Moebius Syndrome Census Update

In the fall of 2020 we asked the Moebius syndrome community to raise their hands and participate in a census to explore and attempt to better understand the specific needs of our community.

We were thrilled to see the responses from members old and new and continue to be amazed by your enduring sense of unity and also your support for the Moebius Syndrome Foundation and its mission.

The results are worth celebrating as there were 147 new Members in 2020, 150% higher than 2019! Geographically, there were responses from the United States, the U.K., Canada, and 27 international members including members from Africa, Asia, Europe, India, Central and South America.

Thank you again for taking the time to share your knowledge with us! If you have not yet responded to the census, it is not too late for you to be counted!
A Letter from our President

Dear Friends,

With the COVID-19 situation continuing in the US and throughout the world and vaccine rollout slower than hoped, we were forced to cancel the Summer 2021 Moebius Conference in Minneapolis. The decision was painful for us since we know how valuable our time together is, but we just couldn’t justify exposing our community to the risks of travel and a large gathering. Even though we won’t be together in-person this summer, we are planning a variety of virtual events to bring our community together.

Despite the Conference cancellation, much of the work at the Moebius Syndrome Foundation is continuing. The research we fund continues to progress and we continue to evaluate and support new projects. Our online and social media efforts continue, allowing many parts of our community remain connected to each other. Moebius Syndrome Awareness Day in January 2021 was different than usual but was a great event across the globe.

This newsletter contains articles describing the breadth of the Foundation’s work and highlights some exciting things happening in the Moebius Community, including some great Moebius Syndrome Awareness Day efforts.

As always, we are grateful for the financial support from you, our community.

Sincerely,

Jacob Licht, President
A Letter from our Executive Director

Dear Friends,

It looks like it will take longer than expected to get back to “normal” but there is light at the end of the tunnel, my friends. We will be having a series of virtual events throughout the year and plan to make the most of our situation until we can be together again, hopefully in 2022!

Thank you to everyone who participated in the most incredible virtual Moebius Syndrome Awareness Day ever! The creativity of our community was inspiring with an array of virtual fundraisers and awareness events.

You may have noticed our new and improved social media presence. This is all thanks to Kelsey Ferrill. Kelsey has taken our social media to the next level and we are so thankful that she has offered her expertise to the Foundation. We look forward to your continued engagement with the creative and informative campaigns Kelsey has planned for us this coming year.

More than 700 of you have participated in the The Community Census already. THANK YOU!

The information collected will be critical to the success of our future advocacy and research efforts. Please take a moment today to update your information by visiting our website moebiussyndrome.org. We need YOU to be counted!

Happy Spring!

Dina Scalone, Executive Director

Planned Giving

This spring the Moebius Syndrome Foundation (MSF) will launch a Planned Giving Program. When you give a planned gift to the MSF, you’ll become a member of the Moebius Legacy Society. Please let us know if you have already included the MSF in your legacy planning! We want to celebrate you!

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 Dina dina@moebiussyndrome.com

Aunt Loretta

One day in the mail I received an article that my aunt sent me from a local newspaper in a Los Angeles suburb; it was about a new support group a few miles away from her, surprisingly, for people with Moebius syndrome. This was in the early 1990’s, before the Moebius Syndrome Foundation was formed. We connected with the small group of parents, children and adults, and joined them at get-togethers in the Los Angeles area, and have been involved in the Foundation since then.

My aunt, Loretta, had always supported the Moebius Syndrome Foundation with annual donations. She looked forward to reading the newsletters and the conference programs, and often wore MSF conference t-shirts to her line dancing and tai chi classes. My aunt included the Foundation in her estate plans, and her legacy gift to the Foundation was received in the spring. It has been earmarked for research to further the underlying cause of Moebius syndrome, definitely the definition of a generous legacy gift.

--Marcia Abbott, MSF Board Emeritus

Loretta Lisowski with great niece Natalie Abbott in Ashland, Oregon
The Moebius Syndrome Foundation (MSF) would like to thank the entire Moebius syndrome community for making this year’s Moebius Syndrome Awareness Day such an outstanding success.

During the month of January, we held an awareness campaign spanning many different social media platforms, resulting in a resounding success. Here are just a few of the quotes that were posted from the Moebius community about what they “Wanted the world to know about Moebius syndrome.”

