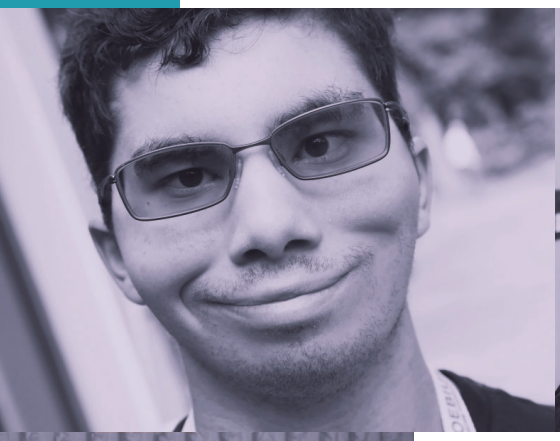
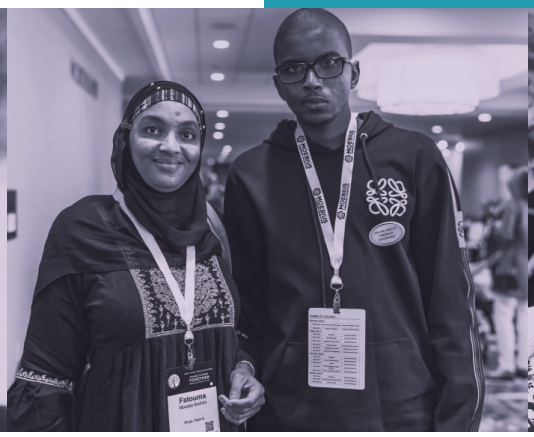
2025 CONFERENCE - SALT LAKE CITY

30th Anniversary

MOEBIUS SYNDROME FOUNDATION

July 24-27, 2025



"Celebrating 30 Years of Community"






2025 Conference Information

Welcome

We Hope You Can Join Us!

You are invited to join us for the 17th Moebius Syndrome Foundation Conference in Salt Lake City, UT, from **Thursday, July 24 to Sunday, July 27, 2025!**

The conference offers a unique opportunity to connect, engage, and learn from others living with Moebius syndrome and similar facial differences. Whether it's your first time attending or you're a seasoned participant, there will be plenty of experiences and activities to enjoy.

Set against the stunning backdrop of the Rocky Mountains, Salt Lake City is a vibrant and dynamic location with something for everyone.

Pioneer Day is an annual state holiday that happens on July 24 every year. City-wide celebrations in Salt Lake City will include a parade, rodeo, fireworks, and family-friendly activities. Consider arriving early to take advantage of this unique celebration!

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The conference will kick off on Thursday, July 24 with fun and festive receptions for first-time and return conference attendees. For many individuals and families, the Moebius Syndrome Foundation conferences have been a life-changing experience. It's a place where our incredible community comes together in a safe space to connect, learn, and form friendships that last a lifetime.

We hope to see you in Salt Lake City!

Warmly,

Rebecca Maher
Rebecca Maher
President

Jenny Whitman
Jenny Whitman
Executive Director

Molly Goldsmith
Molly Goldsmith
Conference and Events Manager

30th Anniversary MOEBIUS SYNDROME FOUNDATION 1994–2024



Hotel And Travel Information



HOTEL DISCOUNT

Web: **https://bit.ly/MSF25ConHotel**
Or, scan QR code:
Phone: (888) 627-8152

Sleeping room rates are at a discounted $175 per night.* To get this discounted rate, you must book within the Moebius Syndrome Foundation block using the phone number or website link listed above. Room discount is valid for July 21-30, 2025, so feel free to extend your trip and enjoy Salt Lake City before or after the conference. Make your reservations early, as certain nights tend to fill quickly. **The last date to reserve at the discounted rate is July 1, 2025,** or whenever the room block fills up.

*Hotel room rates are subject to a 13.82% state and local tax, and a 2% county fee.

The Sheraton Salt Lake is a spacious hotel in the heart of downtown Salt Lake City. Check out all the wonderful amenities here:
https://bit.ly/SheratonSLC

Please note the hotel is dog-friendly, not only for service dogs but also for everyday pets.

The hotel has ADA rooms available. Please request an ADA room when you make your reservation if this accommodation is needed.

