

MOEBIUS SYNDROME FOUNDATION CONFERENCE

GROWING STRONGER TOGETHER

MINNEAPOLIS, MN JULY 20–23, 2023

2023 CONFERENCE INFORMATION

WELCOME

YOU ARE INVITED!

The 16th Moebius Syndrome Foundation Conference is being held in Minneapolis, MN on Thursday, July 20 - Sunday, July 23, 2023 and you are invited!

We are delighted to gather again this summer after such a fantastic conference in Atlanta last year. We received great feedback following the last conference and we've adjusted the agenda to include more structured social opportunities, physically active breakout sessions for kids, additional social sessions for teens, a lunch with seating by geographic regions, a new track for parents, new "Just For" sessions, and new medical presentations. We also changed the ending excursion to Sunday afternoon to enable more people to attend.

The conference is an amazing opportunity to meet, socialize and learn from others whose lives are also affected by Moebius syndrome and similar facial differences. Whether you are a first-time attendee or someone who has attended many conferences, there will be plenty for you to enjoy! Plus, Minnesota, the land of 10,000 lakes, will be a beautiful location to visit in July.

The Moebius Syndrome Foundation Conference has been life-changing for many individuals and families. The event brings together our incredible community and forges friendships that last a lifetime.

Join us to kick off the conference on Thursday, July 20 at the Welcome Reception!

See you in Minneapolis!

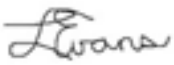
Regards,



Jacob Licht
President, Moebius Syndrome Foundation



Jenny Whitman
Executive Director, Moebius Syndrome Foundation



Loralynne Evans
Senior Marketing and Events Manager, Moebius Syndrome Foundation

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GROWING STRONGER TOGETHER

Cover photos provided by Positive Exposure

conference@moebiussyndrome.org | 844-663-2487 x704

HOTEL INFORMATION



MINNEAPOLIS MARRIOTT NORTHWEST

7025 Northland Dr. North
Brooklyn Park, MN 55428

To Book Discounted Hotel Reservations

Phone: 1-877-303-1681

Web: **tinyurl.com/MSF23ConHotel**
Or, scan code.

Sleeping room rates are at a **discounted $154 per night***. To get this discounted rate you must book within the Moebius Syndrome Foundation block using either the phone number or website listed above. This discount is valid for July 18-26, 2023, so feel free to extend your trip and enjoy Minneapolis before or after the conference! Make your reservations early! Last date to reserve at the discounted rate is **June 29, 2023**, or whenever the room block fills up.

The Minneapolis Marriott Northwest is a spacious all-suite hotel located in Brooklyn Park, a suburb northwest of downtown Minneapolis. There is easy access to a variety of restaurants, shopping and parks within 5 miles of the hotel.

**Hotel room rates are subject to a 10.525% state and local tax.*

ACCESSIBILITY

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

In addition, the hotel has a limited number of King/Double adjoining rooms available. To confirm adjoining rooms for your family, please email **conference@moebiussyndrome.org** for assistance.

HOTEL PARKING

All parking at the conference hotel is complimentary.

TRAVEL PLANS

For your travel planning, the First-Time Attendee Reception will begin at 4 pm on Thursday and the Welcome Reception begins at 4:45 pm. The conference will end at noon on Sunday. The optional excursion to the Twins baseball game on Sunday will be at 12:30-5:30 pm.

AIRLINE DISCOUNT

Delta Air Lines is pleased to offer special discounts for the Moebius Syndrome Foundation. You may book discounted flights to Minneapolis for the conference at **https://tinyurl.com/MSFCon23Delta** or call Delta Meeting Network® at 800-328-1111* on Monday–Friday, 7:00 am – 7:30 pm (CST) and refer to Meeting Event Code: NY24F

**Please note there is not a service fee for reservations booked and ticketed via our 800 reservation number.*

AIRPORT AND TRANSPORTATION

The Minneapolis – Saint Paul International Airport (MSP) is the closest airport to the conference location. **https://www.mspairport.com**

The airport is located 25 miles from the hotel. Below are a variety of transportation options available at the airport.

