JOIN TODAY
ConnectMPS.org

Our Patient Registry

Your health information can help researchers learn about MPS and move us closer to promising treatments. This data is so vital to finding cures that advocacy groups and societies from around the world have united to create this program.

1 Join MPS Families Around the World
Share your loved one’s MPS health information in a program that safeguards your privacy and ensures that you control your information. Opt in or out at any time. ConnectMPS is available in English, Portuguese, Spanish, Mandarin, Japanese, and German.

2 Engage with Opportunity
Take health surveys and learn about the experiences of others living with MPS. See how your health information fits into the larger picture of the MPS experience around the globe. Receive notice of clinical trial recruitment and the latest news in MPS research.

3 Help Advance Research & Treatments
Patient data critical to development and approval of new treatments. This registry is already hard at work with researchers and clinical trials for promising therapies. Add your data and help build on this momentum.

Speed Research. Find Cures.

With your help, researchers can better understand the progression of MPS and related diseases while discovering potential commonalities and differences across its many forms. ConnectMPS provides a safe way to help overcome knowledge gaps faced by researchers. It offers ONE pan-MPS data location, accessible by families, organizations, researchers and companies.

Connect MPS is fully compliant with the new European Union General Data Protection Regulation (GDPR), which became law on May 25, 2018.

Questions? Contact the Registry Coordinator:
coordinator@pin.invitae.com | www.ConnectMPS.org