TRAVEL PLANS

For your travel planning, the First-Time Attendee Reception will begin at 4:00 PM on Thursday and the Welcome Reception begins at 4:45 PM. The conference will end around noon on Sunday. The optional excursion to the Olympic Park on Sunday afternoon will begin after the conference closing and will take approximately 4-5 hours. **More detailed information will be available when registration opens on February 1.**

AIRLINE DISCOUNTS

The Moebius Syndrome Foundation has discounts with Delta Air Lines and United Airlines for the conference.
Scan the QR codes to book a flight!

AIRPORT AND TRANSPORTATION

Salt Lake City International Airport is the closest airport to the conference hotel.
https://slcairport.com/

Conference attendees can take advantage of a special rate of **$10 per day for parking** in the hotel lot. Please note that parking is available on a first-come, first-served basis.

The airport is located approximately 8 miles from the hotel. There are a variety of transportation options available at the airport.

- **Light Rail - Green Line (TRAX):** 20-25 minutes to downtown, $2.50 per person (one-way)
- **Ride-Sharing Services (Uber/Lyft):** 10-15 minutes to downtown, depending on traffic. Typically between $15 and $25
- **Car Rental:** all major car rental companies are available
- **Shared Shuttle Services:** Various shuttle services operate from SLC to downtown hotels. These will require prior reservations. 15-30 minutes to downtown. Around $10-$20 per person.
- **Rideshare:** a rideshare list for those looking to travel together will be available in the event app when registration opens.

Featured Sessions

Keynote Speakers



Rick Guidotti
Founder and Director, Positive Exposure

Rick is the founder and director of POSITIVE EXPOSURE which has significantly impacted the field of human rights, mental health, medicine, and education by providing new opportunities to see each individual as a human being and valued member of our society. Rick's address will focus on the spirit of difference; highlighting the beauty and richness of human diversity through photographs.



Steven and Leah Maldonado
Not Nervous: Fully Wired

Leah and Steven will discuss navigating challenges through building confidence and courage in the midst of life's trials. This dynamic husband-and-wife duo, both living with Moebius syndrome, will share their compelling perspective and passion for empowering others with Moebius to thrive in every aspect of life.



Susannah Fox
Author, *Rebel Health*

Susannah Fox's recent book, *Rebel Health: A Field Guide to the Patient-Led Revolution in Medical Care* (MIT Press, 2024), showcases how consumers are building up our collective capacity for better health and how the healthcare ecosystem can leverage the power of connection with those they serve. Susannah's presentation will focus on expert networks of patients, survivors, and caregivers who are inventing new ways to pursue health.

Other Special Sessions



A Good Life and Successful Employment: Tips and Tools *by Sean Roy*
Sean, the Chief Innovation and Training Officer for TransCen Inc., provides training to employment professionals and schools, leading to improved success for individuals with disabilities who are transitioning from school into the workforce and community. This session will be for anyone interested in gaining practical skills to maximize opportunities in both personal and professional settings.



Building Resilience and Coping Skills *by Leah Stock-Landis, PhD*
The facial difference community has made groundbreaking strides in advocating for acceptance and accurate representation in the media and broader culture, yet we remain vulnerable to the ignorance of others. This session will explore building resilience, handling questions and comments effectively, and the importance of parent/caregiver self-care.

Break Out Sessions By Track

MEDICAL

Smile Surgery and Moebius Syndrome
- Gregory Borschel, MD

Innovations in Facial Reanimation Surgery
- Patrick J. Byrne, MD, MBA

Common Pulmonary Symptoms in Moebius Syndrome
- Hollis Chaney, MD

Neuromuscular Retraining for Facial Paralysis
- Jackie Diels, OT

Orthopedic Manifestations of Moebius Syndrome
- Philip McClure, MD

Through Their Eyes: Navigating Life with Limited Eyelid Closure in Moebius Syndrome
- Chilando Mulenga

Dental Concerns and Sleep Apnea/Snoring: Information relative to Moebius Syndrome
- Greg Osborne, DDS

Understanding the Unique Needs in Speech Development and Feeding of Children and Adults with Moebius Syndrome: A Guide for Families and Therapists
- Renee Roy Hill, MS, CCC/SLP

