

# Pathways Program



Support for a new diagnosis of MPS or ML



TRAVELING THE JOURNEY TOGETHER

A program of the National MPS Society

# 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

# Providing comprehensive resources and educational materials through face-to-face visits

Connection  
Together



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

Equipping  
Empowering  
Reliable



Strength

Education  
Tools  
Information



ML

Community  
Courage

Support  
Resources

Encouragement

Family

Resiliency

Hope  
MPS



*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)



*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)



## Pathways Timeline

(for example purposes only)

### Initial Diagnosis

- Initial intake and support
- Assessment of needs
- Disease education and discussion of treatment options

### Getting to Know You

(month 1)

- Scheduling face-to-face visit and continued conversation
- Connection with other families
- Exploration of identified areas of need with continued education
- How to access team member support and who to contact

### Joining the Community

(months 2-3)

- Understand how to access services on local, state, and national levels
- Engaging family to participate in follow up and specialty care appointments
- Utilize team member support for collaboration as needed in medical and educational settings

### Sharing Your Story

(months 4-5)

- Assist family to share their story and experiences within their family and on a larger scale in the community as desired
- Check in to address follow-up needs and ensure connection with services

### Symptom Management

(months 6-8)

- Education on daily symptom management and what to expect in the future
- Target behavioral needs, sleep concerns, eating, mobility, pain
- Encourage further involvement
- Goal to have strong management of current symptoms and future plans for needed support

### Staying Afloat

(months 9-11)

- Focus on self-care, connecting with others, developing strategies for maintaining current level of positive functioning
- Support for siblings and whole family unit

### Moving Forward

(one year)

- Transition to established services and long-term maintenance
- Ensure linkage to services in community and National MPS Society programs

### Next steps

Future expansion of the Pathways program includes increased newborn screening support, virtual meetings, hospice care, and enhanced digital resources.

**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.



### **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.



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