI
- Recruit new members for the UDNI
- Publicize the efforts of the UDNI and build awareness of its beneficial impacts on the global undiagnosed patient community

An application form should include the organization's mission statement with included diagnosis-related goals, proof of non-profit status, list of board of directors with their respective affiliations, and 3-5 sentences on organizational activities that serve the undiagnosed cause.

Applications will be reviewed by the UDNI Board Committee on Membership. Additional membership criteria and structures may be created as the UDNI develops.

**Please return your application form, including your board membership, mission statement, description of proven activities, and non-profit status, to: [UDNI@iss.it](mailto:UDNI@iss.it)**