



PROJECT ALIVE

Project *Alive* Roadmap

2025-2027





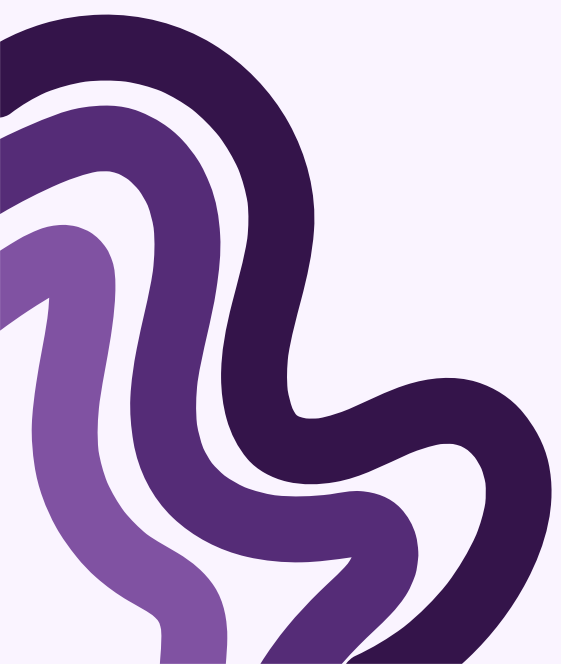
PROJECT ALIVE

Mission

Project Alive exists to find a cure for Hunter syndrome through research and advocacy, and provide education and resources to the Hunter syndrome community.

Vision

Project Alive envisions a world where every individual with Hunter syndrome has access to curative medicine.





Our Impact

- **Advancing a Cure**
We support the advancement of science to improve medical treatment and find a cure.
- **Advocating for Access**
We expand access to quality medical care, including early diagnosis and life improving treatments.
- **Empowering our Community**
We equip our community with knowledge and resources to navigate all stages of life.

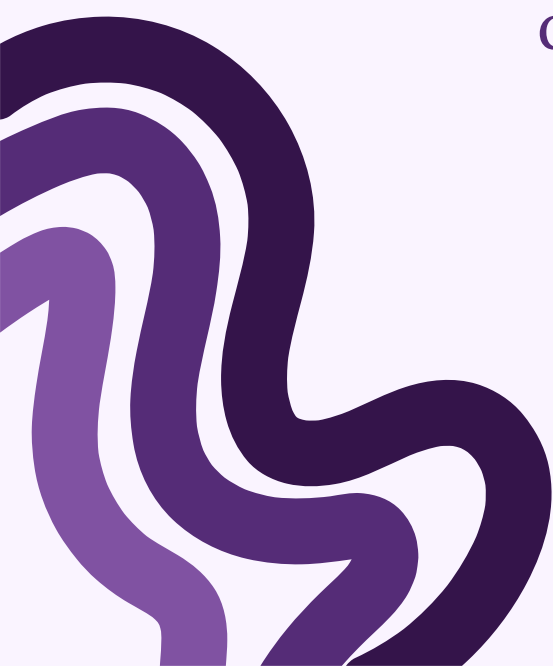




Impact Goals

ADVANCING A CURE

- By the end of 2027, Project Alive will have established research priorities, streamlined the grant application process, and invested \$600,000 in impactful scientific research.
- By the end of 2027, we will appoint a Chief Scientific Officer and become the leading organization advancing Hunter syndrome science.
- Project Alive will support the development of the first open access Hunter syndrome patient database by the end of 2027 to foster continued research and scientific innovation.

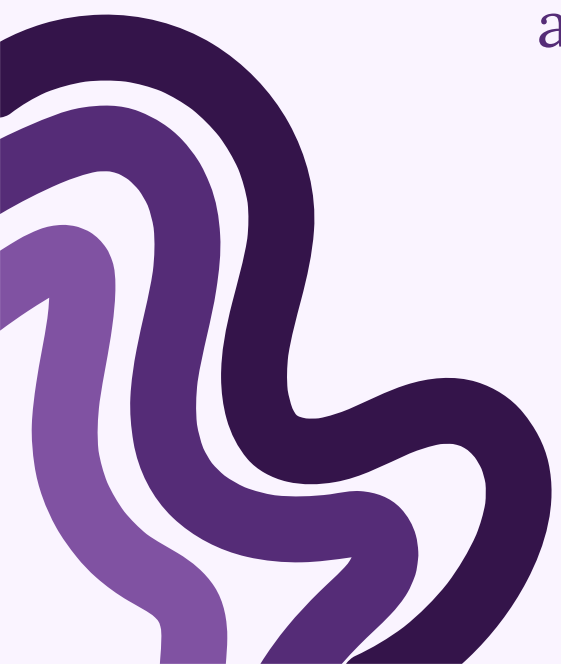




Impact Goals

ADVOCATING FOR ACCESS

- By the end of 2027, we will have defined legislative priorities, developed expertise to influence policy, and establish ourselves as the go-to advocacy organization for Hunter syndrome.
- By the end of 2027, we will produce a publication for payors that addresses access barriers and continue advocacy efforts to eliminate those barriers.
- By the end of 2027, we will publish one MPS II standard of care consensus guideline that is freely available.





Impact Goals

EMPOWERING OUR COMMUNITY

- By the end of 2027, we have created state resource guides for all states that includes information on clinical trial sites, local organizations, and resources.
- By the end of 2027, we will have a care coordination program to assist families with health care and insurance navigation.
- By the end of 2027, we have a case management department with staff capable of providing comprehensive services, including home visits.





Our Organizational Strategy

Skills & Mission Alignment

Analyzing current skills and strengths within the organization to implement a diverse board and volunteer structure to better meet the organization's strategic needs.

Enhance Resource Generation

Create a strategic development plan to improve resource generation which should provide financial stability to maintain mission-aligned programming.

Community Trust Building & Responsiveness

Enhance relationship between the organization and the Hunter syndrome community through listening, understanding, and responding to the community's needs.

Enhance Stakeholder Relationships

Enhance relationships with pharma, clinicians, researchers, legislators, and nonprofit organizations working in the Hunter syndrome space.

