Call to Action: Be a part of the 2025 International MPS Day
"It’s About Time" Campaign

Dear IMPSN Members,

As part of our "It's About Time" campaign, we are gathering videos, photos, images, statements, and stories from individuals and families affected by MPS, as well as from healthcare providers and advocates. These contributions will help raise awareness of the critical need for timely diagnosis, treatment, and support.

About the IT'S ABOUT TIME: Global MPS Awareness Campaign

"IT'S ABOUT TIME" carries a dual meaning:

1. Time Matters – Early diagnosis, swift treatment, and continuous support are critical for those with MPS. Delays can mean irreversible damage, while timely intervention can transform lives.
2. Time for Change – The campaign demands action: newborn screening, equitable access to treatments, and better support systems for MPS-affected individuals worldwide.

Why Every Second Counts
MPS is a progressive disorder; with each passing second, irreversible damage occurs. Early detection and diagnosis are vital to slow disease progression. Including MPS in newborn screening can change lives.

Access to Treatments & Support
Timely access to therapies improves mobility, quality of life, and survival. But support goes beyond medicine—emotional, financial, and educational resources are crucial for families navigating MPS.

Mental Health & Lifelong Care
MPS affects individuals at every stage of life. From infancy to adulthood, needs evolve, requiring tailored support, specialized care, and mental health services.

A Global Responsibility
MPS knows no borders, yet access to care varies dramatically worldwide. This campaign advocates for global healthcare equity, ensuring every individual, regardless of location, gets the care they need.

How Will These Assets Be Used?

Your submissions will be featured in:

* A global awareness video launching on International MPS Day (May 15, 2025).
* Social media content leading up to and on MPS Day.
* Advocacy materials shared with policymakers and healthcare organizations.
* The IMPSN website and other international awareness initiatives.

Submission Guidelines

* Videos: Up to 60 seconds (landscape or portrait). Share a personal experience, a message of hope, or a call to action, emphasizing the impact of timing in diagnosis, treatment, or support .
* Photos: High-quality images featuring individuals with MPS, families, or advocacy moments.
* Statements: A short, one- or two-sentence message that relates to the "It's About Time" theme (e.g., "It's About Time that every child with MPS gets diagnosed at birth.").
* Stories: A 100-200 word account of your experience with MPS, emphasizing the impact of timing in diagnosis, treatment, or support.

Key Messages:

* Every Second Matters – Delayed diagnosis leads to suffering. IT’S ABOUT TIME we act.
* We Have Therapies. We Don't Have Time – Early intervention is essential. IT’S ABOUT TIME we prioritize access.
* MPS Robs Children of Their Childhood – IT’S ABOUT TIME we give them a chance to live fully.
* Mental Health Matters – IT’S ABOUT TIME emotional support is prioritized.
* Lifelong Care is Essential – IT’S ABOUT TIME we address the needs of MPS patients at every stage of life.

How to Upload & Share Your Submissions

* OneDrive Shared Folder: [MPS Day Assets](https://impsnetwork-my.sharepoint.com/%3Af%3A/g/personal/kimangel_impsn_ca/Esq45Q_HAU5Cu6tC3oeiWIkBvPpSRmPp15AMNBm1Tbq9RQ?e=zQFC1V) – Upload all files directly.
* Email Submissions: Send to kimangel@impsn.ca with the subject line: "MPS Day Submission - [Your Name]”
* If Files Are Large: Use WeTransfer ([www.wetransfer.com](https://www.wetransfer.com/)) and send to kimangel@impsn.ca.

Consent Forms Required

A completed and signed consent form must be submitted for each submission. You can find the consent form on the following page and a separate file will also be attached in the email request.

Please upload completed forms to the OneDrive folder [Consent Forms](https://impsnetwork-my.sharepoint.com/%3Af%3A/g/personal/kimangel_impsn_ca/ElxFo1gWTeBCgLasCjt1aWEB0CPPIRPWs4dHVaY2VzfO-A?e=fCivNy) or send them via email to kimangel@impsn.ca with your submission.

Submission Deadline: March 31, 2025

Please help us spread the word by reaching out to your members, healthcare providers, and partners to encourage participation. If you have any questions, feel free to reach out.

Thank you for helping us show the world why "It’s About Time" for a future where timely diagnosis, treatment, support and hope are within reach for all families affected by MPS.