



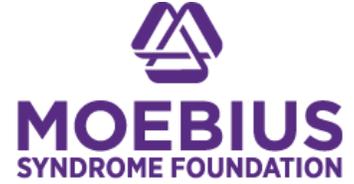
# Event Planning Toolkit



Raising Awareness of  
Moebius Syndrome

## **Raising Awareness of Moebius Syndrome**

We are excited that you would like to invest your time and energy to raise awareness of Moebius Syndrome and strengthen the Moebius Community in your local community!



Moebius syndrome is a rare condition that lacks public awareness. You can help us to raise awareness as well as educate those within our own communities such as classmates, educators, peers, legislators and medical professionals. By getting our voices heard, we will increase funding for Moebius Syndrome research, connect with everyone impacted by Moebius and overall, build a stronger community.

If you want to host a social event, educational session or fundraisers for the Foundation. This is a toolkit that will help you on your way.

If you have any questions as you ramp up, please do not hesitate to contact us.

Warmest Regards,

Dina Scalone  
Moebius Syndrome Foundation  
Executive Director  
Dina@moebiussyndrome.org

Jenny Whitman  
Event and Marketing Director  
Jenny@moebiussyndrome.org

## What are the symptoms of Moebius syndrome?

- Lack of facial expression; inability to smile or frown
- Feeding, swallowing or choking problems
- Motor delays due to upper body weakness
- Absence of lateral eye movement
- Absence of blinking
- Strabismus (crossed eyes)
- Drooling
- High palate
- Short or deformed tongue
- Limited movement of tongue
- Submucous cleft palate
- Dental problems
- Hearing impairment
- Hand/feet deformities

### What is Moebius syndrome?

Moebius syndrome is a non-progressive rare neurological disorder that is present at birth and affects the cranial nerves that control facial expression and eye movement. It primarily affects the 6th and 7th cranial nerves, meaning that people with Moebius syndrome are unable to smile, frown, raise their eyebrows, grimace, move their eyes laterally or blink. Their eyelids may not close completely when blinking or sleeping, which can result in dry or irritated eyes. Weakness in the facial muscles may cause problems with sucking and the ability to feed, an early symptom that arises with newborns. [Read more here.](#)

It is estimated that Moebius syndrome affects 2 to 20 per 1 million people.

### How common is Moebius syndrome?

The causes of Moebius syndrome are unknown, although the condition probably results from a combination of environmental and genetic factors. Researchers estimate that the condition affects 2 to 20 per 1 million people.

### Are there treatments available?

There is no cure for Moebius syndrome but there are [treatments available](#). Children with Moebius syndrome usually benefit from physical and speech therapy to improve their gross motor skills and coordination, and to gain better control over speaking and eating, as well as occupational and sensory integration therapies. Infants may require special bottles (i.e. Special Needs or Pigeon Feeder) or feeding tubes to maintain sufficient nutrition. Strabismus (crossed eyes) is usually correctable with surgery.

Limb and jaw deformities may often be improved through surgery. In addition, plastic reconstructive surgery of the face can offer benefits in individual cases. In that surgery, nerve and muscle transfers to the corners of the mouth have been performed to provide an ability to smile. **For more information, visit [www.moebius syndrome.org](http://www.moebius syndrome.org)**

## Easy Event Ideas!

### **Host a Picnic**

This is a very easy event to organize – and may attract a large group of people. You'll want to choose a location that is free or can be reserved at a low cost, appealing so people will want to attend your event, and large enough to accommodate a group. You could have an activity for people to take part in –horseshoes, a hike, or live music to enjoy.

Make it a potluck so everyone will bring a dish to share. When promoting the event to the community, be as specific as you can with the location. It would be useful to provide parking information and a map.

### **Have a Moebius Syndrome Foundation Table at a local event**

If there is a community health fair, town celebration or school event, ask the event coordinators if you can set up a table to share information. Hand out wristbands and brochures.

### **Enter a "Moebius Syndrome Foundation" Team in a local event**

Instead of planning an entire walk-a-thon on your own, gather a local group and enter a local walk, 5K, or other event as the "Moebius Syndrome Foundation" and wear MSF t-shirts! Raise funds by using Websites such as Gofundme.com or Facebook!

### **Plan a Mighty Moebius Walk & 5K**

Plan a walk in your neighborhood, at a park, or on a school track. Contact the park, school, or your local municipality to see if you need to have any kind of permit or reservation. Make flyers that give a starting time and an easy description of the route, invite your neighbors, and put up flyers all around town (libraries & supermarkets both have community boards). All attendees should be asked to raise funds for the Foundation.

