You are invited!
The 14th Moebius Syndrome Foundation Conference is being held in Minneapolis, Minnesota from Friday, July 17 - Sunday, July 19, 2020 and you are invited!

The conference is an amazing opportunity to meet, socialize and learn from others whose lives are also affected by Moebius syndrome. This year’s conference will offer more educational and social opportunities than ever before. Whether you are a first-time attendee or someone who has attended many conferences, there will be plenty for you to do!

Learn about new research being done, meet one on one with the world’s leading researchers and physicians dedicated to Moebius syndrome, or be hands on with new art or music sessions.

The Moebius Syndrome Foundation Conference has been life-changing for many individuals and families. The event brings together our amazing community. So join us in Minneapolis – a location that will be sure to make a great vacation!

See you in Minneapolis! You will meet new people and hopefully forge friendships that will last a lifetime.

Regards,

Jenny Whitman
Chair, Conference Planning Committee

Dina Scalone
Executive Director, Moebius Syndrome Foundation
Marriott Minneapolis Northwest
7025 Northland Dr. N.
Brooklyn Park, MN 55428
https://tinyurl.com/14MSFcon

To Make Your Hotel Reservations
Phone: 763 536-8300 Web: https://tinyurl.com/14MSFcon
Sleeping room rates are at a discounted $149 + $15.68 tax per night (total = $164.68 per night), and you must book within the Moebius Syndrome Foundation block. This discount is good for July 16-21, 2020, so feel free to extend your trip and enjoy Minnesota before or after the conference! Make your reservations early! Last date to reserve at the discounted rate is June 18, 2020, or whenever the room block fills up.

Marriott Minneapolis Northwest is a spacious hotel, located near restaurants, Shoppes at Arbor Lake, Guthrie Theater, and more in close neighboring cities.

Accessibility
Please contact us if you require reasonable accommodations.

Getting to the Conference Hotel
Taxis and Other Ride Services
The hotel does not provide shuttle service. Taxi service by Yellow Cab and United Cab is available at the curbside outside the Baggage Claim Level at MSP Airport. Other ride services are available in the area by using your mobile phone. Estimated Taxi Fare is $65. Uber or Lyft are commonly used, and are more affordable.

Minneapolis-St Paul International Airport (MSP)
Airport Phone: 1 612 726-5555
Hotel direction: 26.2 miles NW

Photographs courtesy Marriott Minneapolis Northwest

Driving directions
Exit the airport on 34th Ave S. Take the ramp onto I-494 W. Travel 3.5 miles and take exit 5A to merge onto I-35W N toward Minneapolis. Travel 7.7 miles and take exit 16A W on the LEFT toward Downtown/I-94 W. Continue straight and take the ramp onto I-94 W. Travel 13.4 miles. I-94 W will merge with I-694 W. Take exit 30 for Boone Ave. Travel 0.3 miles and keep LEFT at the fork. Follow signs for Boone Ave S and merge onto Northland Dr. N. The hotel will be on the left.
Keynote Presenter

We are excited to announce that Susana Romero will present the keynote address at the 14th Moebius Syndrome Foundation Conference. Susana Romero was born with Moebius syndrome in Caracas, Venezuela, on July 9th, 1957. She has been happily married for 34 years, graduated as a Civil Engineer from the Central University of Venezuela (1983) and worked for 25 years in the Ministry of Transportation and Communications.

Susana recently earned a degree from Teachers Online and has prepared a master class online to help people understand how to help children with disabilities. She wrote the autobiographical book, SuSana (English and Spanish) and has given lectures about Moebius in the USA, Belgium, Argentina, Ecuador, and Spain. She works to collect data on children with special conditions, gives online workshops, and is the designer of ‘THE BAG FOR HAPPY THERAPY.’

Special Session with Rick Guidotti

Rick, an award-winning photographer, is the founder and director of Positive Exposure, an innovative arts, education and advocacy organization working with individuals living with genetic difference. Positive Exposure utilizes the visual arts to significantly impact the fields of genetics, mental health and human rights.

Positive Exposure utilizes the arts, film and narratives to present the humanity and dignity of individuals living with genetic, physical, behavioral and intellectual differences. It celebrates the beauty of human diversity, inclusive of ethnicity, religion, age, ability, learning style, gender expression and sexual orientation.

