

# MOEBIUS SYNDROME FOUNDATION NEWS



Moebius Syndrome Foundation – The Home for the Moebius Community™  
Fall 2021



Ava



Brant



Emma



Lennox



Claire



Jillian



Julia



Easton

## First Day of School!

First day of school photos taken, lunches packed, and the children are out the door for school! Ava Butler, Brant



Savannah

Bontjes, Emma Moreno, Lennox Pierce (top row), Claire Peppin, Jillian Borbajpeg, Julia Bryant, Easton Washer (middle row), and Savannah Williams (bottom row) look super excited to be heading off to school after a very long summer! Thank you to all the parents for sharing these great pictures of your awesome children!

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**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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Jenny Whitman**

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The newsletter is on the website at:  
www.moebiusyndrome.org

## A Letter from our President



Dear Friends,

I am excited to welcome The Moebius Syndrome Foundation's new Executive Director, Jenny Whitman. Jenny served for the past three years as Foundation's Events and Programs Manager, and we are excited to welcome her to her new, expanded role.

While changes in leadership can be bittersweet, and saying goodbye to someone you respect is never easy, welcoming someone new is exciting. We've had the benefit of seeing Jenny Whitman in action for the past three years in her conference and event planning role, and were continually impressed with her ability to plan and execute great events for the Moebius community while reaching out and establishing deep, meaningful connections throughout our community. If you haven't already met Jenny I encourage you to do so, because her enthusiasm, charm and talents shine through in every interaction.

In the past few months the Foundation has been the fortunate recipients of two substantial bequests. We are honored and humbled to have been considered by the executors of each of these estates, and that they have entrusted a portion of their legacy to the foundation. These bequests allow us to solidify our future support of research and access to therapies for the Moebius Syndrome community. The foundation will share more on this in the future.

Sincerely,  
Jacob Licht, President

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## A Letter from our Executive Director



Dear Friends,

It is my great pleasure to address you in my new position as executive director. It is truly an honor to be given the opportunity to serve in this expanded capacity, and I look forward to working with you and getting to know you even better in the coming years.

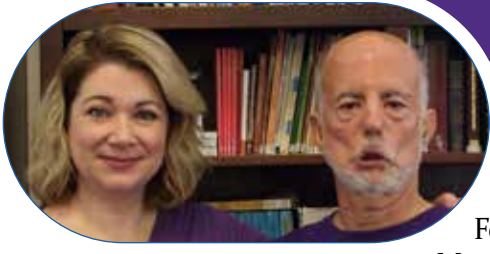
Please mark your calendars for the 2022 Moebius Syndrome Foundation

Conference being held on July 15-17, 2022 in Atlanta, Georgia. It has been a tough time not to meet face to face during the pandemic, and I know this will be a wonderful opportunity to gather and celebrate as a community. The conferences are truly a remarkable experience to connect with other families and individuals affected by Moebius syndrome. There will be opportunities to contribute to research studies, join in personal consultations with medical professionals, attend many educational and fun classes, and join in social events designed to celebrate our togetherness. We truly feel like we are a family, and hope you will join us!

Thank you for your support. Please feel free to contact me with any questions or suggestions for the Moebius Syndrome Foundation. I look forward to serving and working with you.

Sincerely,  
Jenny Whitman, Executive Director





## New Executive Director Announcement

The Moebius Syndrome Foundation welcomes Jenny Whitman as its new Executive Director. Hired in January of 2018, Jenny Whitman served in the role of Events and Programs Manager until August 1, 2021 when she moved into the position of Executive Director. Her position is to help the Moebius Syndrome Foundation fulfill its vision and mission in providing 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. Jenny will be working closely with the Board of Directors, volunteers, future staff, and key stakeholders to ensure smooth internal operations, that worthy goals are being implemented and met, and that the members of the Moebius community's concerns and feedback are being heard and addressed. She is dedicated to helping the Foundation continue to grow and looks forward to this exciting work.

Jenny Whitman lives in Castle Rock, Colorado with her husband and two dogs. She loves to travel, read, and looks forward to meeting many new members of the Moebius community at future conferences and events.

Please feel free to reach out directly to Jenny at [jenny@moebiusssyndrome.org](mailto:jenny@moebiusssyndrome.org).

