

MOEBIUS SYNDROME FOUNDATION NEWS

Moebius Syndrome Foundation
The Home for the Moebius Community™
Spring 2021



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 it's 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 to late for you to be counted!

2020 Census Responses

New Members in 2020

Professionals interested in Moebius syndrome

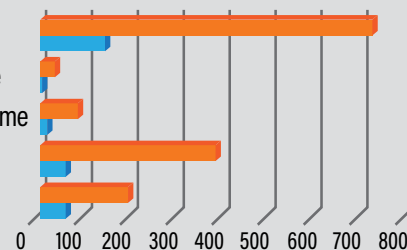
Family / Friends of someone with Moebius syndrome

Adults with Moebius syndrome

Parents of children with Moebius syndrome

Members

New Members



New Member Country of Origin

United States

UK

Canada

Australia

Colombia

Denmark

Ecuador

India

Philippines

South Africa

Spain

Argentina

147
New
Members in
2020



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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

"...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."

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 Moebius Syndrome News is published two times per year. Articles, photographs, questions and comments welcomed. The Moebius Syndrome News reserves the right to edit submitted material. Opinions expressed in the Moebius Syndrome News are each author's and do not reflect that of the Moebius Syndrome Foundation or the Moebius Syndrome News.

The newsletter is on the website at:
www.moebius syndrome.org



FACE EQUALITY
INTERNATIONAL



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 moebibussyndrome.org. We need YOU to be counted!

Happy Spring!

Dina Scalone, Executive Director

“You may have noticed our new and improved social media presence. Kelsey has taken our social media to the next level...”



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@moebiusyndrome.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

Moebius Syndrome Awareness Day, 2021

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."



The Phillips Family

"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."



The Morales Family

"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."

"Don't let the lack of expressions fool you; I still have emotions like everyone else."



The Santana Family

Paula Santana, Mathias Santana's mom shared that, "We celebrated here at home and created MSF goodie bags for all of Mathias' classmates, including a letter home to parents about him and Moebius syndrome. His classmates and their families' reactions reminded me that it is well worth the effort we put in to advocate for our community. Each year we receive thoughtful questions from people looking to learn more about Moebius syndrome, and witness an increased

"You can live a full and interesting life with Moebius syndrome."

"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."

sense of acceptance for our son within our school and local communities."

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.

"Moebius syndrome is a part of me but doesn't define me as a person."

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



Addison Garvey

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.



RAREDISEASEDAY.ORG

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://moebius syndrome.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!

**2020 MOEBIUS SYNDROME FOUNDATION
EDUCATIONAL SCHOLARSHIPS AWARDED**



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.

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

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.

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
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Mark Feldman
Nell Minow
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Jim & Glenda Lush

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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

Alan Guttman
Frank & Marian Setzman
Meredith Setzman

In Honor of Roland G. Bienvenu
Anne Broussard

In Honor of Sydney Burkdoll
Jeff & Stacy Burkdoll

In Honor of Anna Cheney
Chuck & Becky Cheney

In Honor of Leah Collins
Eric Collins,
Spirit & Truth Apostolic Church

In Honor of Carmen Delone
Marilyn T. Miller, MD,
University of Illinois

In Honor of Faith Dressel
Marsha Gardner

In Honor of Noah Druzbecki
Sara Hill,
Goodyear Early Childhood Center

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

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Nancy & Marc Lueckhoff

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Rebecca & Timothy Maher,
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In Honor of Allen Marshall
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

In Honor of Mathias Santana

Jen Ambrosini
Anonymous
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In Honor of You!

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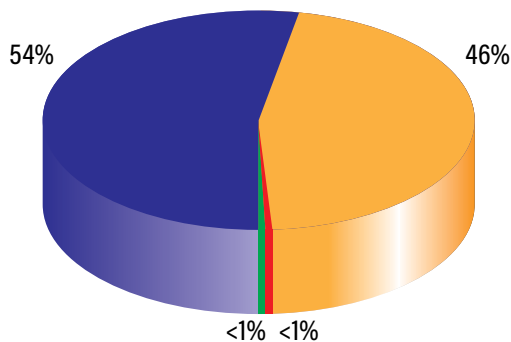
Moebius Syndrome 2020 Financial Summary

INCOME

| | |
|-------------------|--------------|
| Donations | \$166,224.30 |
| Investments | \$144,799.87 |
| Conference Income | -\$522.83 |
| Sales Income | \$100.00 |

Total Income 2020

\$310,501.34

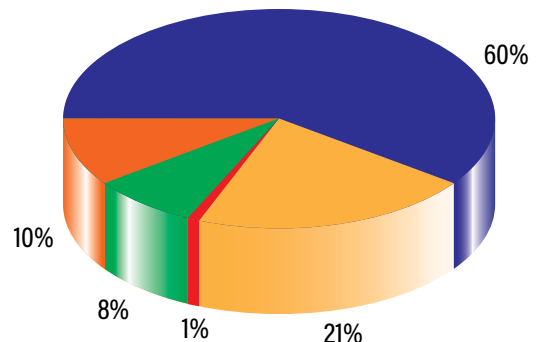


EXPENSES

| | |
|------------------------------------|--------------|
| Research | \$254,344.00 |
| Management | \$88,702.06 |
| Conference | \$5,313.21 |
| Scholarships, Communications, MSAD | \$34,939.95 |
| Operations | \$43,604.40 |

Total Expenses 2020

\$426,903.62



Moebius Syndrome Foundation

The Home for the Moebius Community™

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Follow Us



Kyle Card Receives Hanna H. Gray Fellowship



Hanna H. Gray Fellowship
recipient Kyle Card

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.