Traveling together on a journey of community, support, & hope

For some, the path to MPS or ML is immediate—babies are diagnosed through newborn screening and connected immediately with information and treatment decisions. For others, the diagnostic odyssey extends decades into life. The Pathways program supports families and equips them with tools to help them through the first year.

The Pathways program offers face-to-face visitation and comprehensive services based upon ongoing assessments and evaluation of need. Support and educational resources are provided to the individual, close and extended family members, siblings, educators, medical providers, and other care providers. Caregivers encounter unique challenges during the first year of diagnosis, with many vividly remembering feelings of distress, uncertainty, and grief. With access to trained professionals, Pathways provides free services and important connections as you find your way forward.

Services provided
- Individual and family current assessment and need
- Connection with others for support and firsthand experience
- Sharing of National MPS Society resources, programs, and educational materials
- Face-to-face visitation with a trained Society professional
- Ability to access direct support throughout the first year of diagnosis
- Assistance navigating insurance and accessing federal, state, and local resources
- Unbiased presentation of all options, including approved treatments and therapies, clinical trials, and resources for symptom management
- Provision of emotional support and plans for coping and resiliency
- Information about Centers of Excellence and medical providers familiar with specific needs

Mission Statement
The Pathways program provides families with education and comprehensive support throughout the first year of diagnosis. Through innovative techniques, we connect members with services, both locally and nationally. We equip and strengthen families to manage care and establish resources needed for their MPS or ML journey.
Pathways Program

Support for a new diagnosis of MPS or ML

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A program of the National MPS Society

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mpssociety.org/pathways
Providing comprehensive resources and educational materials through face-to-face visits

Caregivers of individuals and adults newly diagnosed with MPS and ML encounter unique challenges during the first year of diagnosis.

The National MPS Society and Pathways program staff have been such a great resource for us. They are professional, compassionate, and so well-suited to help families. Though the new diagnosis wasn’t easy for us, we didn’t feel alone. We are deeply appreciative.
— Pat and Susan Bell, parents of Brandon (MPS IIIC)

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We want you to know that you don’t have to be alone on this journey! We provide immediate access to resources at the time of diagnosis. Many vividly remember the feelings of distress, uncertainty and grief they experienced upon receiving a new diagnosis of MPS or ML. Pathways services are free. Our Pathways team will come alongside you as you find your way forward.

Tiered levels of support offer intensive and frequent contact with the Pathways team upon diagnosis, tapering throughout the first year. Services in Pathways emphasize increasing independent care management and decision-making. Upon completion of the Pathways program after the first year, individuals and families are equipped with resources and knowledge to take the next steps within the MPS and ML community.

I was first diagnosed with MPS IVA at the age of 42 and I turned to the National MPS Society. Most of my doctors had never encountered MPS. It was a relief to find a reliable source of information and answers to my questions after a lifetime of misdiagnosis, failed surgeries, and physical challenges. The Pathways program educates patients and families in critical ways that are really needed at the time of diagnosis.
— Tracy Greenberg (adult with MPS)

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