

MOEBIUS SYNDROME FOUNDATION NEWS

Moebius Syndrome Foundation – The Home for the Moebius Community™
Spring 2022



Spring is a season that brings to mind growth and new possibilities. It is also a time for gratitude and reflection for the Moebius Syndrome Foundation as we think about the amazing Moebius syndrome awareness events that recently took place and others that will be happening throughout this year.

On January 24th, we were thrilled to see the world being painted purple, as we saw our social media pages flooded with photos of celebrating, pride, and love. We would like to thank everyone that sent us pictures to share or tagged us in their posts. It was wonderful to see the overwhelming support for the Moebius community!

A special thank you to our partner organizations for promoting MSAD and spreading awareness about Moebius syndrome, and also to the many members in the Moebius community that hosted fundraisers and awareness campaigns.

We'd like to thank the many generous donors that made gifts in honor or memory of a loved one. Your gifts keep our work serving the Moebius community moving forward.



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MOEBIUS
SYNDROME FOUNDATION

Moebius Syndrome Foundation News Spring 2022

Our Mission

The mission of the Moebius Syndrome Foundation is to provide information and support to individuals with Moebius syndrome and their families, promote greater awareness and understanding of Moebius syndrome, and to advocate for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions.

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Moebius Syndrome News

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The newsletter is on the website at:

www.moebiusyndrome.org



A Letter from our President

Dear Friends,

Although most of us are still living in the shadow of the pandemic, it feels like there is light at the end of this long, dreary tunnel we've been living in for the past two years. Some days, it even feels like we might be creeping back to more normal lives with respect to the pandemic, which is a wonderful feeling.

Preparations for our in-person conference in Atlanta this summer are proceeding full steam ahead, and conference and hotel registration are open. We look forward to seeing as many of you as possible in Atlanta in July for the conference.

Despite the Covid precautions being taken by much of the Moebius community, it was gratifying to see so many people rally to observe Moebius Syndrome Awareness Day in January. My social media channels were inundated with wonderful pictures of our community members wearing purple clothing and holding creative gatherings and commemorations. I'm continually amazed by the global Moebius syndrome community, and it was so amazing to see everybody come together for MSAD. I am honored and humbled to be part of this community.

Sincerely,

Jacob Licht, President

A Letter from our Executive Director

Dear Friends,

This past year has held many inspiring moments for me. I had the honor of stepping into the role of Executive Director and getting to know on a deeper level the many incredible people who make our work at the Moebius Syndrome Foundation possible, including the Board of Directors, Scientific Advisory Board, staff, volunteers, community members, partner organizations, and supporters across the globe. I have also had the opportunity to dive into our program planning and have worked and strategized with many people about the new and existing ways we can continue to support and inspire the Moebius community. Thanks to your support, we had an incredible 2021, and this year is off to a great start.

The Moebius Syndrome Foundation is an exemplar of the Margaret Mead quote: "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has." I am proud to be a part of such an amazing organization, and I am looking forward to the work ahead as we continue to support the Moebius community through education, awareness and advocacy, research, and life-changing socialization opportunities. It is my deep belief that together we can create a kinder, more inclusive, and healthier world.

I hope to see many of you at the Atlanta, Georgia conference this July.

Warmly,

Jenny Whitman, Executive Director



Join us at the next Moebius Syndrome Foundation Conference!



The 15th Moebius Syndrome Foundation Conference will be on July 15-17, 2022 in Atlanta, GA. We are delighted to gather the Moebius community in person again and look forward to reconnecting with old friends and meeting many new friends.

With more than 60 breakout sessions, 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 and medical procedures being implemented, attend sessions on mental health, life resources and advocacy, meet one on one with the world's leading researchers and physicians dedicated to Moebius syndrome and connect with other members of the Moebius community during the various social events.

In addition, there will be separate breakout sessions for teens and kids include a teen "Happy Hour," college major and career coaching sessions, a siblings workshop, art therapy, and much more! Plus, Dina Zuckerberg, Director of Family Programs with myFace, will lead the Wonder Program, an educational initiative focused on anti-bullying, for kids ages 6-12.

A highlight of the conference will be the "We Are Limitless" keynote presentation by David Garcia. David is a Colombian-American scientist, motivational speaker, adaptive athlete, advocate, and model. Despite the numerous challenges presented with having Moebius syndrome, he believed in himself, worked diligently, and stayed true to his vision of being limitless. His passion and mission is to motivate people to be relentless in the pursuit of their dreams, inspire those who were told they can't be great, and overall to be LIMITLESS!