## Board of Directors Applications Being Accepted

The Moebius Syndrome Foundation (MSF) is excited to open a community-wide call for nominations to its Board of Directors!

We seek members for the Board of Directors who share MSF's commitment to serve as a collaborative center of education and support for children and families living with Moebius syndrome and its related conditions. We look for Board members with a commitment to work closely together with our executive director to help achieve our mission and who embody MSF's values of professionalism, integrity, collaboration, and stewardship for all

The Board of Directors has the principal responsibility for fulfilling the MSF mission and legal accountability for its operations (in accordance with the articles of incorporation, bylaws, organizational policies, and state law). As a group, the Board helps to establish our strategic plan and evaluate its implementation, volunteers on

committees, hires and oversees the Executive Director/CEO, and ensures our financial solvency.

We welcome nominees from any background – including parents, caregivers, physicians, nurses, allied health professionals, youth leaders, business professionals, government workers, community-based service providers – to support our work, bring a diversity of lived experiences, skills, and personal attributes that enrich our awareness, broaden our reach, and help ensure that we serve the entire Moebius community.

Thanks for considering, or for sharing this information with someone you feel might be interested.

Interested in applying? Please complete this link <https://bit.ly/MoebiusBoard> by October 20, 2021. Have questions? Please contact [board@moebiusssyndrome.org](mailto:board@moebiusssyndrome.org).

## New Social Media Intern, Kelsey Dickison

We would like to extend a warm welcome to Kelsey Dickison, the new social media intern for the Moebius Syndrome Foundation. Kelsey will be with us for the next few months.

ten years, but since Nash was born I have been lucky enough to be able to stay home. There I enjoy time with the kids and give extra care to Nash, who has Moebius Syndrome.



“Hello, I am Kelsey, and I am from Faribault, MN. My husband Brandyn and I have been married for five years. We have two very energetic boys: Porter is three and Nash is one. I worked as a cosmetologist for

Before Nash was born, we knew he would have bilateral clubbed feet and missing digits on his left hand. It wasn't until he was six months old that we got a final diagnosis of Moebius Syndrome. I remember feeling so alone and afraid of his unknown future...until I came across the Moebius Syndrome Foundation, and all the support groups they had listed on their website. We have been shown so much love, support, and encouragement this past year, I now know Nash will never feel alone. I am so thankful to be a part of this community!”



Scientific Advisory Board Panel

# 2021 Virtual Events

Throughout 2021, the Moebius Syndrome Foundation has been hosting virtual sessions to help support the needs of the Moebius community. From medical webinars, social events, and private group chat sessions, we've been able to reach many new and familiar members and supporters.

We would like to thank all those that have participated in these virtual events whether as an attendee, or presenter. These have been unusual and difficult times for many, and although meeting virtually is not a replacement for being together face to face, we have felt strengthened and supported by seeing and learning from each other virtually.

There are still many virtual sessions taking place through December, and we hope you'll review the upcoming events and sign-up for ones that you are interested in.



Dr. Hunter Eye Basics

For more information, please visit:  
<https://moebius.org/get-involved/events/2021virtualevents/>



Our friend the llama attended the children's chat session!



Back to School for Parents

Employment Resources



# Join us at the next Moebius Syndrome Foundation Conference!

**SAVE THE DATE!**  
**July 15-17, 2022**

The 2022 Moebius Syndrome Foundation Conference will be held in Atlanta, Georgia!



The Moebius Syndrome Foundation, the nation's largest organization dedicated to providing information and support to individuals with Moebius syndrome, is hosting its 15th biennial national conference on July 15-17, 2022 at the Atlanta Airport Marriott in Atlanta, Georgia. The purpose of the conference is to bring families and individuals affected by Moebius syndrome together for education, research, and socialization opportunities.



There will be a separate Scientific Research Symposium held at the same location on Thursday, July 14, 2022. This is by invitation only for researchers and scientists that have an interest in the Moebius community. **For more information about this special session, please contact us at [research@moebiussyndrome.org](mailto:research@moebiussyndrome.org).**

Atlanta is a great place to visit and for those wanting to extend their stay and make this an even greater vacation, we encourage you to explore some of the planning options listed on our website, request off your vacation days at work, and begin designing your trip now.