“Even though those of us with Moebius speak in different ways, it does not mean that we don’t have anything to say!”

““The challenges I have encountered have made me a stronger, more compassionate person.”

“My beautiful daughter Violet is six years old and has been through so much at her young age. She is the most positive, happy, inclusive person and everyone who meets her just falls in love with her. This is what she wants the world to know: I smile from my heart.”

“I encourage you strongly to truly take the time out to listen to people in your life who have a disability. Nine times out of ten they have been through things that you have never even thought of.”

“I wouldn’t change having Moebius syndrome, for it has shaped the person that I have become.”

“Do not let the lack of expressions fool you; I still have emotions like everyone else.”

“Who you are in the inside of you is more powerful than anything that is outside of you. Do not let your limitations or people’s opinion of you let you feel like you can’t be you.”

Moebius syndrome is a part of me but doesn’t define me as a person.”

Backyard Brine is a local company that makes organic, delicious pickles and condiments. The owners are Aunt and Uncle to Addison Garvey, a member of the Moebius community. Addison’s Aunt and Uncle know the importance of advocacy and awareness and have used their company to give back philanthropically to the Moebius community. They created a “Kindness is Everything” campaign which spent over a month leading up MSAD bringing awareness. They taught ASL daily through videos, sold shirts for the big day and throughout the year they have collected a percent of their proceeds from their Everything flavored pickles to be donated. These actions promoted awareness to people who are different, and reminded everyone to always choose kindness.

To see the videos and infographics from Moebius Syndrome Awareness Day, please visit our website at https://moebiussyndrome.org/events/moebius-syndrome-awareness-day.

Thank you to everyone that held fundraisers, shared our social media posts, and raised awareness about Moebius syndrome in your own way. Because of you, the Moebius Syndrome Foundation will continue to have a bright future.
Rare Disease Day Goes Digital!

Rare Disease Day was February 28 and this year, events were almost wholly digital. The Moebius syndrome community showed up (digitally, of course) in droves to help raise awareness of and educate about rare conditions such as, but not limited to, Moebius syndrome. Millions of people around the world live with rare conditions and that can have an effect on every facet of life from health, to economic and social status to employment opportunities.

Rare conditions are sometimes difficult to treat and access to healthcare/proper treatment/knowledgeable health professionals is of paramount importance. Rare Disease Day is not only to raise awareness of rare conditions but also to break down these barriers and help everyone live their best lives. Thank you, everyone for your support this year and we look forward to seeing you all next year for Rare Disease Day!

2021 Minneapolis Conference Cancelled

We have made the difficult decision, once again, that it will be impossible for us to hold the Moebius Syndrome Foundation’s Conference and Scientific Research Symposium scheduled at the Marriott Minneapolis Northwest from July 22-25, 2021.

We did not make this decision lightly. The Moebius Syndrome Foundation, like the rest of the world, hoped a COVID-19 vaccine would return our lives to some semblance of normalcy by July 2021. However, it is now quite clear to us that this is most likely not a realistic hope, and the Foundation’s leadership and Scientific Advisory Board medical professionals believe there’s still too much uncertainty surrounding travel and large gatherings to hold an in-person conference.

Please see website https://moebiussyndrome.org/events/2021conference/ for more information.

2021 Moebius Syndrome Foundation Educational Scholarship

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, 2021.
Thank you -to all of our donors!

Because of your generous contributions, the Moebius Syndrome Foundation was able to award eight educational scholarships in 2020, fund more than $254,334 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. All donations listed are through February 28, 2021.

Thank you for your donations. It is with your generosity that we can continue supporting 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.

Cheers to all we have accomplished together in 2020!

- Reached $1,200,000 in critical research funded
- Awarded 8 college scholarships
- Hosted an amazing virtual conference
- Completed a census of our membership now totalling 4,584 Members and Supporters
- Welcomed 141 new members

Thank you for being part of our community, have a great 2021!