Don't miss the opportunity to attend this life changing conference! Registration is open and early bird pricing ends on April 30, 2022. Visit the website for more information and to register: <https://cvent.me/44XgRg>. If you have questions, email us at conference@moebiusysndrome.org.

Building community and making lifelong friendships is a very important aspect of the conference! We will have the following social opportunities for attendees to connect:

- First-Time Attendees Reception
- Welcome Reception
- Talent Show and Neon Glow Dancy Party
- Adults with Moebius Coffee Social
- Afternoon Coffee Breaks
- Dinner at Ponce City Market
- Moms Night Out
- Georgia Aquarium Excursion
- Shoot the Hooch Excursion





Moebius Syndrome Awareness Every Day



In January 2022, the Moebius Syndrome Foundation's theme was "Moebius Syndrome Awareness Every Day" and we invited the Moebius community to share how they were raising awareness.

Our social media pages were flooded with purple as pictures and messages of support and love were shared with us from all over the world. Many chose to celebrate with family and close friends, at school, at work, and some even held creative fundraisers supporting the Moebius community.

Andrea Gentry, mother of Dylan, worked with a local brewery in North Aurora, IL to raise awareness about Moebius syndrome through the entire month of January. The brewery team had a special table with information about Moebius syndrome set-up, and donated \$1 from pints sold the entire month. Brother Chimp Brewing Company said they "would like to thank every person who takes the time to learn more about Moebius syndrome because it is a big step in reaching a more all-inclusive worldwide community."

The Moebius Syndrome Foundation would like to thank everyone that showed support for Moebius Syndrome Awareness Day in any way. We invite you to continue raising awareness about Moebius syndrome every day of the year!

I wouldn't change having Moebius syndrome, for it has shaped the person I have become – Kelsey Ferrill

Moebius Syndrome Awareness Every Day



Backyard Brine, along with Kindness is Everything, once again hosted a virtual fundraiser and awareness campaign in honor of Addison Garvey.

By creating “Kindness is Everything” apparel and receiving donations, over \$5,000 in funds were raised and donated to the Moebius Syndrome Foundation!

Addison, along with her siblings and family, created many fun and informative Tik Tok videos and awareness posts on social media. Addison’s school supported raising awareness about Moebius syndrome, too. This truly became a full community and nationwide campaign as friends, family, and community members spread Addison’s messages about kindness and Moebius syndrome.



To learn more about the Backyard Brine Kindness is Everything campaign, please visit <https://www.backyardbrine.com/pages/kindness-is-everything>.

Finding Meaning From Grief: A Mother's Journey

Celeste was born not breathing.... The nurses and hospital staff desperately worked to get her breathing then rushed her away to the NICU, where she stayed for seven weeks. Celeste remained on oxygen for two days until she was stabilized enough to breathe room air. From the beginning of her life to the end, she had a difficult time but was a happy baby.

At two days old, Celeste was transferred to the Children's Hospital Colorado NICU, where it was discovered she had trismus, a cleft palate, and was diagnosed with

Moebius syndrome. She was seven weeks old and had a G-tube when she was discharged from the hospital. Celeste stayed home for eighteen days until she ultimately passed away.



I am Alexis, Celeste's mother, and I have been working with OtterBox (my company of employment) to give back to the Moebius Family. My team and I make Teddy Bears for the Moebius Syndrome Foundation to give in Welcome packages. This project has become a company-wide effort to make as many teddy bears as possible. I have also been working to make teddy bears to give to families I have become acquainted with through Facebook. I also donated \$250 through the OtterCares Foundation to the Moebius Syndrome Foundation and rallied my friends and family to donate as well. My primary mission is to spread awareness of Moebius syndrome, which is rare. Celeste's care team was not properly equipped to handle her disease, but they did the absolute best they could.

I want to create a more equitable environment for those with facial differences. I am finding meaning through my grief and will continue to advocate for Celeste and other children born with Moebius syndrome.

-Alexis White, Mother of Celeste

Mentorship Program

If you are a child, teen, adult with Moebius, or a parent of a child with Moebius and could use the support of a mentor or friend, please sign up for the new Moebius Syndrome Foundation Mentorship Program.



This program is for those needing advice and encouragement about self esteem, friendship, professional development, or

for those who want to connect with another member of the Moebius community. Someone who could be a friend that helps understand what you are going through.

<https://bit.ly/MoebiusMentors>



“ Many people in the Moebius community could use additional support, guidance, or just a friend. We often hear from adults and teens with Moebius syndrome and from parents of children born with Moebius syndrome who need advice or just want someone to listen. Luckily for us, many people want to help and be that support for someone else. Our community members want to help others, and many have a lifetime of experience to share. If you would like to connect with a peer, please complete the confidential form online. We are all in this together.”