See his photographs displayed throughout the conference.

Wonder Program

Random House Children’s Books has launched its WONDER CERTIFIED KIND CLASSROOM PROGRAM, an educational initiative focused on using the property to teach kindness in schools with rewards and incentives.

With over six million copies sold around the world, R.J. Palacio’s inspiring book WONDER (Knopf Books for Young Readers) has inspired global kindness and anti-bullying campaigns, becoming part of curricula in schools across the country.

Our Wonder Program: Session for younger and older children by Children's Craniofacial Association.
All Attendees
 Genetic Research into Moebius syndrome with Drs. Elizabeth Engle, Ethylin Wang Jabs, and Irini Manoli
 Special Sessions for Parents of Medically Complex Children
 Sleep Issues with Dr. Suresh Kotagal
 Blinking Surgery with Dr. Greg Borschel
 Self Esteem and Depression with Dr. Leah Stock Landis
 Pulmonology with Dr. Michael Shreve
 Building Confidence in Families and Adults, by Will Harrison and Steven Maldonado
 Dental needs of individuals with Moebius syndrome with Dr. Erin Bumanne
 Confidence in Adults with Steven Maldonado
 Therapy for the Face with Jackie Diels, OT
 Speech Communications Research with Dr. Erika Levy
 Smile Surgery with Dr. Ronald Zuker
 Ophthalmology with Dr. David Hunter
 Orthopedic Surgery with Dr. Phillip McClure
 A Bright Future: Looking Beyond Moebius syndrome with Emoni Williams, Austin Halls, Jessica Maher, and Kevin Smant
 Caregiver Burnout with Pat Lang
 Speech/Feeding Therapy with emphasis on oro motor, with Renee Roy Hill MS CCC/SLP and Shannon McElroy MS CCC/SLP
 Massage Therapy with Julie Leahy
 Introduction to ADA Compliance
 Special Needs Planner: Financial Tools with Roger Strege, CES
 Teen Talk for Parents with Elizabeth Lawrence, Jessica Maher, Austin Halls, Kelsey Ferrill, David Garcia, and Steven Maldonado
 Scientific Advisory Board Updates
 ‘Just For’ discussion sessions (Moms, Dads, Grandparents, Men, Women, Grandparents and Other Relatives, Spanish)
 Mom’s Night Out
 Dad’s Night Out

Adults with Moebius
 Special Gathering for Adults with Moebius on Thursday Evening
 Preparing for the Job World and Resumes - 2 sessions
 Painting Class (early sign-up encouraged)
 Creative Writing Workshop
 Music Therapy
 ‘Just for Adults with Moebius’ session

Teens with Moebius
 Communications Workshop
 Music Therapy
 Sing Me a Story
 Painting Class (early sign-up encouraged)
 Creative Writing Workshop
 Preparing for the Job World and Resumes - 2 sessions
 ‘Just for Teens’ session

Children
 Programs in Child Care (6 months – 3 years) and Camp Moebius (4 – 12 years)
 Sing Me a Story Workshop
 Music Therapy
 Wonder Program (ages 6 – 10 and 10 – 12)
 Self Esteem and Differences with Dr. Rhonda Robert (ages 7 – 9 and 10 – 12)
 ‘Just for Siblings’
 Fire Truck Visit
 Northstar Therapy Animals Visit

Photograph courtesy Timothy Maher
Daycare
KiddieCorp will again serve as our on-site daycare provider for the 14th 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 6 months – 12 years old. 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 – 3 years)
Children ages 6 months – 3 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.

Camp Moebius (4 years – 12 years)
Children enrolled in the Camp Moebius 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:

- Visit from Therapy Animals
- Visit from Fire Department
- Wonder Program
- Arts and crafts
- Games and entertainment
- Snacks (meals will be eaten with their families)

Pricing
There is a $30 charge per child for conference childcare, with a family maximum of $90. This includes Friday, Saturday and Sunday, during conference hours. Childcare must be paid to the Moebius Syndrome Foundation through the conference registration process. Snacks and beverages will be provided. Children will be picked up by their parents at mealtimes, and then returned to the childcare rooms.