Everything You Want to Know About Smile Surgery
- Alison Snyder-Warwick, MD

Genetic Research Updates
- Bryn Webb, MD, Elizabeth Engle, MD & Ethylin Wang Jabs, MD

Postmortem Neuroradiology, Pathology, and Genetic Studies of Adults with Moebius Syndrome - Elizabeth Engle, MD & Matthew Rose, MD

Scientific Advisory Board Panel

LIFE RESOURCES/ ADVOCACY

Challenging Ableism Toward the Moebius Community
- Kathleen Bogart, PhD

Button Pop-Up: Moebius Advocacy DIY - Laura Berge

How to Plan and Execute a Successful Moebius Syndrome Foundation Event - Jan Fisher

Recharge Your Mind and Body: Self-Care Strategies for Everyday Life
- Julia Lavopa-Leahy

College to Career and Everything in Between
- Tara Lewis, PhD

Small Group Coaching Session: All Things College and Beyond
- Tara Lewis, PhD, Career Coach

Love Languages and Moebius Syndrome: Navigating Relationships with Heart
- Tina Michael

Navigating the Unknown: The Caregiver's Perspective on Moebius Syndrome
- Chilando Mulenga

A Good Life and Successful Employment: Tips and Tools
- Sean Roy

Moebius and Milestones: Achieving Joy as a Husband, Father, Attorney and Judge
- Scott Wales, JD

MENTAL HEALTH

Roundtable Discussion: Aging with Moebius
- Amanda Hemmesch, PhD & Kathleen Bogart, PhD

Hope Through Grief
- Sunshine Zuniga





PARENTS

A Presentation for Parents of Children with Physical Limitations: Five Simple Responses to Manage Others' Well-Intentioned Nosiness
- Tricia Waiwood

Building Resilience and Coping Skills - Leah Stock-Landis, PhD

Basics of Sign Language
- Amanda Davis and Elizabeth Lawrence

ADULTS/TEENS

Art and Dance Class

Let's Roam® Scavenger Hunt for Teens

Teen Happy Hour

Pop-Up Choir - Jon Fisher

JUST FOR SESSIONS

Just for Moms
Just for Dads
Just for Women with Moebius
Just for Men with Moebius
Just for Adults with Moebius
Just for Teens with Moebius
Just for Children with Moebius
Just for LGBTQIA+ with Moebius
Just for Spanish speakers
Just for Grandparents
Just for Moms of Medically Complex Children
Just for Parents of Medically Complex Children

CHILDREN

SibShop® for siblings (age 8-12)
- KiOwana Phillips

Kids Dance, Art and Music Class

Just for Kids with Moebius (age 7-12)

Childcare Overview



DAYCARE

KiddieCorp will again serve as our on-site daycare provider for the Moebius Syndrome Foundation Conference. Kiddie Corp offers high-quality children's programs and youth services at conferences like ours. They have enjoyed a long-time partnership with the American Academy of Pediatrics, and have managed child care at Moebius Syndrome Foundation conferences for many years.

AGES AND RATIOS

The goal of KiddieCorp is to provide your children with a comfortable, safe and happy experience. The staff to child ratios are high to ensure that every child feels special (1:2 for children ages 6-11 months old; 1:3 for children ages 1-2 years old; 1:5 for children ages 3-5 years old and 1:7 for children ages 6-12 years old).

CHILDREN'S PROGRAM

(6 MONTHS – 3 YEARS)

Children ages 6 months – 3 years will have attentive and experienced people caring for them in a safe and bright environment. Cribs, highchairs, snacks, and play activities will be provided.

KID CAMP

(4 YEARS - 7 YEARS) (8 YEARS – 12 YEARS)

Children enrolled in the Kid Camp will have a full day of planned activities in a safe environment, watched over by experienced and trained caretakers. Some of the planned activities include the following:

- Arts and crafts
- Games, books and entertainment
- Music and singing
- Body movement activities
- Snacks (lunch is eaten with families)

PRICING

There is a $45 charge per child for conference child care, with a family maximum of $135. This includes Friday, Saturday, and Sunday during conference hours. Child care must be paid in advance to KiddieCorp through their online registration system. Snacks and beverages will be provided, although children must be picked up by their parents at mealtimes and then returned to the childcare rooms.

