

15th Anniversary Moebius Syndrome Awareness Day

Media Contact Toolkit

Thank you for downloading the **15th, Anniversary Moebius Syndrome Awareness Day Media Contact Toolkit**.

This toolkit was created to help individuals and families share *their own* stories with local and regional media in a way that feels personal, authentic, and worth a reporter's time. Media stories have the greatest impact when they focus on people — not organizations — and this guide is designed to help you do just that.

There is no single “perfect” way to contact the media. What matters most is that your message feels real, specific, and human. Reporters can tell when an email is copied and pasted. They can also tell when someone is speaking from lived experience.

If you ever need guidance or encouragement, you’re welcome to reach out to me at tim@mfoms.org. I’m happy to help.

Warmly,
Timothy Smith
Many Faces of Moebius Syndrome

A Note Before You Reach Out to Media

Not every email will get a response — and that’s normal. But messages that feel thoughtful and personal are far more likely to be read, remembered, and followed up on.

You don’t need to write a press release.
You don’t need perfect wording.
You *do* need to give the reporter a reason to pause.

That usually means:

- A specific detail
- A real moment
- A reason *now* feels relevant

How to Approach Your Media Email

Instead of thinking, “*How do I promote awareness?*”
Think, “*Why might someone reading this care?*”

Your email should sound like **you**, not like a campaign.

Things that help grab attention:

- Mentioning your city or region
- Referencing your own age, your child, or a recent experience
- Tying your story to January 24 (Moebius Syndrome Awareness Day)
- Writing the way you speak — not formally

Sample Media Email (Use as a Guide, Not a Script)

Subject: A local story for January 24 — living with Moebius syndrome

Hello [Name],

I live in [City], and I was born with Moebius syndrome — a rare neurological condition that affects facial movement and expression. January 24 is Moebius Syndrome Awareness Day, and I wanted to reach out to see if you might be interested in sharing a local story tied to that day.

Growing up, people often assumed I was unfriendly or uninterested because I couldn't smile. Those assumptions followed me into adulthood, and they've shaped how I experience school, work, and relationships.

I'd be happy to talk more if this is something you'd like to explore. Thank you for taking the time to read this.

Best,
[Your name]

This is **not** meant to be copied word for word.
It's an example of *tone*, not a formula.

Finding the Right Media Contacts

- Start local: newspapers, TV stations, radio, community blogs
- Look for “News Tips,” “Contact,” or “Submit a Story” pages
- Search:
 - *health reporter* + city
 - *community news* + city
- If needed, call the newsroom and ask:

“Who should I send a local human-interest story to?”

Timing & Follow-Up

- Sending your email **2–4 weeks before January 24** works well
- If you don't hear back, one polite follow-up is appropriate
- If they decline or don't respond, that's okay — move on

If Your Story Is Picked Up

If your story is published or aired, feel free to share it and let us know at tim@mfoms.org. Seeing individual stories reach the public helps remind others that their voice matters too.

Final Thought

You don't have to overshare.
You don't have to be polished.
You just have to be *real*.

Stories that come from real people are what keep awareness moving forward.