NOTE If you need to register more than three children for child care, 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 or 844 663-2487 x 1) and we will sign them up for you. It is very important to do this immediately as child care will likely fill up soon. Thank you.

KiddieCorp is always available to answer any questions. Contact them at 858 455-1718 or info@kiddiecorp.com.

Photographs courtesy Rick Guidotti
Welcome Reception
Friday night come have a party with us and get to know each other!

Adults with Moebius Social
After the Welcome Reception, adults with Moebius can gather to socialize.

Moebius Has Talent!
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. You must sign up when you register for the conference.

Getting Creative
We are pleased to offer music workshops for Moebius individuals of all ages, and painting and writing classes for adults and teens with Moebius. The painting and writing classes require pre-registration on the conference registration form.
*Painting is $20 per person, writing is free.

Excursions
Join us on Monday, July 20 for your choice of excursions: a trip to the Mall of America, or a River Boat Cruise down the Mississippi.

The Mall of America is a fun destination where you can experience the largest mall in America complete with rollercoaster and other rides, games, restaurants, and endless shopping. This outing includes roundtrip bus transportation for $22 per person. Children ages 2 and under are free. Once at the mall, attendees will pay for their own activities and food.

Enjoy breathtaking views of the Mississippi River and Minneapolis skyline on the River Boat Cruise. Roundtrip bus transportation and ticket for the boat tour is $32 per person. Children ages 2 and under are free. The boat is accessible for people with disabilities.
We realize that attending 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.

First-time Moebius Syndrome Foundation Conference Attendee Scholarships
A limited number of scholarships will be available to first-time conference attendees who have a financial need. Scholarships of $800 are awarded to eligible first time attendees and their families. One person in the family must have Moebius syndrome and there must be a financial need for the scholarship.

The scholarship will pay your Registration Fee and the Registration Fee of other family members and child care, up to the maximum of $800. See page 9 for more details.

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. They are listed at http://www.ccakids.org/state-funding.html. You can also check with the National Association of Councils on Developmental Disabilities at 703 739-4400 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 that some airlines offer or the National Patient Travel HELPLINE at 800 296-217 or http://patienttravel.org.
First-time Moebius Syndrome Foundation Conference Attendee Scholarships

We realize that attending the Moebius Syndrome Foundation Conference can be financially difficult for some individuals and families. For 2020, we are excited to offer even more assistance for first time attendees with a financial need.

Scholarships of $800 are awarded to eligible first time attendees and their families. One person in the family must have Moebius syndrome and there must be a financial need for the scholarship. The scholarship will pay your Registration Fee and the Registration Fee of other family members and child care, up to the maximum of $800.

After Registration Fees are paid, the remaining amount will be issued to you at the conference when you sign in and is to be used to reimburse you for travel and hotel expenses. (If you are approved and your family’s registration fees or child care exceed the $800, you will be responsible for the remaining payment in order to register the other family members.)

To apply, instead of registering for the conference, complete the online scholarship application at:

https://moebiussyndrome.org/2020-conference-scholarship

Scholarships will be accepted beginning in early February and will remain open until filled. The scholarship cannot be used to sign up for the Monday excursion or to purchase conference t-shirts.

Contact conference@moebiussyndrome.org or call 844 663-2487 x1 with any questions.

Local Raffle Baskets

Consider bringing the flavor of your hometown, state or country to our conference. Ideas include local foods, sport items or crafts. Your basket 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 Thursday or Friday near the registration desk. If you plan to bring a Raffle Basket, be sure to check on your registration so we can have a receipt ready for you.

Conference Sponsorships

Do you know an organization or individual that may be interested in sponsoring at the 14th Moebius Syndrome Foundation Conference?

There are several ways to participate:

Exhibit: Showcase your product or nonprofit organization for the entire conference - Friday, Saturday and Sunday.

Sponsor: There are various levels of sponsorship.

Donate: You can make a donation, of any amount, which will be used to fund conference events as well as families traveling to the conference.

Questions? Contact us at 1-844-MOEBIUS (663-2487) or conference@moebiussyndrome.org for more information.
Consultations and research opportunities for adults and children with Moebius syndrome and their families are offered at the conference. The appointments are made as registration is received and many fill up, so it is important to register early. Except where noted, there is no charge for the individual appointments.