REGISTRATION

A link to register for childcare will become available on February 1 when conference registration opens. **Please note that childcare availability is limited, so register early if this is something you want to take advantage of.**



SIBSHOP®

Sibshop is a fun and interactive two hour program designed for siblings, ages 8-12 years, of children with disabilities. Sibshops provide siblings with peer support, information, and a safe space to talk about how it feels to have a sibling with different abilities and how to navigate certain situations. The session will include interactive activities and games to help spark discussion. Advance registration is required to participate.

Special Events

FIRST-TIME ATTENDEES RECEPTION
Thursday, July 24

We want to connect with all first-time attendees and personally welcome you to the conference! Join members of the Moebius Syndrome Foundation Board of Directors, Scientific Advisory Board, and staff at a special reception on Thursday at 4:00 PM. Light refreshments will be provided.

GENERAL WELCOME RECEPTION
Thursday, July 24

All attendees are invited to the General Conference Welcome Reception on Thursday from 4:45 PM - 6:30 PM to reconnect with old friends, meet new ones, and kick off the conference! Refreshments and fun activities will be provided.



MOMS NIGHT OUT
Friday, July 25

Moms of children with Moebius syndrome are invited to gather without kids on Friday, July 25, from 8:30 to 10:30 PM at the hotel bar.



FAMILY POOL SOCIAL
Friday, July 25

Following a day full of inspiring and fun sessions, come hang out by the pool for a relaxing evening with fellow attendees. Whether attending the conference with loved ones or flying solo, this is the perfect chance to connect, kick back, and relax. The MSF will provide poolside desserts, so don't miss out!



ADULTS AND OLDER TEENS NIGHT OUT
Friday, July 25

Attention all adults with Moebius and teens ages 16+ with Moebius - this event is especially for you! Join in the fun at Bad Caddy Golf for simulators featuring golf, soccer, baseball, football, hockey and more. You'll have a semi-private room with comfy seating and plenty of space to hang out. Pizza, wings and cheesy bread will be provided by the MSF, and individuals can purchase beverages of their choice.



SATURDAY NIGHT CELEBRATION
Saturday, July 26

Get ready for an evening that is considered one of the highlights of the conference. You're invited to join us for a special dinner, awards ceremony, inspiring talent show, and end the evening on the dance floor showing off your best moves. This is a family friendly event from start to finish, and you won't want to miss it!



OLYMPIC PARK OUTING
Sunday, July 27

Join us on Sunday afternoon for an optional excursion to the Olympic Park in Park City, UT, home of the 2002 Winter Olympics. There are two different museums on-site that are full of rich history about the Olympics, walking trails, food options, tours of the sprawling grounds, and an option to buy a pass for hours of unlimited extreme Olympic sports!

Funding Your Way To The Conference

Attending the Moebius Syndrome Foundation Conference can present financial challenges for some individuals and families. Below are some ideas to help make attending more affordable.

MOEBIUS SYNDROME FOUNDATION SCHOLARSHIPS

The Moebius Syndrome Foundation is excited to offer four scholarship options for the 2025 conference.

First-time Attendee Scholarship: A limited number of scholarships will be awarded in the amounts of up to US $800 for adult individuals with Moebius, and $1,000 for families. There must be a financial need to apply. Either the applicant or one person in the family must have Moebius syndrome.



Financial Need Scholarship: A limited number of scholarships will be awarded in the amounts of up to US $800 for adult individuals with Moebius, and $1,000 for families. Applicants must not have received a conference scholarship in 2023, and there must be a financial need to be eligible. Either the applicant or one person in the family must have Moebius syndrome.

Hylton Family International Scholarship: For our international members, the Hylton Family International Scholarship will award three individuals or families with $500 scholarships. International applicants may also request that they be considered for the other scholarship opportunities so those funds can be combined. Applicants must not have received a conference scholarship in 2023, and there must be a financial need to be eligible. Either the applicant or one person in the family must have Moebius syndrome.

Alice Profumo Goeldner Memorial Scholarship: Up to five $1,000 scholarships will be awarded to international members. International applicants may also request that they be considered for the other scholarship opportunities so those funds can be combined. Applicants must not have received a conference scholarship in 2023, and there must be a financial need to be eligible. Either the applicant or one person in the family must have Moebius syndrome.

The scholarship applications will open on February 1, 2025, and close on March 15, 2025. Additional applications may be accepted after March 15, based on scholarship availability.

