National
MPS
Society

Media Toolkit

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1 The Impact of Storytelling

Every story matters—every voice in our MPS and ML community helps shape who we are. Whether you're a parent, patient, sibling, or friend, your experience is uniquely powerful. By sharing your journey, you’re not only raising awareness—you’re helping others feel seen, understood, and less alone.

Storytelling brings us together. It builds community, inspires hope, and can even lead to meaningful change. When we tell our stories, we find strength in vulnerability and discover just how connected we truly are.

Why Storytelling Matters

Sharing your story can:

- **Support Fundraising:** Personal stories move people to action. Your words can inspire donations that fuel research, family support, and other critical programs.
- **Drive Advocacy:** Policymakers are more likely to act when they understand the real impact of rare disease. Your voice brings the data to life.
- **Build Community:** Your journey may be exactly what someone else needs to hear to feel less isolated and more hopeful.
- **Empower You:** Telling your story helps reclaim your voice and can offer healing, clarity, and confidence.

We’re here to help you share your story in a way that feels right for you—because your voice has the power to educate, connect, and change lives.

Example: Carl Kapes, a Board member at the National MPS Society, shared the story of his two sons with MPS III to fundraise for the 2024 Annual Fund.

1 The Impact of Storytelling

The Ethics of Storytelling: Respect Dignity and Give Informed Consent

If you're sharing someone else's story, especially that of a child or adult with MPS or ML, ask yourself:

- Can this person give informed consent? If not, am I honoring their dignity and autonomy?
- Would they want this shared publicly?

Avoid content that could feel exploitative or overly medicalized. Instead of focusing solely on hardship, uplift the individual's personality, relationships, and impact. Photos or videos should also be used with care. Ensure that those pictured are aware that their image is being posted—and that it will be made public.

The Ethics of Storytelling: Amplify, Don't Exploit

We want our stories to build awareness—but always with care. That means:

- Centering the person living with MPS or ML, not the illness
- Avoiding language like "suffering from" or "tragic"
- Focusing on empowerment, not pity

If you're unsure about wording or content, step back and ask: Does this uplift the person at the center of the story? If you need additional support or have questions, you can always contact our team at **info@mpssociety.org**.

Example: Blakely (ML II) passed away at just two years old. Although her family grieves her loss, they continue to share her story with an emphasis on the positive legacy she left behind to raise awareness for ML.

2 Getting Your Story in the News

What is media?

Media includes the news outlets that share information with the public—television and radio stations, newspapers, magazines, and online news platforms. This can range from your hometown newspaper to major national news organizations like ABC, CBS, etc. Whether local or national, the media plays a critical role in educating the public, raising awareness, and influencing change.

Why is media coverage important?

Sharing your MPS or ML story with the media can make a powerful difference:

- Media outlets are often looking for compelling, human-centered stories—especially when they involve someone from the community or address underrepresented topics like rare diseases.
- State and federal policymakers frequently monitor news from their districts and states. Your story can help shape public policy.
- Media coverage can lead to earlier diagnoses, improved access to care, stronger community support, and increased research funding for MPS and ML.

How can I share my story?

Step 1: Identify potential media contacts

Start by creating a list of 3–5 news outlets—both local and national—that you think may be interested in your story. You can find phone numbers and email addresses for newsroom contacts or specific reporters on the outlets website.

To get started:

- Search “[Your Town/City] news outlets” or “[Your State] health reporters.”
- Look for reporters who have covered similar health, advocacy, or human interest stories.
- If a direct contact isn't available, use general newsroom addresses like info@, editor@, or tips@.

2 Getting Your Story in the News

For national media outreach, consider submitting your story idea to online platforms, disease-specific podcasts, or national health reporters. If you're seeking wider visibility, we can help guide you through this process.

Step 2: Write and send your pitch
A pitch is a short message that explains why your story matters and why it's relevant. Your pitch should include:

- A statement that you are a resident of the area (for local media) or a member of the rare disease community (for broader media).
- Why your story is timely, such as MPS Awareness Month, a fundraising event, or proposed legislation.
- A concise description of your story (no more than three to four sentences).
- Key facts about MPS or ML, with a personal connection or local relevance when possible.
- A clear ask: that the outlet considers covering your story to raise awareness.
- Any relevant photos or videos.
- Your name and contact information.

Need help crafting your pitch? Reach out to our Director of Communications, Amber Adams, at **amber@mpssociety.org**.

