Our Voices, Our Future:
Changing the Course of Hunter Syndrome Care (MPS II)

DENALI THERAPEUTICS

PROJECT ALIVE

We asked, and our community answered.
To understand real experiences living with and caring for someone with Hunter syndrome (MPS II), Project Alive fielded a Community Survey in partnership with Denali Therapeutics. The results highlight ongoing needs and how our community views the future.

We listened and are pleased to share back the voice of the community.

Impact on Quality of Life

Cognitive abilities are a key concern for all MPS II community members, even among those living with the non-neuronopathic type.

Caregivers of individuals with neuronopathic Hunter syndrome mentioned that the challenges of the condition most disruptive to their daily life included:

- Independent toileting
- Speech difficulties
- Personal care
- Behavioral challenges
- Sleep difficulties

In addition to cognitive challenges, individuals with the non-neuronopathic form are also concerned about:

- Hearing difficulties
- Stiffness
- Reduced physical stamina
- Socialization

Community members identified the impact on cognitive abilities as the most disruptive aspect of MPS II and expressed significant concern about physical limitations—such as challenges with walking, stamina, and overall health—progressively worsening over time.

Care Challenges & Future Treatment Landscape

The key challenges associated with Hunter syndrome care mentioned by community members include:

- Inability of current treatment **to cross the blood-brain-barrier to effectively address cognitive symptoms**
- **Taking time off work/school and traveling** for infusions and other medical care
- **Barriers to accessing care,** including insurance issues and the burden of high medical expenses

When considering the future and potential to switch to a new treatment, MPS II community members were most influenced by:

- Information received from advocacy organizations
- Their main treating doctor
- Online information from pharmaceutical companies

In thinking about investigational treatments for Hunter syndrome that may be FDA approved in the future, individuals and families are willing to switch to a new option that provides significant improvements in cognition and physical health over current treatment.

Resources & Education Needs

Community members shared **that peer-to-peer communication and patient advocacy organizations provide the most help in finding information** on life with Hunter syndrome, while other effective resources include:

- Social media
- Online message boards
- Healthcare providers
- Conferences

Still, about half of respondents seek more information on symptoms, lifestyle, treatments, and clinical studies.

we heard *you.*

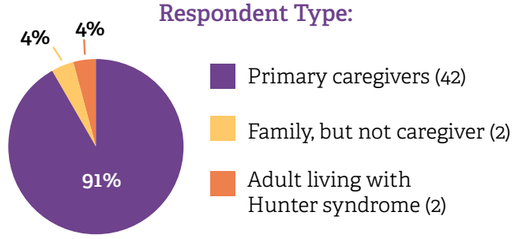
Methodology

- Online survey fielded Dec. 2024 through Jan. 2025
- Open to Hunter syndrome community through Project Alive social channels and network
- Conducted by Project Alive in partnership with Denali Therapeutics

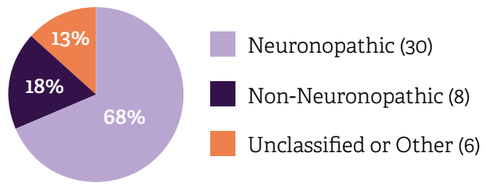
Demographics

- **47 responses were collected,** including 25 fully complete and 22 partial responses
- Majority of respondents were caregivers for individuals with neuronopathic Hunter syndrome
- Caregivers represented mostly pre-teens with Hunter syndrome (mean: 12.5 years / median: 11 years)

Respondent Type:



Hunter Syndrome Type:



"[More information is needed about] forging your own path/life plan when you can't relate to the community at large … not allowing disease assumptions to bias education, jobs, and life goals."

- Caregiver of individual living with non-neuronopathic Hunter syndrome

Our Voices, Our Future…

Your voice and *every* voice within the Hunter syndrome Community matter. While key challenges remain for individuals with MPS II, new treatment options are on the horizon. The crucial factor for families making treatment decisions will be the ability to address cognitive and physical impacts of the disease.

Check out these resources to take action, get involved and engage with your care team:

projectalive.org/resources-selection