- Local Taxi ($80+tip)
- Uber/Lyft/other ride share services ($55+tip)
- Super Shuttle – Large private or shared vans to/from the airport. Great for large families or groups. Reservation required. **https://booking.supershuttle.com**
- Car Rental – all major car rental companies are available
- A rideshare list will be available in the event app when registration opens.



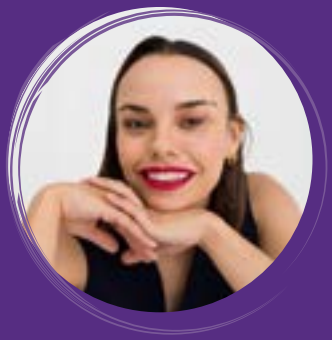
FEATURED SESSIONS

Keynote Speakers

In the spirit of "Growing Stronger Together", the Moebius Syndrome Foundation is excited to welcome members of our global partner organizations to speak about how their organizations serve the craniofacial community, resources they provide, and how our organizations work together to increase awareness and advocacy for facial differences.



Erica Klauber
Executive Director, Children's Craniofacial Association



Phyllida Swift
Chief Executive Officer, Face Equality International



Dina Zuckerberg
Director of Family Programs, myFace

OTHER SPECIAL SESSIONS



Engaging Families in the Employment Process

by Sean Roy

Sean Roy is the Chief Innovation and Training Officer for TransCen Inc. He provides training and technical assistance to states, employment professionals and schools, leading to improved success for individuals with disabilities who are transitioning from school into the workforce and life in the community. Sean will be leading a session for parents and caregivers on how to support the employment process of a teen or adult with Moebius syndrome.



Teen Communication Workshop

by Kathleen Bogart, PhD

Dr. Kathleen Bogart, Psychology Professor and fellow person with Moebius, will lead a fun and interactive workshop about communication skills for teens (13-17) with Moebius syndrome. Teens will get to know each other, share experiences, learn about communication, play games, and build confidence.

Mental Health First Aid for Parents

by Dwquita Nash

Just as CPR helps you assist an individual having a heart attack, Mental Health First Aid helps you assist a child or teen experiencing a mental health or substance use-related crisis. In the Mental Health First Aid session, you learn risk factors and warning signs for mental health and addiction concerns, strategies for how to help someone in both crisis and non-crisis situations, and where to turn for help.

BREAKOUT SESSIONS BY TRACKS

MEDICAL

Orthopedic Management by Philip McClure, MD

Aerodigestive and the Clinical Impacts for the Medically Complex Child by Arthur Beisang, MD

Blink, Hand and Smile Surgery by Gregory Borschel, MD

Speech and Swallowing Concerns in Moebius Syndrome: The Craniofacial SLP's Role by Graham Schenck, PhD, SLP

Beginning Your AAC Journey by Heather Prenovost, PRC-Saltillo

Neuromuscular Retraining for Facial Paralysis by Jackie Diels, OT

Speech and Feeding Issues by Renee Hill, MS, CC/SLP

Genetic Research Updates by Elizabeth Engle, MD; Ethylin Wang Jabs, MD; and Bryn Webb, MD

Eye Basics for People with Moebius Syndrome by David Hunter, MD

Pulmonary Complications by Hollis Chaney, MD

Scientific Advisory Board Q&A Panel

Roundtable Discussion on Aging (age 50+) by Amanda Hemmesch, PhD



MENTAL HEALTH

Emotional Balance: How To Keep It and What To Do When You Are Struggling by by Leah Stock-Landis, PhD

The Power of Perception by Austin Halls

Building Self-Confidence Through Self-Compassion by Tara Lewis

Presentation of the Facial Differences Disclosure Study and the Sleep Study Findings by Kathleen Bogart, PhD