What if no one responds?
Don't be discouraged if you don't receive a reply right away. Silence doesn't mean your story lacks value. Here's some ways you can check on the status of your submission:

- Follow up in a few days with a polite reminder.
- Consider reaching out to a different reporter or outlet.
- Submit a letter to the editor or an opinion piece—many publications accept them and provide submission guidelines on their websites.

2 Getting Your Story in the News

What if my story gets covered?

If your story is published or aired, take steps to maximize its impact:

- Share the article or segment on your social media platforms.
- Add it to your blog or website if you have one.
- Reach out to your community, i.e. your job, church, social clubs, etc. and ask them to share it.

Tell us about your media success

We want to hear from you. If your story is featured in the news, email our Director of Communications, Amber Adams, at **amber@mpssociety.org** with the link or article. With your permission, the National MPS Society will share it across our communication channels to help amplify your voice and inspire others.

News examples:

Guy Fieri, anonymous buyer team up to buy $24,000 pig at Sonoma County Fair, supporting girl raising money for sick little brother

The animal was raised by 10-year-old June Trappe, whose 7-year-old brother, Jett, has MPS-1 Hurlers Syndrome, a rare and and life-threatening metabolic disease

local news

For these elementary students, lemonade + cookies = $542 for rare disease research

By SHARYN KOPF - May 22, 2025

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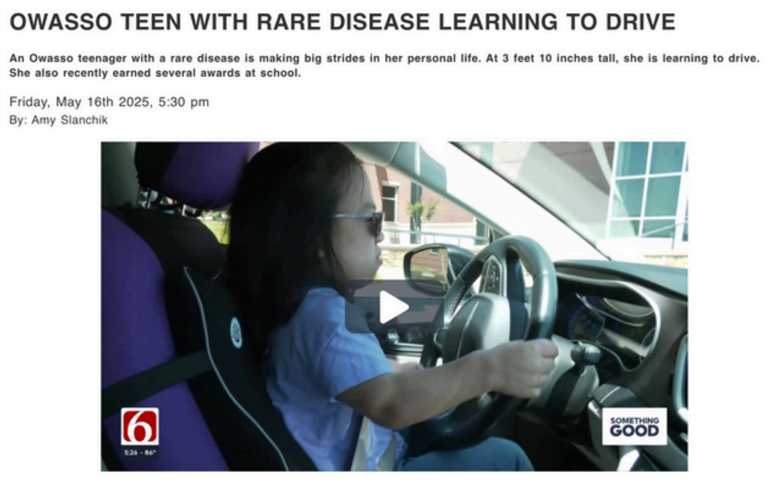

OWASSO TEEN WITH RARE DISEASE LEARNING TO DRIVE

An Owasso teenager with a rare disease is making big strides in her personal life. At 3 feet 10 inches tall, she is learning to drive. She also recently earned several awards at school.

Friday, May 16th 2025, 5:30 pm

By: Amy Slanchik

3 Sharing Your Story with the Society

Your story matters.
The voices of individuals and families impacted by MPS and ML are powerful tools for awareness, advocacy, and connection. By sharing your journey, you help others feel less alone, inspire community action, and educate the world about the realities of living with a rare disease.

We invite you to submit your story using our online form: Submit Your Story

Whether it's about a recent diagnosis, a personal milestone, or a moment of strength in the face of challenge, your story helps build hope.

How to Make Your Story Personal and Powerful
Introduce yourself or your family member with MPS or ML. Include:

- Your name(s) and where you're from (city and state)
- Diagnosis and age at diagnosis
- A few personal details to bring your story to life (hobbies, personality, family traditions, etc.)

You don't have to tell every detail—but focus on moments that have shaped your experience. Consider including:

- How you received the diagnosis and how it affected you
- Challenges you've faced and how you've overcome them
- Any involvement with the National MPS Society that has been meaningful to you

Example: Fanny (MPS IV A) shared her story on our blog, *Living with Courage*, to encourage others to feel empowered beyond their diagnosis and discuss how her involvement with the Society impacted her life.

→

3

Sharing Your Story with the Society

Keep it Honest and Uplifting

It's okay to share hardships—but balance your story with hope, love, or resilience. Your story can be a light to others walking a similar path.

Use Your Voice

Write as you speak. You don't need perfect grammar—just authenticity. Our team will edit your submission for spelling, grammar, and clarity.

Submit compelling photos that help bring your story to life.