We will be sending out more information in January to announce registration, present some of the speakers and presentations, and to provide information on applying for conference scholarships. Interested in being a sponsor or supporter? Please contact us at [conference@moebiussyndrome.org](mailto:conference@moebiussyndrome.org).



“To all first-time conference-goers who have never been to a Moebius conference before, my thoughts are that if you have not experienced it, GO. Go for the chance to meet so many other people like yourself who have similarities (and differences), for the chance to have unique conversations with kindred people and their families - or to create a network. Go for the fun of it, if you're extroverted, to perform in the Talent Show or just to get your picture taken by Rick Giudotti, among hundreds of other community members. If you're more introverted, go for the multitude of informational sessions, like I first did. I wanted to get to know more about what it means to have Moebius, from a scientific perspective.

When you first arrive you'll feel like you've entered a 'culture shock' environment but when you leave you'll know you made the right choice because over the period of the conference you'll have made friends and advocated for yourself in a way that might even surprise yourself. I keep going back to reconnect with those friends and to be a role model for all the younger generation who have the same disability that I have. These friends and people aren't strangers anymore to me; they are a family.”

– Jon Fisher, Colorado, Moebius Ambassador



SCAN ME

# MSF Scientific Symposium

## Bryn D. Webb, MD



The Moebius Syndrome Foundation (MSF) is proud to announce that it held its 7th MSF Scientific Research Symposium on July 22, 2021. This virtual event highlighted the work of 12 investigators and ~30 researchers and MSF board members were in attendance.

Two speakers were new to the event this year. Dr. Pier Francesco Ferrari from the Université Claude Bernard Lyon presented his work studying somatotopic organization and neuroplasticity in Moebius syndrome patients following smile surgery. He also gave an additional presentation on an EEG study to assess brain mechanisms involved in dynamic facial expressions in Moebius syndrome patients.

Dr. Anand Chandrasekhar from the University of Missouri presented work studying zebrafish harboring facial nerve abnormalities.

Additionally, recent recipients of MSF grants (Dr. Bryn Webb, Dr. Zhongyang Zhang, Dr. Alan Tenney, Dr. Kathleen Bogart, and Dr. Greg Borschel) reported updates on their research.

The virtual event was successful, though the group looks forward to holding the 8th MSF Scientific Research Symposium in person next year in Atlanta!

## 2021 Scholarships Announced

Congratulations to the 2021 Moebius Educational Scholarship Recipients!

### Moebius Syndrome Foundation Educational Scholarship Program

#### 2021 MOEBIUS SYNDROME FOUNDATION EDUCATIONAL SCHOLARSHIPS AWARDED



**KAITLYN WEBER**  
XAVIER UNIVERSITY



**BEN NASH**  
ECKERO COLLEGE



**KAITLYN GREENBERG**  
RUTGERS UNIVERSITY



**GUSTAVO GOMEZ**  
SACRED HEART UNIVERSITY

Recently the Moebius Syndrome Foundation awarded four educational scholarships of \$2,000 each to deserving individuals who have Moebius syndrome and will be attending an undergraduate college/university/post-secondary vocational school in 2021.

“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, 2020 scholarship recipient

Congratulations to the 2021 Moebius Educational Scholarship Recipients!

**Are you a high school or current college student planning to enroll in the fall of 2022? The next scholarship application enrollment period will be announced in the spring of 2022. Announcement for open enrollment will be made via email and social media posts.**

The Moebius Syndrome Foundation is extremely grateful to all our donors who have made offering these educational scholarships a reality.

# Thank You to all our donors!

Because of your generous contributions, the Moebius Syndrome Foundation was able to award four educational scholarships in 2021, fund more than \$111,000 in research projects which will help identify the Moebius syndrome gene(s), and financially support many regional events so that families across the United States could meet. Donations listed 3/01/21 through 9/15/21.

## Thank you for your donations.

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.

It is with your generosity that we can continue supporting our mission.