Music and Meditation by Jon Fisher

LIFE RESOURCES/ ADVOCACY

Healthy Habits for Adults and Teens by Paula Santana

Prepare Wisely: Estate Strategy Essentials by Leif Erickson, Thrivent Financial

ADA 101 and How To Be An Effective Advocate by Nicole Zeitler

Communication Skills for Job Searching and the Workplace by Tara Lewis

Engaging Families in the Employment Process by Sean Roy

YOUNG ADULTS/TEENS

Teen Communication Workshop by Kathleen Bogart, PhD

Adult/Teens Dance Class

Teen Movie and Afternoon Break

Sing Me a Story: Songwriting by Jon Fisher

Screen Addiction, Social Media and Mental Health by Rhonda Robert, PhD

Taking the Leap: Transitioning to Independent Living and Healthcare Self Management by Megan Menard, Michael Mendenhall and Mandy Weber

The Art of Journaling by Leah Richter-Maldonado

KIDS

"Twenties and Tweens": Ice Breaker Games and Activities (7-12 years old)

T-shirt Painting by Kat Borba

Obstacle Course by KiOwana Phillips

Just for Kids with Moebius

Healthy Habits for Kids by Paula Santana

Music Therapy (age 3-6)

Kids Dance Class (age 7-12)

SibShop for Brothers & Sisters (ages 8-12) by KiOwana Phillips and Destiny Bachman

Girl Talk: Building Confidence and Connection by Rebecca and Jessica Maher, Mandy Weber and Zayne Herron

Therapy Dog Visit

PARENTS

Mental Health First Aid by Dwquita Nash

Supporting Children and Teens with Moebius Syndrome, Autism, and Sensory Processing Needs by Rebekah Hudock, PhD, LP

A Dad's Perspective Panel by Hunter Herron, James Garvey, Ross Hunter and Jacob Licht

Driving with Moebius Syndrome by Steven Maldonado, KiOwana and Khaleb Phillips, and David Hunter, MD

Adventure is Out There: Navigating Travel with Children with Disabilities by Dani Doughty

Our Parenting Journey: Parents of Adults with Moebius Syndrome by David Baldridge, Jan Fisher, Angela Coakley, and Mary Kay Mendenhall



JUST FOR SESSIONS

Just for Moms

Just for Dads

Just for Women

Just for Men

Just for Parents of Medically Complex Children

Just for LGTBQ+

Just for Parents

Just for Adults with Moebius

Just for Young Men (ages 18-35)

Just for Spouses/Partners

Just for Grandparents

CHILD CARE 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 to conferences, like ours. They have enjoyed a long-time partnership with the American Academy of Pediatrics.

AGES AND RATIOS

Our goal 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 months through 11 months old; 1:3 for children ages 1 through 2 years old; 1:5 for children ages 3 through 5 years old and 1:7 for children ages 6 through 12 years old).

CHILDREN'S PROGRAM (6 MONTHS – 4 YEARS)

Children ages 6 months – 4 years will have attentive and experienced nannies caring for them in a safe and bright environment. Cribs, high chairs, snacks, and play activities will be provided.

KID CAMP (5 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 nannies. Some of the planned activities include the following:

- Arts and crafts
- Games and entertainment
- Music and singing
- Body movement activities
- Snacks (meals will be eaten with their 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 the Moebius Syndrome Foundation through the conference registration process. Children need to be signed up for child care both in the MSF conference registration and through KiddieCorp's website.

Snacks and beverages will be provided. Children must be picked up by their parents at mealtimes, and then returned to the child care rooms.

Childcare fills up quickly, so register early by filling out the form at:

https://www.jotform.com/KiddieCorp/msfkids

NOTE: If you need to register more than three children for childcare, please sign up the first three children when you register online. To sign up more children for child care, please contact us (**conference@moebiussyndrome.org**) and we will sign them up for you. It is very important to do this immediately as childcare will fill up quickly.



SIBSHOP

SibShop is an exciting 2-hour program just for siblings ages 8-12 years of children with special needs. The session will include interactive activities and games to help spark discussion. Registration in advance is required to participate.