-Jenny Whitman, Executive Director

MSF 2023 Logo Contest

Calling all students, artists, and inspired Moebius community members!

The Moebius Syndrome Foundation is looking for a logo design for the 2023 conference in Minneapolis, MN and want give you the opportunity to show off your creative design ideas! The theme for the conference will be "Growing Stronger Together". We are seeking talent from the Moebius community to draw or design a creative and inspiring conference logo. To achieve this, we are launching our first ever conference logo design contest!

The winning logo may be used for all of the 2023 conference marketing materials, registration website, promotional items, social media posts, conference t-shirts, etc. The winner of the contest will receive a complimentary registration to the 2023 MSF conference and a t-shirt with the logo design. Plus, all the bragging rights as the logo designer!

Details regarding logo design guidelines, contest rules and submission requirements are available at www.tinyurl.com/MSF2023logocontest

We are very excited to see all the logo designs created by the talented artists in the Moebius community!



The deadline for entries is midnight Pacific Time on Friday, April 22, 2022. Contest entries may be submitted online at www.tinyurl.com/MSF2023logocontest.

The winning design will be selected by the MSF conference planning committee and announced by April 29, 2022.

2022 Moebius Syndrome Foundation Educational Scholarship

2021 MOEBIUS SYNDROME FOUNDATION EDUCATIONAL SCHOLARSHIPS AWARDED



KAITLYN WEBER
XAVIER UNIVERSITY



BEN NASH
ECKERO COLLEGE



KAITLYN GREENBERG
RUTGERS UNIVERSITY



GUSTAVO GOMEZ
SACRED HEART UNIVERSITY

Do you have Moebius syndrome? Do you attend college, or do you plan to attend next year?

Applications are being accepted now!

This spring the Moebius Syndrome Foundation will award four educational scholarships of \$2,000 each, to individuals who have Moebius syndrome and will be attending an undergraduate college/university/post-secondary vocational school.

Three scholarships will be awarded to undergraduates and one to a graduate student!

The deadline to apply is NOW – April 30, 2022.

"This scholarship has gotten me another step closer to my dreams without letting financial problems deter me. I'm so grateful for everything the Foundation does!" ~Austin Halls

"The MSF scholarship is helping me accomplish my dreams. It is a much-needed support through these difficult times that is allowing me to continue my education. I'm so thankful to the Foundation and the board that selected me as a recipient!" ~Valerie Garcia

Thank you - for your donations!

It is through your generosity that we can continue supporting the mission.

The mission of the Moebius Syndrome Foundation is to provide information and support to individuals with Moebius syndrome and their families, promote greater awareness and understanding of Moebius

syndrome, and to advocate for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions.

All listed donations were made September 15, 2021 – February 21, 2022

In Memory of Jack Ashby

Linda Boling

In Memory of Ronna Baker

Adrianna Kayden

In Memory of Alexandria C. Zuniga

Marcia Abbott

David W. Alfaro, DDS

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Vilma Orozco

Sally Ramirezphelps

Anita Phillips

Hector Ramirez

Richard Rodriguez

John & Adeline Schwehr

Lori Thomas

James Tiedt

Sunshine, Jesse, &

Nicholas Zuniga

In Memory of Fay M. Creguer

Susan Wright

In Memory of Hannah Jade Devine

Mark & Susan Knox

In Memory of Roman Fisher

Elaine Dyer

In Memory of her friend's nephew

Patricia Nelson

In Memory of Celeste J. Hayden

Jolene Ericksen

In Memory of Catherine Kay Todi

Ann Callahan

Sue & Dana Fowle

Michael & Lori Langone

Joanne & Stephen Manley

Jane Robertson

In Memory of Christopher Lennon

Joe & Bernodette Lennon

In Memory of my nephew, Kirk Marschel

Jolene Pugh

In Memory of Burton Minow

Mary Minow

Nell Minow & David Apatoff

In Memory of David C. Moffitt

Maryke Moffitt

In Memory of Sue's mother

Norm & Sue Nelson

In Memory of Robert W. Thabit

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In Memory of Celeste White

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In Honor of Marcia & Natalie Abbott

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In Honor of Barbara Ast

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In Honor of Hamilton Bachman

Destiny Bachman

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Amy M. Mattingly

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In Honor of Kevin Brailsford