### **Go Bowling, Golfing, or other Fun Activity**

A day at the bowling alley, golf course, or even a miniature golf course can be very fun! Contact your local bowling alley or golfing spot a few months in advance to reserve space—tell them you are hosting the event for the Moebius Syndrome Foundation. Ask if they have a party room that you can use and if you can bring your own food. All attendees can be responsible for paying their own way and renting their own shoes/equipment. If you have a group of volunteers to help you, you could consider turning your event into a fundraiser.

### **Be Creative!**

These are only a few ideas – feel free to get creative! Think about what would work best in your community and is easy for you to pull together with the volunteers and resources you have available locally.

## Getting People to Your Event

Good publicity takes time, planning, creativity, effort, and good timing – so plan ahead! Below are some ideas to get you started – but be creative!! If you put pizzazz in your promotions then people will be excited to attend!

### ✓ **Reaching out through the media**

Further along in the toolkit, there are materials for reaching out to your local media. A press release can provide reporters with all the information they need.

### ✓ **Flyers**

Drive around town and surrounding communities and hang flyers in local businesses and public libraries. Make the fliers look professional and fun. A basic flyer template can be found [HERE](#)

### ✓ **Word of Mouth**

Tell everyone you know about the event!

### ✓ **Personal letters or e-mails**

Send an email out to all the MSF members in your region. Let Jenny know if you want to send an email announcement to the MSF database ([jenny@moebius syndrome.org](mailto:jenny@moebius syndrome.org))

Also send the info to friends, family, influential leaders, town officials, local physicians, and others.

### ✓ **Social Media**

Send the info to Jenny ( [jenny@moebius syndrome.org](mailto:jenny@moebius syndrome.org)) and she can help you post it to the MSF social media networks.

### ✓ **Community Calendars**

Many media outlets provide an online community calendar for local events. Submit your information early!

Also send information to local churches and organizations to include in their newsletters/bulletins.

### ✓ **Talk with your doctors**

Tell your doctor (or your child's pediatrician) about your event and ask if you can hang flyers in their office.

## How to Order from the MSF Store

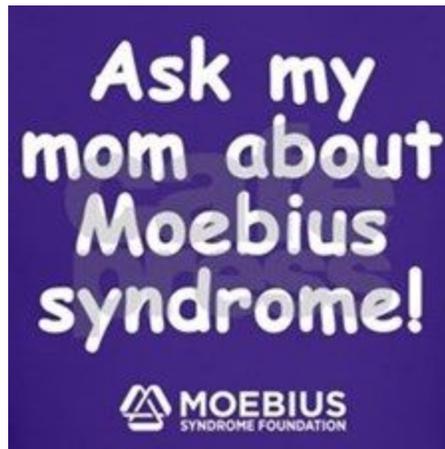
All purchases help to support MSF's mission by funding awareness, education, advocacy and research for Moebius syndrome. These items make great give-aways at your event!

To purchase online visit

[moebius syndrome.org/support-resources/store/](http://moebius syndrome.org/support-resources/store/)

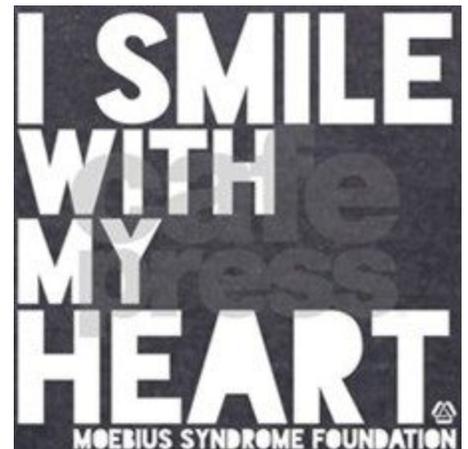


**MIGHTY**  
=care  
**MOEBIUS**



Ask my  
mom about  
Moebius  
syndrome!

 **MOEBIUS**  
SYNDROME FOUNDATION



**I SMILE**  
**WITH**  
**MY**  
**HEART**

**MOEBIUS SYNDROME FOUNDATION**

### GIVEAWAYS

With adequate notice, the foundation staff can send you some giveaways and foundation marketing materials for your event. Contact ([jenny@moebius syndrome.org](mailto:jenny@moebius syndrome.org))

### EVENT SPECIFIC T-SHIRT

If you would like to design a T-shirt with the Moebius Syndrome Foundation Logo. Please submit the design and event details to ( [jenny@moebius syndrome.org](mailto:jenny@moebius syndrome.org)) atleast 90 days prior to your event for approval!