Moebius Syndrome Foundation
The Home for the Moebius Community™
P.O. Box 147 Pilot Grove, MO 65276

In Memory of Hannah Jade Devine
Mark & Susan Knox

In Memory of Mary Dillner
Jacob & Panina Licht

In Memory of Michael Fuller Graham
Susan Conway
Jean Graham

In Memory of George Jennison
Jan Mostrom

In Memory of Russell Mammen
Cheryl Doering

In Memory of Bill McDaid
Linda McDaid, South Shore Staffing

In Memory of Elaine Minow
David Feldman
Mark Feldman
Nell Minow
Barbara Winn

In Memory of Kaylee Grace Roberts Lush
Jim & Glenda Lush

In Memory of Mary Louise Zang
Michael & Joy Bachman
Michael & Traci Bernecker
Barbara Bidek
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Daniel & Julie Middendorf
Doug & Lois Moerlien
Terri Schatzman
Paul & Julia Sillis
Marianne Sommerkamp
Arlene & Donald Zang
Carol Zang
Jeffrey & Sandra Zang

In Honor of Natalie Abbott
Marcia Abbott
In Honor of Marcia & Natalie Abbott
Carole & Richard Perry
In Honor of Emma Baca
Monica Baca
In Honor of Kimberly Banning
Dave & Cheryl Banning
In Honor of Ben Becker
Rebecca Becker
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Frank & Marian Setzman
Meredith Setzman
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Anne Boussard
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Jeff & Stacy Burkdoll
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Chuck & Becky Cheney
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Eric Collins,
Spirit & Truth Apostolic Church
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Marilyn T. Miller, MD,
University of Illinois
In Honor of Faith Dressel
Marsha Gardner
In Honor of Noah Druzbicki
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In Honor of Addison Garvey
Backyard Brine
In Honor of Avery Marie Giannini
Janet & Tony Giannini
In Honor of Benjamin Graf
Alexa Graf
In Honor of Nicholas &
George Jennison
Lennart & Sandra Lindstrand
Antoinette Shewell
In Honor of Nicholas Jennison
Paul Hawkins
In Honor of Chase Koch
Douglas Koch
In Honor of Jacob Licht
Jeremy Epstein
In Honor of Miriam Licht
Dr & Mrs Melvyn Ciment
In Honor of Medow & Licht Families
Stanton & Ellen Stein
In Honor of Bill Moody &
Stefanie Littlewood
Stephen Moody
In Honor of Alyssa Lueckhoff
Nancy & Marc Lueckhoff
In Honor of Tobias Lugo
Nora Quinn
In Honor of Jessica Maher
Rebecca & Timothy Maher,
Novartis Pharmaceuticals
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Linda Marshall
In Honor of Emma Matthews
Ronald & Margaret Bulbulian
In Honor of Kelly Marie Mercier
Dave & Dawn Mercier
In Honor of Brody Peterson
Julie Peterson
Thank you to all of our donors!

In Honor of Larkin Pottle
Amy Beilman
Barbara Pottle

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Jen Ambrosini
Anonymous
Sharon Cheng, Connor Group
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Kimberly Em
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Yasmine Zaeni
Suzanne Zaretsky Miller

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Ruth & Jack Smart

In Honor of Linda Tate
Rob Hirschboeck

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Nicole Zeitler

Gina Alvino
Amazon Smile Foundation
Anonymous
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Kirsten Rice
Andrew Rowles
Beatrice Schultz
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Mark J. Sullivan
Carlos Torres,
Royal Oaks Energy Services
United Way of Greater Philadelphia
Jenny Whitman

Moebius Syndrome 2020 Financial Summary

INCOME

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<th>Category</th>
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<td>Donations</td>
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<tr>
<td>Investments</td>
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<tr>
<td>Conference Income</td>
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<td>Sales Income</td>
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<td><strong>Total Income 2020</strong></td>
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EXPENSES

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<tr>
<th>Category</th>
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<td><strong>Total Expenses 2020</strong></td>
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The repeatability of adaptation is a fundamental question in evolution. Will independent populations evolve in a similar fashion when facing the same environmental challenge? This question also has important public-health implications related to the global problem of antimicrobial resistance. For example, our efforts to control the emergence and spread of resistance might benefit from our ability to predict when and how it evolves. In my research, I study how genetic, demographic, and ecological factors influence bacterial populations’ potential to evolve resistance, with the goal of using this knowledge to design better treatment strategies.

I was honored to receive the Howard Hughes Medical Institute (HHMI) Hanna H. Gray Fellowship, which supports diverse early-career researchers in the biomedical sciences. This award will support me throughout my postdoctoral training and provide four years of funding for my future laboratory. Most importantly however, this award will help me elevate inclusive diversity within my scientific community and perform innovative research that will better the lives of others.