SPECIAL EVENTS

FIRST-TIME ATTENDEES RECEPTION
Thursday, July 20

We want to connect with all the first-time attendees and personally welcome you to the conference! Join members of the Moebius Syndrome Foundation Board of Directors and Scientific Advisory Board at a special reception on Thursday afternoon. Refreshments will be provided.

WELCOME RECEPTION
Sponsored by Minneapolis NORTHWEST
Thursday, July 20

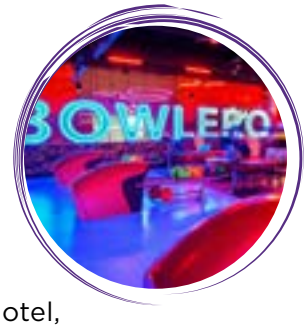
All attendees are invited to the Welcome Reception on Thursday late afternoon to reconnect with friends and kickoff the conference! Refreshments will be provided.



FRIDAY EVENING FAMILIES IN THE PARK
Friday, July 21

Attendees are invited to enjoy an evening outdoors at Elm Creek Park and Swim Pond with swimming in a manmade, chlorinated pond, large playground, sand volleyball, and dinner in a private picnic shelter. Transportation to/from the hotel, swimming pass, food and non-alcoholic beverages are all included. *Thanks to the generosity of our donors and sponsors, the Foundation can provide this excursion free of charge..*

TEENS AND ADULTS WITH MOEBIUS BOWLING
Friday, July 21



Teens and Adults with Moebius syndrome and spouses are invited to a fun evening of bowling, arcade games and socializing in the sports bar at Bowlero. Transportation to/from the hotel, 1.5 hours of bowling, shoe rental, pizza buffet and non-alcoholic beverages are all included. *Thanks to the generosity of our donors and sponsors, the Foundation can provide this excursion free of charge.*

MOMS NIGHT OUT
Friday, July 21

Moms of children with Moebius syndrome are invited to gather without kids on Friday, July 21 at 8:30-10:00 p.m. in the hotel bar area.



MOEBIUS HAS TALENT!
Saturday, July 22

Join us Saturday evening for dinner and a showcase of many talented members of the Moebius community. Each act should include at least one individual with Moebius syndrome and should be limited to three minutes. Material must be suitable for all ages. **Sign up by July 1, 2023 to participate.** Following the talent showcase we will have a family friendly 80's dance party for all attendees!

MINNESOTA TWINS BASEBALL GAME
Sunday, July 23



Take me out to the ballgame! Attend the Sunday afternoon baseball game between the Minnesota Twins and Chicago White Sox at Target Field, a very family-friendly ballpark. We will all sit together in the same section, and ADA seating is available. Transportation to/from the hotel and the game ticket are included. *This excursion will be an additional fee of $39 per person and must be purchased in advance with the conference registration.*

FUNDING YOUR WAY TO THE CONFERENCE

The Moebius Syndrome Foundation Conference can be financially difficult for some individuals and families. Ideas to consider for helping to finance the conference are below.

MOEBIUS SYNDROME FOUNDATION SCHOLARSHIPS

For 2023, we are excited to offer two scholarships for attendees with a financial need: **First-time Conference Attendee Scholarship** and **Financial Need Scholarship.**

A limited number of scholarships will be awarded up to $800 each to be used toward the conference registration, child care, and travel expenses. To be eligible for a scholarship, applicants must meet the following criteria:

- Either a First-time Conference Attendee OR currently experiencing a financial hardship.
- One person in the family must have Moebius syndrome.
- There must be a financial need for the scholarship.
- You were not awarded a scholarship for the 2022 conference.

The scholarship applications will open on February 1, 2023 and close on March 1, 2023. Scholarships will be awarded prior to the Early Bird discount deadline on March 15. Additional applications will be accepted after March 1 based on scholarship availability.

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 consultation opportunities.

In some states, The Arc offers financial assistance to attend conferences. The Arc in your state may offer financial assistance. Locate your local or state organization at **www.thearc.org**.