## Fundraising at Your Event

The Moebius Syndrome Foundation is a 501(c)(3) organization and is dedicated to improving the lives of those living with Moebius syndrome. Donations help us achieve our mission, specifically:

- Sending packets of information to all new members. Babies and toddlers receive a Moebius Syndrome Foundation t-shirt!
- Providing educational scholarships to those attending college and graduate programs.
- Supporting scientific research into the causes and treatments for Moebius syndrome.
- Sending newsletters to all of our members.
- Funding the Moebius Syndrome Foundation Conference - a truly amazing event which is held every two years.
- Providing financial assistance to families in need through our conference scholarship fund.

Ideas for incorporating a fundraising component into your event. This can be:

- An admission charge for each attendee/family attending
- Selling raffle tickets for prizes (jewelry, books, tshirts, items donated from local businesses, etc.)
- Sponsors - for example at the Mighty Moebius Walk & 5K, each walker will raise funds (through GoFundMe or Fundraise.com)
- Local businesses providing donations/sponsorships

Checks can be made out to "Moebius Syndrome Foundation. Online donations are appreciated and are currently being accepted at:  
<http://moebius syndrome.org/get-involved/donate/>.

**All money collected at your event should be sent to P.O. Box 147, Pilot Grove, MO 65276. Make sure we know which event it is coming from.**

## Working with Local Media



Working with the local media can increase the success of your event. It also increases awareness of Moebius syndrome and educates local families about what resources and support services are available to them.

Media relations may seem like a daunting task, but here are some tips & tools to get you started!



### 1. Start with a good media list

Include your daily newspaper, community newspapers, as well as television and radio stations. In choosing whom to approach, it is important to consider who is likely to cover health issues. Most of the time, you want to contact the health/science reporter. This is a great resource for building media lists:

[www.mondotimes.com](http://www.mondotimes.com) and it's FREE as long as you find the contacts yourself.

### 2. Prepare talking points

Before calling a reporter, you want to know what you're going to say. Come up with 2 or 3 talking points that describe the event and why you are raising awareness of Moebius syndrome. Your chances of local coverage are greatly increased if there is a local adult or family who is willing to share their story with the media.

### 3. Introduce yourself

Once you have a media list and talking points, start reaching out to the reporters and introduce yourself. Let them know that you are planning an event and ask how they like to receive information, and invite them to join you!

### 4. Write a Press Release

A press release provides reporters with the basics they need to develop a news story. There is a sample press release and cover "pitch" letter included in this toolkit – just fill in your information and it's ready to send!

### 5. Write a Media Alert

A media alert (sample on page 15) gives reporters brief answers to the "who, what, when, where, and why" of your event. Use this tool to get your information into local community calendars as well as a last-minute reminder to get media to your event.

### 6. Don't be afraid to ask for coverage

While you don't want to be too pushy, it's not wrong to ask for media coverage. Let reporters know that Moebius syndrome is a rare but important story.

### 7. Write a Letter to the Editor

You want to keep letters short & sweet, under 200 words is best.

## Finding Local Media Contacts

Building a media list does not have to take a long time but you want to include as much information as you can find!

- Start by writing a list of all the surrounding communities/towns you think may be interested in attending your event.
- Then make a list of all the newspapers, TV stations and radio stations that cover those communities.
- Visit [www.mondotimes.com](http://www.mondotimes.com). This resource will help you expand that list (you'll find media outlets you never even heard of!) as well as provide you with a link to each media outlet. You want to include daily newspapers, community/weekly newspapers, television, and radio stations.
- Visit each of the media Websites and look for contact information. You will be looking for reporters who cover local news, health, or lifestyle stories. This may take awhile, as some media outlets don't make it easy to contact them! If you can't find the reporter's contact information online, call the main phone number, tell them about your event, and ask them to help guide you to the right person.
- **Tip:** Collect phone, email and fax numbers. You never know how people will want to be contacted and you won't want to go back to find the information!
- **Tip:** Read your local paper to figure out which reporter may be interested in covering your event. And use online searches to find contact information that may be hard to find!

## Sample Event Timeline

### Six week before the event:

- Confirm the event location and make any payments/deposits.
- This is the time you want to build your media list and start reaching out to reporters.
- Will your local radio station run a free PSA?

### Four weeks before the event:

- Finalize flyer and send to the Foundation for approval. Hang them up all over town.
- If there are any VIPs that you want to attend, invite them now. Send a personal email invitation, not a press release. You want to give them plenty of notice!
- Order any supplies you might need at the event. Save your receipts!

### Two weeks before the event:

- Send out your press release to the local media.
- Make sure there are enough volunteers that will be working at the event.

