

# Advocacy 101

Advocacy can feel overwhelming at first, but it doesn't have to be. You do not need to be an expert to make a difference. Whether you are a parent, sibling, friend, or supporter, you already have the most powerful tool: your story.

## What is advocacy?

Advocacy means speaking up to create change.

For families affected by Hunter syndrome, advocacy can look like:

- Sharing your experience to raise awareness.
- Educating other about MPS 2.
- Asking leaders to support policies that improve care and access.

At its core, advocacy is about helping others understand what life is really like, and why change is needed.

## Why advocacy matters for Hunter syndrome?

Hunter syndrome is rare, and many people may not fully understand it.

Advocacy helps:

- Increase awareness so families are seen and heard.
- Improve access to care and treatments.
- Advance research and innovation
- Drive policy changes like newborn screening and faster approvals.

Real change happens when families and communities come together and speak up.

## Types of Advocacy

There are many ways to get involved - choose what feels right for you:

- Awareness Advocacy
  - Sharing posts on social media
  - Participating in awareness campaigns
  - Talking to your community, school, workplace

- Legislative Advocacy
  - Contacting lawmakers
  - Writing letters or emails
  - Participating in advocacy days or meetings

- Personal Storytelling
  - Sharing your family's journey
  - Creating vidos or writing your story
  - Helping others understand the real impact of Hunter syndrome

You don't have to do everything. One small action makes a difference.

## How to Get Started

Not sure where to begin? Start here:

- Learn the basics about Hunter syndrome and current advocacy priorities.
- Share a post or your story during an awareness campaign.
- Sign up for Project Alive advocacy updates
- Use a template to email or call your representatives.
- Invite a friend or family member to learn alongside you.
- Join a Project Alive program like the Young Leaders or Advocacy Council.

Advocacy is more powerful when we do it together. Project Alive is here to support you everystep of the way.



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