FUNDACJA CANOMAD

Horizon Europe 2027 | Partner profile | Poland

WHO WE ARE

Fundacja CANOMAD is a small Polish patient-led foundation established in 2025 and an Associate Member of EURORDIS. We aim to support people living with CANOMAD, an ultra-rare immune-mediated neuropathy, and related conditions.

Our contribution is based primarily on the lived experience and engineering expertise of our founder, a person with severe motor disability, and an operational home living lab, rather than on a large patient membership or recruitment capacity.

OUR REAL-WORLD ENVIRONMENT

CANOMAD Observatory is an operational, single-household home monitoring and assistive technology environment developed with direct patient leadership. It brings together longitudinal physiological recordings, non-invasive ventilation information, environmental sensors, accessible voice interaction and home automation. The research dataset is being inventoried and quality-assessed; it is not yet clinically validated.

WHAT WE CAN CONTRIBUTE

- Lived experience of severe motor disability, engineering expertise and patient-directed decision-making.
- A real-world home living lab for feasibility work on assistive technology, accessibility and independent living.
- Co-design of patient-relevant outcomes, communication pathways and practical care workflows.
- Exploratory assessment of caregiver workload, autonomy, participation and technology burden.
- Experience with provenance-aware integration of Oura, O2Ring, ResMed and contextual home data.

PROPOSED ROLE IN A CONSORTIUM

A small, clearly defined patient-led living-lab contribution focused on co-design and feasibility of home-based support. Academic and clinical partners would lead study design, ethics, wider patient recruitment, clinical validation and comparative evaluation.

PARTNERSHIP INTERESTS

HORIZON-HLTH-2027-01-STAYHLTH-01: independent living, disability inclusion and community-based care. We are also open to collaboration on feasibility and data-quality methods for patient-led research in ultra-rare conditions.

CONTACT

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Communication in writing (e-mail or b2match messages) due to disability.

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