Please note that scholarship funds that are awarded are first used to cover the costs of registration and childcare services (if applicable). Then any remaining balance will be issued as a check that can be picked up when the awardee arrives at the conference, or receive payment through PayPal. We are not able to issue payments in advance.

STATE FUNDING ASSISTANCE FOR CONFERENCES

You may qualify for state funding to subsidize the Moebius Syndrome Foundation Conference expenses. Most states have funds available for families attending educational meetings or conferences through the State Department of Developmental Disabilities (names vary). Check with the agencies in your state to see if you qualify. You can also check with the National Association of Councils on Developmental Disabilities at 202-506-5813 or **www.nacdd.org**, to locate the department in your state.

LOCAL ORGANIZATIONS

Check with local organizations such as Lions, Rotary, and Kiwanis. Ask your doctors, social workers, clinics and therapists if they can put you in touch with any organizations that provide financial assistance to attend conferences with evaluation opportunities. In some states, The Arc offers financial assistance to attend conferences. Locate your local or state organization at **www.thearc.org**.

Additional Opportunities



SWEEPSTAKES DONATIONS NEEDED

Bring a taste of your hometown, state, or country to our conference by donating a unique item for our sweepstakes contest! Think local foods, sports memorabilia, or handcrafted items. Gift cards and event tickets are also really popular. These items can be something you create, or things you purchase or secure as a donation from a local business. Your contribution will be featured as a prize in our sweepstakes, with all proceeds going toward offsetting conference costs. If you plan to donate an item, please let us know on your registration form, or contact us at conference@moebiussyndrome.org. When you arrive, drop off your donation at the designated area near the registration desk on Thursday or Friday. Receipts for in-kind donations are available upon request. Attendees aged 21+ will receive one free entry into the sweepstakes, with the option to purchase additional entries for even more chances to win.

Important Note: Due to Utah law, alcohol cannot be included in any prizes.



EXHIBITORS

Being an exhibitor enables businesses and individuals to showcase products and services to the Moebius community. Do you have a business with products that benefit individuals and families affected by Moebius syndrome? Do you sell crafts, books, or represent a company that sells items that would benefit our attendees? Please consider being a conference exhibitor to share your products and services with attendees.

CONFERENCE SPONSORSHIPS

Sponsorships are critical to maintain lower registration rates for the conference! Do you know an organization, company, or individual that may be interested in sponsoring the Moebius Syndrome Foundation 2025 Conference? There are multiple sponsorship levels to choose from.

Exhibitor and sponsorship information is available at **https://bit.ly/MSFCon25Sponsor**

BUTTON POP-UP: MOEBIUS ADVOCACY DIY

Show your spirit by creating a Moebius Awareness Button. You can use one of the provided designs or decorate one of your own. We will assist you with the button press to make a creation to keep and take home with you. Children should be accompanied by an adult, and every person is welcome to create one button. This creation station will be in the exhibitor hall during the conference. Thanks to Laura Berge for this exciting new opportunity!

T-SHIRTS

Conference shirts will be sold on the MSF online store from February 1 - June 25. Shirts will be mailed directly to your home. Limited sizes and quantities of adults and youth t-shirts will be sold at the conference.



Scan the QR code to order!

Adult tee: $21
Adult tank: $24
Women's slim fit: $22
Crewneck sweatshirt: $30
Youth tee: $18

Discussions with Specialists



Complimentary evaluations for adults and children with Moebius syndrome and their families are offered at the conference. This year, we will also offer career coaching! More detailed information about signing up for appointments will be available when conference registration opens on February 1. The appointments fill up quickly, so we recommend registering early.

MEDICAL SPECIALIST

Smile Surgery Evaluations
by Gregory Borschel, MD

15-minute appointments for children aged 4 and over. 1-hour group meeting for families with children aged 0-3

Pulmonary Evaluations for Children and Adults *by Hollis Chaney, MD*

30-minute appointments to discuss any pulmonary issues including COPD, asthma, aspiration, sleep issues, oxygen and ventilators.

Neuromuscular Retraining for Facial Paralysis *by Jacqueline Diels, OT*

30-minute appointments to discuss this non-surgical approach to the treatment of facial paralysis. For ages 10+.