### Week of the event:

- Send the media alert to all media outlets. This serves as a final reminder!
- Make a sign-in sheet for your event. A template will be shared with you.
- Post on your own social media networks - ask the Foundation to do so as well.

### Day of the event:

- Have fun!!!
- Take Pictures!!!

### After the event:

- Send thank you emails to all attendees.

## Sample Media Alert

FOR IMMEDIATE RELEASE  
DATE

Media Contact:  
[Add your name and contact information]

### [Your City/State/Region] Hosts First Annual Mighty Moebius Walk & 5K

**Who:** More than [Approximate number of attendees] Moebius Syndrome Foundation families from across [State] gather together to participate in the First Annual Mighty Moebius Walk & 5K.

**What:** [Describe your event]

**When:** [Date and time]

**Where:** [Location of the event. Be as specific as possible here]

**For more information...[Do people have to register? Describe how they should register. If there will be refreshments, please include that here.]**

Moebius syndrome is a non-progressive craniofacial/neurological disorder that manifests itself primarily in facial paralysis. Individuals with Moebius syndrome cannot smile or frown, and do not have lateral eye movements.

[Name of the event] is being held in conjunction with the Moebius Syndrome Foundation, the Home for the Moebius Community™. Founded in 1994, the Moebius Syndrome Foundation provides information and support to individuals with Moebius syndrome and their families. The Foundation promotes greater awareness and understanding of Moebius syndrome and advocates for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions. For more information on Moebius syndrome, the Foundation or becoming a member, please visit [www.moebius syndrome.org](http://www.moebius syndrome.org).

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## Sample Press Release

FOR IMMEDIATE RELEASE  
DATE

Media Contact:  
[Add your name and contact information]

### **[Your City/State/Region] Moebius Syndrome Families Gather Together**

[City, State] – On DAY, DATE, community members from across [City] will be gathering at [Name of Event] at [Location of the event].

**[Use this paragraph to describe the details of your event – special activities planned, times, who’s invited/open to all.]**

Moebius syndrome is a nonprogressive craniofacial/neurological disorder that manifests itself primarily in facial paralysis. Individuals with Moebius syndrome cannot smile or frown, and do not have lateral eye movements. The causes of Moebius syndrome are unknown, although the condition probably results from a combination of environmental and genetic factors. Researchers estimate that the condition affects 2 to 20 per 1 million people.

**[Describe how people should register. If there will be refreshments, please include that here.]**

For more information, please [Website/phone?]

[Name of the event] is being held in conjunction with the Moebius Syndrome Foundation, the Home for the Moebius Community™. Founded in 1994, the Moebius Syndrome Foundation provides information and support to individuals with Moebius syndrome and their families. The Foundation promotes greater awareness and understanding of Moebius syndrome and advocates for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions. For more information on Moebius syndrome, the Foundation or becoming a member, please visit [www.moebiussyndrome.org](http://www.moebiussyndrome.org).

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## Sample Letter to the Editor

Dear Editor:

**[Please insert your personal story/connection]** - i.e. "I am a Moebius Mom. Which means that I have a wonderful, intelligent, beautiful child, who happens to have Moebius syndrome."

**Moebius syndrome is a rare disorder that affects both young children and adults and it is my hope that I can educate teachers, classmates, friends and colleagues about Moebius syndrome.** Individuals with Moebius syndrome cannot smile or frown, and do not have lateral eye movements. Many individuals have skeletal involvement with limb abnormalities, respiratory problems, speech and swallowing disorders and sleep disorders.

Join us on DATE and meet some of the Moebius families in our community.

Signed by,

Name  
Address  
Phone Number

## **What to do after your event**

**First, take a few days and RELAX!!  
Congratulations on planning a successful event!!**

### **Let MSF know how your event went**

Please reach out to Roland and let him know how your event went:

- How many attendees did you have?
- How much money did you raise?
- Was it a success? Why?
- What would you do differently next time?
- Did MSF provide enough support to you and your planning committee? What can we do differently next time?
- Did you receive any media coverage? Send us the links so we can promote on the MSF Website!

### **Follow-up to send MSF:**

1. Answers to the questions above.
2. Please share your photos with us! We are excited to see your event in action.
3. Please share any participant contact information that you received during the event. You can send your sign in sheet directly to Jenny. ( [Jenny@moebiussyndrome.org](mailto:Jenny@moebiussyndrome.org) )
4. Send any money that you raised at the event. You can mail that to: P.O. Box 147, Pilot Grove, MO 65276. All checks should be made out to: "Moebius Syndrome Foundation."
5. Remember to track your expenses from the event.

***Thank you for !!  
We appreciate your time & dedication.***

***Contact us with any questions you may have - we want to support you in any way we can!***