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Christine Casiano

In Honor of Carter

Judith Lorenz

In Honor of Becky, Chuck & Anna Cheney

Julia McGirt

In Honor of Kimberly "Kimmer" Crawford

Pam & Bob Crawford

In Honor of my granddaughter, Dakota

Tammy Nash

In Honor of my daughters

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Backyard Brine

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Margaret Marengi

Theresa O'Daly

Sunquam Elementary School

In Honor of Avery Marie Giannini

Janet Giannini

In Honor of Benjamin Graf

Alexa Graf

In Honor of Lori Grossberg

Dawna & Bob Bailey

In Honor of Reese Hunter
 Lisa Clinton
 Robert Hunter

In Honor of "We smile for Ivy."
 Alicia Parisian

In Honor of Raphael Kiessling
 Riley Kiessling

In Honor of Elizabeth Lawrence
 Amanda Davis
 Jimmy Lawrence

In Honor of Gabriel Kramer
 Karen Ast
 Marty & Barbara Ast
 Jonah Gewitz
 Linda Joshowitz
 Larry & Miriam Kramer
 Lisa & Jeremy Kramer
 Debra Kurtz
 Devorah Lamm
 Tina Lamm
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In Honor of Miriam Licht
 Jacob & Panina Licht

In Honor of Jacob Licht
 Eric Marterella

In Honor of Licht Family
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In Honor of Jessica Maher
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In Honor of Jessica & Rebecca Maher
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In Honor of Allen Marshall
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In Honor of Sean McCarrell
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In Honor of Tim McCaughan
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In Honor of Dustin McGowan
 John & Judy McGowan

In Honor of Jacob Middendorf
 Terri Schatzman

In Honor of Marlon Moraes
 Thorne Research

In Honor of Sophia Orozco
 Vilma Orozco

In Honor of Claire Peppin
 Jake & Kaitlyn Drallmeier
 Ellen Skinner
 Jill Solomon

In Honor of Jennifer Peters
 Janet Carey

In Honor of Brody Peterson
 Julie Peterson

In Honor of Khaleb Phillips
 KiOwana Phillips

In Honor of Ava Rae Buck
 Nancy Buck
 Rachel Butler

In Honor of Mathias Santana
 Chris Abad
 Amanda Chung
 Leesamarie Dayao
 Kim Dolinsek
 Rosemary & Joseph Keebler
 Tina Ory
 Paula & Ivan Santana
 Sara Santana
 Jenna Tippie

In Honor of Lisa & Kevin Smant
 Ruth & Jack Smant

In Honor of Dorothy & Linda Tate
 Rob Hirschboeck

In Honor of Linda Tate
 Dorothy Tate

In Honor of Lucas Miguel Torres
 Carlos Torres,
 Royal Oaks Energy Services

In Honor of Carter West
 Nina West

In Honor of Jenny Whitman
 Erica Klauber

In Honor of Jared Williams
 VLMY&R Foundation

In Honor of Pierce Zeitler
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Research Updates

Part of the mission of the Moebius Syndrome Foundation (MSF) is to advocate for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions. Currently, we are supporting two research projects, thanks to the generosity of our donors.

Gregory Borschel, MD

is conducting research on surgical treatment to enhance dynamic eyelid closure in patients with Moebius syndrome. Most people born with Moebius syndrome have dry eyes and resulting complications because of their inability to blink.



Dr. Borschel is the Chief of Plastic Surgery at Riley Hospital for Children in Indianapolis, Indiana. He will be presenting updates on this study at the 2022 Moebius Syndrome Foundation Conference being held in Atlanta, Georgia.

Jessica R. Dietch, Ph.D.

is conducting research into the sleep health of children and adults with Moebius syndrome. The research seeks to comprehensively characterize sleep health among individuals with Moebius syndrome which will aid in identifying potential treatment targets to address with behavioral sleep medicine interventions.



Dr. Dietch is an Assistant Professor at the School of Psychological Science in Oregon. She will be presenting updates on her research at the 2023 Moebius Syndrome Foundation Conference.

We thank you for your continued support of this great work.

Ask the Experts: Jackie Diels

Q. for Jackie Diels, OT, Facial Retraining, LLC, Mcfarland, WI.

Jackie Diels is a leading authority on non-surgical facial neuromuscular retraining (NMR), a therapeutic approach to the treatment of facial paralysis, paresis, and synkinesis.

Jackie lectures extensively to patients, physicians, and therapists and has authored book chapters and articles. She trains therapists in the U.S. and abroad.

Jackie is a member of the Scientific Advisory Board of the Moebius Syndrome Foundation and currently serves on the medical advisory boards of the Facial Paralysis Foundation and Bell's Palsy Information Site. She lives near Madison, Wisconsin with her husband and feline friends.

1. What is facial retraining?

Facial Retraining is a non-surgical physical therapy designed specifically for the treatment of facial nerve disorders. Treatment techniques focus on "finding the address" of the facial muscles to access and coordinate them, rather than simply strengthening them.