### In Memory of Hannah Jade Devine

Mark & Susan Knox

### In Memory of Roman Fisher

Elaine Dyer

Mark & Sue Hartenstein

Laura Matcham

Dee Moore

### In Memory of Kaylee Grace Roberts Lush

Glenda Lush

### In Memory of Russell Mammen

Lynne L Bolger & Russell Mammen

George Lamb

Local Union 701

J. Newberry

### In Memory of Owen Roberts

Moebius Awareness 4 Owen Roberts

### In Memory of Marion Roiger

Children's Minnesota

### In Memory of Dr. Sandy Schwartz

Frank & Marian Setzman

### In Memory of Eric A. Washer

Holly Kahle & Chris Washer

### In Honor of Marcia and Natalie Abbott

Carole & Richard Perry

### In Honor of Natalie Abbott

Loretta Lisowski Trust

### In Honor of Ben Becker

Linda & George Becker

Alan Guttman

Meredith Setzman

### In Honor of Harrison Berge

Michigan Center for Fertility

### In Honor of Ava Rae Buck

Nancy Buck

### In Honor of Linda Conness

Alpine Kiwanis

### In Honor of Lori Grossberg

Dawna & Bob Bailey

### In Honor of her grandson

Lesley Fitton

### In Honor of Austin Halls

Emma Masset

### In Honor of Ione Idell

David Idell

### In Honor of Beth Jellinek & Tayyib Smith

Frank & Marian Setzman

### In Honor of Tobias Lugo Moody and William Bill & Stephanie Moody

John & Sharon Moody

### In Honor of Miriam Licht

Robert & Chelle Medow

### In Honor of Mickey Granick

Frank & Marian Setzman

### In Honor of Xavier Tinius

Erica Tinius

### In Honor of Lucas Miguel Torres

Carlos Torres

### In Honor of Kylie VanderVeer

Gary & Carleen Wargowsky

### 2021 Virtual Event Speakers

Kathleen Bogart, PhD

Gregory Borschel, MD

Emily Calhoon

Kyle Card, PhD

Hollis Chaney, MD

Jackie Diels, OT

Elizabeth Engle, MD

Ethylin Jabs, MD

Jessica Maher

Irini Manoli, MD

Debra Morton

Leah Richter

Rhonda Robert, PhD

Ronald Zuker, MD

### Individual and Business donations

Amazon Smile Foundation

Pamela Barber

Brianne Battina

The Benevity Community Impact Fund

Markara Bermel

Bright Funds

Nancy Buck

Nancy Calhoon

Charities Aid Foundation of America,  
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Evelyn Jean Shoemaker Estate

David R Skinner

Brie Stephens

United Way of Central Ohio

United Way of Greater

Milwaukee & Waukesha

Christianna Walter

UKOGF

We know that many of you have donated anonymously and through platforms such as Facebook, Amazon Smile, and community fundraisers. We wish that we had all your names and could thank you individually, but we want you to know how grateful we are for every dollar contributed. Your impact is great and helps ensure that the Moebius Syndrome Foundation is fulfilling its mission to serve the Moebius community.



# Moebius Syndrome Foundation

The Home for the Moebius Community™

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## Moebius Mentors

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 professional development, self esteem, friendship, or those that just want to connect with another member of the Moebius community that can be a friend and understands what you are going through.

<https://bit.ly/MoebiusMentors>



## Ryan Leeper is off to school



Ryan is headed to Kindergarten!

**Ryan** is an energetic six year old and the son of Chris and Lauren Leeper. Ryan made news this summer at his daycare in Washington Pennsylvania as they discussed pediatric extended care facilities:

<https://bit.ly/RyanLeeper>

**GivingTuesday** is a global day of generosity that will take place on November 30, 2021. It is an opportunity for people around the world to come together to thank, help, give, show kindness, and share what they have with those in need.



**We** know you have many worthy organizations to consider donating to, and we appreciate all that choose to support the Moebius Syndrome Foundation. Donations go towards supporting scientific research to advance the diagnosis and treatment of Moebius syndrome, scholarships for college students and conference attendees, resources for families, and efforts to raise awareness through education and events.

If one specific aspect of the Moebius Syndrome Foundation's mission is important to you, you can specify which part you would like us to apply your donation. Donations can be made by going to our website at <https://moebiusyndrome.org/get-involved/donate>, or by sending a check in the envelope included in this newsletter.

**Thank you for your support!**