Once you have registered for the conference, you will receive an email that will explain how to sign up for any of the consult and research appointments.

_evaluations_

**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 who has it. For many with Moebius syndrome, certain areas of the face may move, while others do not.

During the 30-minute consultation 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 to adult.

**Speech & Feeding Evaluations for Children and Adults with Moebius syndrome by Renee Roy Hill MS, CCC/SLP and Shannon McElroy MS, CCC/SLP**

Renee Roy Hill and Shannon McElroy 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.

The sessions are offered at a reduced rate of $75, which may be paid at the time of the assessment by cash or check.

**Smile Surgery Evaluations and Hand Surgery Evaluations by Dr. Ronald Zuker and Dr. Gregory Borschel**

Dr. Ronald Zuker and Dr. Gregory Borschel will conduct evaluations and offer more information on smile (gracilis muscle transplant) surgery for children with Moebius syndrome. Parents with children under 4 will meet in small groups (1-hour). Individual 20-minute appointments will be made for parents and their children 4 years and over.

Evaluations on patients with Moebius with congenital hand anomalies may also be scheduled.

**Research**

**Genetic Research in collaboration with the NIH study on Moebius syndrome by Drs. Ethylin Wang Jabs, Elizabeth Engle and Irini Manoli**

Drs. Jabs, Engle and Manoli 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 consultations and research screening and enrollment during the conference.

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

**Research on Parents by Dr. Kathleen Bogart:**

This focus group will be a group for parents of children and adults with Moebius syndrome to discuss their experiences. Some topics will include challenges and triumphs you’ve experienced as a parent of someone with Moebius; things you have learned being a parent of someone with Moebius; and how your relationships have been shaped by Moebius.

The one and a half hour long discussion will be audiorecorded as part of a research study to examine the experiences of family members of people with Moebius syndrome.
Speech treatment research by Dr. Erika Levy
There is almost no research-based information on speech communication and appropriate speech treatment techniques for individuals with Moebius syndrome (MS). This assessment will be free and will benefit speech treatment research in individuals with Moebius syndrome.

Individuals interested in participating in this research study will complete a survey on communication prior to the conference. While at the conference testing will be done in a 45-minute private setting, where assessments will be performed and audio-recorded using research-based techniques for improving speech communication.

Eye Paralysis research by Dr. Gilles VannusCorps
In this study we will investigate how people with congenital eye paralysis of different types and severity move their gaze in different contexts. We hope to reach a better understanding of the different strategies that can be used to compensate for gaze paralysis and provide useful advice to the community.

This study is for ages 18+ and will involve one 60-minute meeting.

Dental Research by Dr. Erin Bumanne
Oral health is important to general health. This study aims to characterize the oral and dental state of individuals with Moebius syndrome and will involve one free 60-minute private meeting where a dental history and oral examination will be completed. We seek to improve future dental care for all individuals with Moebius syndrome.

Getting Social with Moebius by Dr. Kathleen Bogart:
A Communication Workshop for teens with Moebius syndrome. Teens (ages 12-18) with Moebius are invited to a two and a half hour long workshop on communication skills at the Moebius Syndrome Foundation Conference.

Registration Fees
Registration fees include attendance at all conference sessions, materials and activities (except those that are noted with an additional fee). Meals included are: Friday breakfast and lunch; Saturday breakfast, lunch, dinner and a snack; and Sunday breakfast and lunch. Early Bird Registration ends on April 30, 2020.

On-site and one-day passes may become available - please check the conference website for more information. Registration will be online only this year and a credit card is required. If you need assistance, call us at 844 663-2487 ext 1 and we can register you over the phone.

http://www.moebiussyndrome.org/registration

Cancellation Policy
Cancellations occurring on or before April 15, 2020 will be refunded less an administrative fee. Cancellations occurring between April 16 and June 14, 2020 will be refunded 50 percent. No refunds will be given on or after June 15, 2020.

Registration Rates
See table at right.
Registration will open in February 2020 at http://www.moebiussyndrome.org/registration
See you in Minnesota!

Important Dates
Early Registration: February - April 30, 2020
Standard Registration: May 1 - July 13, 2020
Make Your Hotel Reservations: June 18, 2020
14th Moebius Syndrome Foundation Conference: July 17-19, 2020