YOUR COMMUNITY

Some people have had bake sales, garage sales, and other personal fundraising activities to raise funds to attend the conference.

CROWDFUNDING

Others have started online requests using sites such as GoFundMe.com, Fundly and Give Forward.

TRANSPORTATION ASSISTANCE

You can check out medical transportation programs offered by some airlines, or the Mercy Medical Angels at **http://mercymedical.org**.

ADDITIONAL OPPORTUNITIES

RAFFLE DONATIONS NEEDED

Consider bringing the flavor of your hometown, state or country to our conference. Ideas include local foods, sport items or crafts. Your item will be raffled off at the conference. You can purchase items for your raffle basket or ask for donated items from local stores or companies.

All proceeds help offset conference costs and you will receive a receipt for your in-kind donation when you drop it off on Thursday or Friday near the registration desk. If you plan to bring a raffle item, be sure to check that on your registration so we can have a receipt ready for you.



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 2023 Conference? There are new sponsorship levels and add-ons available this year.

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, essential oils, books, homemade goods, etc?

Please consider being a conference exhibitor to share your products and services with attendees.

Sponsorship and exhibitor information is available at **https://tinyurl.com/MSFCon23Sponsor**

T-SHIRTS

Conference shirts will be sold on the MSF online store on Feb. 1 – June 20. Shirts will be mailed directly to your home. A wide variety of shirt sizes and styles, include baby onesies and toddler tees, are available.

Limited sizes and quantities of adult and youth t-shirts will be sold at the conference.

Purchase at **https://bit.ly/MSFStore**

Adults and Ladies: $23.99
Children: $19.99



DISCUSSIONS WITH SPECIALISTS



Complimentary evaluations and research opportunities for adults and children with Moebius syndrome and their families are offered at the conference.

When you register for the conference, you will receive an email with information to schedule appointments. The appointments fill up quickly, so we recommend registering early.

MEDICAL SPECIALISTS

Neuromuscular Retraining for Facial Paralysis

by Jacqueline Diels, OT

Facial retraining is a non-surgical approach to the treatment of facial paralysis and paresis. Just as every face is different, facial paralysis is different in each person. For many with Moebius syndrome, certain areas of the face may move, while others do not. During the 30-minute discussion a brief evaluation will determine the available degree of movement present in the various regions of the face. Participants will gain a better understanding of how their facial muscles work. If appropriate, a potential treatment program will be discussed. For ages 10+.

Orthopedic Evaluations

by Philip McClure, MD

It is common for individuals with Moebius syndrome to have clubfoot, scoliosis, muscular weakness, and other orthopedic manifestations. Dr. McClure will discuss and evaluate orthopedic concerns and may provide recommendations for further evaluation or treatment. The 15-minute appointments will be scheduled for individuals of all ages with Moebius syndrome. Individuals are encouraged to bring their x-rays on a disk to be reviewed.

Pulmonary Evaluations for Children and Adults

by Hollis Chaney, MD

Dr. Hollis Chaney will provide 20-minute appointments to discuss any pulmonary issues including difficulties with exercise, chronic cough, recurrent pneumonia, asthma, aspiration, sleep issues, oxygen and ventilators. All ages welcome to sign up.

Smile Surgery, Hand Surgery and Facial Paralysis Evaluations

by Gregory Borschel, MD

Dr. Gregory Borschel will conduct evaluations and offer more information on smile (gracilis muscle transplant) surgery and facial paralysis surgery for children with Moebius syndrome. Parents with children ages 1-3 years old will meet in small groups (1 hour). Individual 20-minute appointments will be made for parents and their children ages 4+. Evaluations on individuals with congenital hand anomalies may also be scheduled.

Speech & Feeding Evaluations for Children and Adults with Moebius Syndrome

by Renee Hill MS, CCC/SLP

Renee Hill will conduct short evaluations of both speech clarity and feeding skills for children and adults. These 45-minute sessions provide an overview of the muscle-based activities that can be used by both therapists and parents to improve verbal communication and feeding safety.
Thanks to an endowment, the Speech & Feeding evaluations will be free at this conference.