2. Who are ideal patients?

Most facial retraining is geared toward individuals with acquired facial palsy such as Bell's palsy, benign brain tumors, and trauma. In the Moebius community,

ideal patients are age 10 to adult, who have some facial movement present on either one or both sides, or for people who have undergone facial reanimation surgery. If there is no movement at all, it is unlikely that facial retraining will be helpful.



3. How can someone make an appointment or find out more information?

For more information: www.facialretraining.com. Or, contact Jackie Diels at jackiediels@facialretraining.com.

4. Will you be giving complimentary consultation appointments at the MSF Atlanta, GA conference?

Yes! 30-minute complimentary consultations will be offered for ages 10 and up at the MSF conference. Looking forward to seeing everyone in Atlanta!

What questions do you have for our Scientific Advisory Board and community experts? Please send your questions to newsletter@moebiusyndrome.org.

Meet the Board

In November 2021, the Moebius Syndrome Foundation elected four new Board Directors. They are each actively involved in Board service and look forward to serving the Moebius community in this elevated capacity.

“I am a mother of three and my oldest, Hamilton, age 9, has Moebius syndrome. I worked in Washington DC in legislative affairs and for a non-profit. I have a MS in Political Science and recently took a course on IEP and 504 plans through a local nonprofit. We currently live in the Seattle area. We hadn't heard of Moebius syndrome when Hamilton was born and have met very few people who have heard of it since.



Let us all continue to *Choose Kind* and show ourselves and the world what we can offer - we are different but not less, and that we Smile with our Hearts!”

— Jon Fisher

Contact Jon at: jon@moebiussyndrome.org

The MSF was incredibly helpful to myself and my husband in learning about Moebius syndrome and finding hope and joy in raising a child with this condition. I also am so grateful my son has a community of people with Moebius syndrome he can get to know, be friends with, and share experiences with.

I'm hoping to help other parents to find that same hope and joy in what can be an intimidating diagnosis. I also hope to help raise awareness of Moebius syndrome and help others have a positive view of those with disabilities. I would also like to help parents navigate the IEP and 504 process for their children.”

— Destiny Bachman

Contact Destiny at: destiny@moebiussyndrome.org

“I'm very excited to be a part of the MSF Board and I'm thrilled for the opportunities that are being presented to me, to be contributing in multiple ways, like brainstorming fundraising goals and scholarships, to creating a better mentorship program and better community connectedness for community members.



“Hello!

My name is Kathy Kraus, and I can't wait to meet more people in the Moebius community! To join this wonderful group and work on the many important MSF projects has been a long term ambition of mine. I am very grateful for this opportunity to serve on the Board of the Moebius Syndrome Foundation.



I am a nature enthusiast, gardener, photographer and retired physician, but most of all, I am mom to an individual with Moebius. In spite of her challenges, my daughter, now age 36, exhibits the toughness and joy that I also see in so many in this community.

In sharing our experiences and learning together, we all can contribute to our common goal to promote awareness and understanding of Moebius syndrome.”

— Kathy Kraus

Contact Kathy at: kathryn@moebiussyndrome.org

“I am so excited to serve our Moebius community as a Board Director. Our family had been a part of the Moebius syndrome community for over 16 years.

My goal is to continue serving our community, spreading awareness, fellowship, and coming up with new ways to strengthen our Moebius syndrome family.”



— KiOwana Phillips

Contact KiOwana at: kiowana@moebiussyndrome.org

My biggest goal within my time as a board member is to foster a nurturing understanding that we, as a foundation, are a family and that we can create a giving, sociable and enthusiastic place to be ourselves while also continuing the message and mission that the MSF provides us all.

Moebius Syndrome Foundation

The Home for the Moebius Community™

P.O. Box 147 Pilot Grove, MO 65276

info@moebiussyndrome.org

844-MOEBIUS

Follow Us



Inviting all Mighty Moebius Moms!



The next "Just for Moms Chat" will be on Tuesday, April 26 at 10 am PT / 11 am MT / 12 pm CT / 1 pm ET. This will be a private virtual event on Zoom for moms to connect and discuss topics related to raising a child with Moebius syndrome.

The conversation will be led by Destiny Bachman, mom to a son with Moebius.

Sign-up to attend at:
tinyurl.com/JustMomsApril22

Planned Giving

Please consider joining the Moebius Syndrome Foundation (MSF) Planned Giving Program.

If you have already included the MSF as a part of your legacy planning, please let us know.

Thank you again for supporting research, families, and individuals with Moebius syndrome as part of your legacy planning.

For more information visit our website or contact Jenny at jenny@moebiussyndrome.org.