Path to Better Sleep: Apnea Screening and Guidance
by Gregory A. Osborne, DDS, FADI

30-minute evaluations for individuals aged 3 and older. These assessments will include oral evaluations and questions designed to screen for obstructive sleep apnea.

Speech & Feeding Evaluations for Children and Adults with Moebius Syndrome *by Renee Hill MS, CCC/SLP*

45-minute appointments.
Evaluations of both speech clarity and feeding skills for children and adults.

Orthopedic Evaluations
by Philip McClure, MD

20-minute appointments, for any age.
Discussion and evaluation of orthopedic concerns and recommendations for further evaluation or treatment.

Genetic Research *by Elizabeth Engle, MD, Ethylin Wang Jabs, MD, Bryn Webb, MD and Brenda Barry, MS, CGC*

Genetic research screening and genetic testing will be available on Friday during the conference. Much more detailed information will be available when registration opens.

CAREER COACHING

Employment Coaching for Success
by Sean Roy

Chief Innovation and Training Officer for TransCen Inc. provides training to employment professionals and schools, leading to improved success for individuals with disabilities entering the workforce. Sean will offer eight 45-minute individual coaching sessions focused on employment, including an analysis of strengths and concrete action steps to be taken.

Small Group Coaching Session: All Things College and Beyond
by Dr. Tara Lewis, Career Coach

Opportunity for participants to discuss anything college-related and beyond, including successes, advice, challenges, and questions. Tara, a student success specialist with over 20 years in higher education and 7 years of career coaching, will provide guidance to the group.

Registration

REGISTRATION FEES

Registration fees include attendance at all conference sessions, materials, and activities (except those noted with an additional fee).

Meals included are:

- Thursday Welcome Reception (light refreshments)
- Friday breakfast, lunch, and afternoon coffee break
- Saturday breakfast, lunch, afternoon coffee break and dinner
- Sunday breakfast and mid-morning coffee break

Guest	Early Bird (2/1-3/15)	Standard (3/16-7/2)
Individuals with Moebius	$50	$50
Adult (non-Moebius)	$290	$360
Teens 13-17 (non-Moebius)	$235	$300
Children 3-12 (non-Moebius)	$150	$210
Children 0-2 (non-Moebius)	Free	Free
Tube Fed Individuals	$0	$0

REGISTER ONLINE!

https://bit.ly/MSFCon25Registration



REGISTRATION OPENS

Registration will open online on February 1st and a credit card is required for payment. If you need assistance, call us at 844-663-2487, ext 704 and we can register you over the phone. **Early bird registration ends on March 15, 2025.**

CANCELLATION POLICY

Cancellations occurring on or before June 19, 2025, will be fully refunded, less a small administrative fee. No refunds will be given after June 20, 2025.

EVENT APP

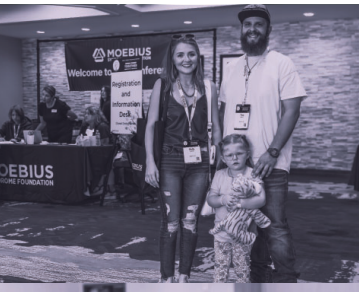
We are pleased to announce that we will continue using Whova for the 2025 conference. The conference agenda, speaker information, hotel map, surveys, scheduling 1:1 consultations and the ability to locate friends and chat with them will all be available in the app. You will also have the opportunity again to share your conference pictures with attendees. Whova will be key to managing your schedule and staying connected at the conference.

Download Whova and take your event mobile! Whova is available from the App Store and Google Play. You can sign up for the app using your email address or social media account. Search for Moebius Syndrome Foundation Conference 2025, and connect!

Moebius Syndrome Foundation
The Home for the Moebius Community
1312 17th Street, #976, Denver, CO 80202

conference@moebiussyndrome.org
844-MOEBIUS, ext 704

Follow Us









2025 CONFERENCE - SALT LAKE CITY

Important Dates

Moebius Syndrome Foundation Conference
July 24 - 27, 2025

Early Registration: February 1 - March 15, 2025
Standard Registration: March 16 - July 26, 2025
Financial Need Scholarship Application Deadline: March 15, 2025
Hotel Room Reservation Deadline: July 1, 2025

REGISTRATION WILL OPEN ON FEBRUARY 1, 2025
https://bit.ly/MSFCon25Registration

See you in Salt Lake City!







