

Crossing Paths

Engage and support patients and families in underserved communities living with mucopolysaccharidosis (MPS) and mucopolipidosis (ML), two ultra-rare lysosomal storage diseases

Why It Matters

Diagnosis and treatment of rare diseases can be far more complex than other chronic diseases, and these complexities are only amplified when there are socioeconomic and other disparities.

During a National MPS Society event in Atlanta, several participating families needed help with an array of issues such as lack of transportation to appointments, inability to participate in clinical studies, and food insecurity.

These families opened our eyes to health inequities and social determinants of health affecting people with MPS and ML in underserved communities.

Solution

Bring services and support to people living with MPS and ML in underserved communities.

The Society developed a new program to meet underserved patients and families where they are. Through direct services and support in targeted underserved cities, the Crossing Paths program helps bridge socioeconomic, language, and cultural barriers by:

- Bringing food and resources
- Offering an accessible meeting place
- Providing in-person disease-specific education and information

This enables The Society to interface directly with MPS and ML patients and families in underserved communities that we were not reaching and provide support that is sensitive and responsive to their specific circumstances.



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Impact

In addition to the pilot in Atlanta, the program was implemented in 6 underserved locations in 2023:

- Cleveland, OH
- Denver, CO
- Los Angeles, CA
- Miami, FL
- Paramus, NJ
- San Antonio, TX

In 2023, Crossing Paths engaged **66 families**, of which **42%** were first-time engagements.



Key Learnings

The Crossing Paths small group events highlighted the value to families, especially the importance of:

- Multiple levels of engagement for our Spanish speaking families
- Education to those families new to the Society
- Clinical study education one-to-one, leading to better understanding of the importance of clinical studies
- Face-to-face assessment for mental health needs and support for referrals as appropriate
- Connecting families to additional local support
- Referrals to MPS specialists