RESEARCH SPECIALISTS

Genetic Research in collaboration with the National Institutes of Health study on Moebius syndrome

by Elizabeth Engle, MD; Ethylin Wang Jabs, MD; and Bryn Webb, MD

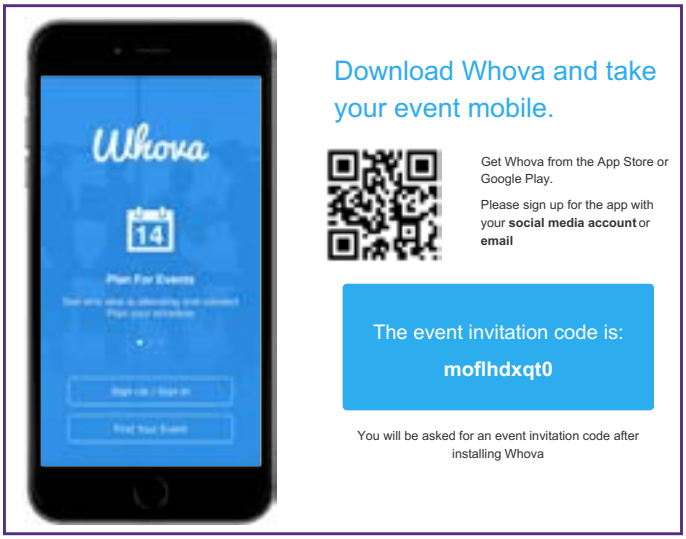
Drs. Engle, Jabs, and Webb are working together, using clinical, genetic and molecular biological approaches to unravel the genetic causes of Moebius syndrome, congenital facial paralysis, and other related conditions. They and their teams will be available for research screening and genetic testing enrollment during the conference.

Adults or children with these conditions and other family members are all invited to request visits with the teams. The appointments with these experts typically take 1-2 hours and involve assessments focused on neurology, ophthalmology, genetics and information about the study.

REGISTRATION INFORMATION

EVENT APP

We have a new event app! The conference agenda, ride share sign-up, speaker information, hotel map, surveys and event alerts will all happen in the Whova event app. The app will be key to managing your schedule and staying connected at the conference.



REGISTRATION FEES

Thanks to the gift of a generous endowment left to the Moebius Syndrome Foundation, we are offering a special $50 registration fee for all individuals with Moebius syndrome for the 2023 conference.

Registration fees include attendance at all conference sessions, materials and activities (except those noted with an additional fee). Meals included are: Thursday Welcome Reception; Friday breakfast, lunch and afternoon coffee break; Saturday breakfast, lunch, afternoon coffee break, and dinner; and Sunday breakfast. **Early Bird Registration ends on March 15, 2023**.

Registration will open online on February 1 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.

REGISTER ONLINE!
https://bit.ly/MSFCon2023

REGISTRATION RATES

	Early Bird 2/1-3/15	Standard 3/16-7/22
Adult	$275	$345
Teen (13-17)	$225	$290
Kids (3-12)	$145	$200
Kids (0-2)	Free	Free
Individuals with Moebius syndrome	$50	$50
Tube Fed Individuals (all ages)	Free	Free

CANCELLATION POLICY

Cancellations occurring on or before June 16, 2023 will be fully refunded, less a small administrative fee. No refunds will be given after June 17, 2023.



MOEBIUS SYNDROME FOUNDATION

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

conference@moebiussyndrome.org
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important dates

Early Registration: **February 1 – March 15, 2023**
Standard Registration: **March 16 – July 22, 2023**
Financial Need Scholarship Application Deadline: **March 1, 2023**
Hotel Reservation Deadline: **June 29, 2023**
Moebius Syndrome Foundation Conference: **July 20-23, 2023**

REGISTRATION WILL OPEN ON FEBRUARY 1, 2023

https://bit.ly/MSFCon2023

SEE YOU IN MINNEAPOLIS!