Here's what we recommend:

- Choose 2-4 clear, high-quality images
- Avoid blurry or heavily filtered photos. Natural lighting works great.
- Feature your loved one with MPS or ML, family moments, or events that are part of your story.
- Smiles, favorite activities, family traditions—images that show the full, rich life behind your story.
- Avoid submitting hospital photos unless they're central to your story
- We aim to show the person first, not just the condition.
- Make sure you have permission to share any photo you submit
- Only upload images that you have the rights to share publicly.

What Happens After You Submit?

- A member of our team will review your story.
- We may reach out to clarify details or request additional photos.
- Your story may be shared on our website, social media, newsletter, or other National MPS Society publications, and beyond.

A member of our team will reach out to let you know when your story is published.

4 Sharing Your Story on Social Media

Guide to Sharing Your MPS or ML Story on Social Media

Sharing your journey with MPS or ML on social media can be a powerful way to raise awareness, build community, and inspire action. Whether you're a patient, parent, sibling, or supporter, your story matters.

Start With Purpose

Before posting, ask yourself:

- *Why* am I sharing this?
- What do I hope people will learn, feel, or do?
- Is this story mine to tell?

Clarity in your purpose helps your message stay focused and meaningful.

Tell a Personal, Honest Story

Make your post relatable by including:

- How you or your loved one was diagnosed
- What daily life looks like
- Moments of strength, challenge, and joy
- How your community or advocacy groups have supported you

Try to balance truth with sensitivity. You don’t need to share every detail—protect what feels private.

Choose Photos with Meaning

Visuals help people connect. Consider sharing:

- Everyday moments that show personality and joy
- Family photos
- Events like walks, conferences, or hospital milestones

Avoid images that feel intrusive or overly clinical unless you’re making a specific, informed advocacy point.

4 Sharing Your Story on Social Media

Use Social Media to Fundraise Thoughtfully

Want to turn your story into action? Here's how:

- Share a donation link to the National MPS Society or another organization that has supported your family.
- Use your birthday, diagnosis anniversary, or special milestone to ask friends to donate in honor of someone you love.
- Include how the funds will make a difference: research, support, advocacy, or programs.

Example post:

"Two years ago, we learned our daughter has MPS I. It's changed everything—and yet, she continues to show us what bravery and love look like every single day. The National MPS Society has given us community, hope, and resources we didn't know we needed. If her story moves you, consider a donation: [insert link]."

Tag Thoughtfully and Use Hashtags

Tag organizations that have supported you so they can amplify your post, and use hashtags to amplify your reach. Some hashtags to consider:

- #MPS
- #ML
- #RareDisease
- #HurlerSyndrome
- #HunterSyndrome
- #Sanfilippo
- #MorquioSyndrome
- #MaroteauxLamySyndrome
- #SlySyndrome
- #HyaluronidaseSyndrome

4 Sharing Your Story on Social Media

Stay Safe and Set Boundaries

Social media is public. Protect your privacy by:

- Avoiding full medical records or identifiers
- Being selective about what you share and where
- Turning off location tagging if needed

It's okay to keep parts of your story offline. Choose what feels right for you.

Example:

Saving Sadie Rae

Sadie (MPS III) has more than 300,000 Facebook followers, and 200,000 more on Instagram. Sadie's family uses their platform to bring awareness to Sanfilippo Syndrome by documenting Sadie's life.

They often include pictures and videos of Sadie, focusing on the positive aspects of her life while also acknowledging the reality of taking care of a child with a neurodegenerative disease.

5

Designs, Assets, and Support

This guide is designed to help you use the National MPS Society's visual identity effectively while bringing your personal story to life. Below are resources, suggestions, and guidance for storytelling assets.

What We Can Help With

We are here to support your storytelling efforts! You can request help with:

- Flyer or poster templates
- Logos, colors, and fonts to align your message with our mission
- Photo/video guidance to highlight your journey or fundraiser
- Support with storytelling structure for impact

Branding Basics

To keep your materials consistent with the Society's trusted identity, we recommend:

- Using dark purple (#611774), our signature color, along with other secondary brand colors available upon request
- Including our official logo—available upon request
- Maintaining a tone of hope, courage, and community

Keeping accessibility in mind: use readable fonts, high-contrast colors, and captions for videos whenever possible.

Get Personalized Support

If you need assistance with digital assets, design, or branding for your fundraiser, social media campaign, or advocacy project, we're here to help! Please reach out directly to:

Amber Adams
Director of Communications
amber@mpssociety.org