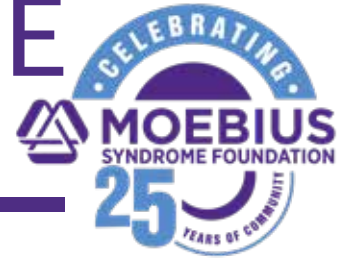


MOEBIUS SYNDROME FOUNDATION NEWS



Moebius Syndrome Foundation – The Home for the Moebius Community™
Spring 2020

Moebius Syndrome Awareness Day

On January 24th we were overwhelmed by all of the support shown around the world for Moebius Syndrome Awareness Day. Our social media accounts were flooded with purple, and it was thrilling to see all of the love, support, and awareness being shared.



The Moebius Syndrome Foundation financially supported many events – some people held fundraisers, some shared messages with friends, others had their employers do “donation matches”, and some people simply got together for friendship and support.

We also noticed an increase in news media coverage, including interviews and film coverage of Addison Garvey, a Kindergartner in Long Island, and Liam Kraushaar, a second grader in Lichtfield, Minnesota.

Well done, Moebius Community!



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For more Moebius Syndrome Awareness Day stories, please visit our website at <https://tinyurl.com/tjj8pz8>



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A Letter from our President

Dear Friends,

It's hard to believe we've been part of the Moebius syndrome family for 18 years, since our daughter Miriam was born. It's been a wonderful and gratifying time with some uncertainty sprinkled in, and we couldn't have done it without the Moebius Syndrome Foundation. I am honored and humbled to be the new President of the Moebius Syndrome Foundation and must acknowledge Vicki McCarrell's extraordinary vision and leadership over the past 25 years since she co-founded the Foundation.



I will always cherish our first phone conversation with Vicki as well as the first time we met others with Moebius syndrome, when Kevin and Lisa Smart welcomed us to their home during a Summer vacation when Miriam was only one year old.

For such a rare condition, the Moebius syndrome community is incredibly diverse. It consists of individuals with Moebius syndrome and their parents, family and friends. Our community also includes dedicated healthcare professionals and researchers who work with the Moebius syndrome community.

Some people with Moebius define themselves by their Moebius syndrome while others barely acknowledge it. Some people with Moebius have cognitive deficits and some are among the most intellectually gifted people you'll ever meet. Some have ten fingers and ten toes, and others have limb anomalies. Our community's diversity is one of our greatest assets.

My primary focus as President is to continue to ensure that the Moebius Syndrome Foundation is the premier resource for the entire Moebius community. We do this by providing information and support to the entire Moebius community and through conferences and the research we support. And I look forward to continuing this great work.

I regret that we won't be able to see each other at a conference this Summer, but I look forward to seeing everyone in Minneapolis in July 2021.

Sincerely, Jacob Licht, President

I am honored and humbled to be the new President of the Moebius Syndrome Foundation and must acknowledge Vicki McCarrell's extraordinary vision and leadership over the past 25 years since she co-founded the Foundation.

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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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.moebiussyndrome.org



FACE EQUALITY
INTERNATIONAL



A Letter from our Executive Director

Dear Friends, 2019 was an incredible year for the Moebius Syndrome Foundation as we celebrated 25 years of service to the Moebius community!

Because of your generous support we have made substantial investments in critical research including Bryn Webb, MD, Mt. Sinai School of Medicine; ‘Determining Genetic Etiologies of Facial Nerve Maldevelopment’ and Zhang Thomas Zhongyang, PhD, Mt. Sinai School of Medicine;

‘Genetic and Environmental Factors in Moebius Syndrome and Related Disorders. This research will enhance our understanding and treatment of Moebius syndrome and associated conditions.

It is disappointing that we postponed the 14th annual Conference in Minneapolis until next July but hope you will take advantage of our virtual offerings this summer. Our number one priority is the health and safety of our conference participants. We will diligently follow guidelines from public health agencies, including the Centers for Disease Control and Prevention (CDC) and World Health Organization (WHO). We will follow all recommended safety measures to ensure a memorable and healthy conference in 2021.

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 has been extended to June 15, 2020 and the application is available on our website.

Thank you for making this community so special and I am looking forward to seeing you (virtually!) this summer.

My best,

Dina Scalone, Executive Director

The deadline for Educational Scholarships has been extended to June 15, 2020.

A Change in Leadership



Jacob Licht, now President of the Moebius Syndrome Foundation with founder and outgoing President Vicki McCarrell.

After 25 years of leadership, Vicki McCarrell, the co-Founder of the Moebius Syndrome Foundation, is stepping down as President of the Foundation. The new President will be Jacob Licht, a 12-year MSF Board member who has served as Treasurer of the Foundation for the past five years.

Vicki McCarrell said, "It has been a tremendous pleasure serving as the president of the Moebius Syndrome Foundation the last several years. I look forward to remaining on the Board of Directors and working with Dina, Jenny and our Scientific Advisory Board as well as the other board members. I have no doubt that the Foundation will continue to grow and prosper under Jacob's leadership." Jacob Licht assumed the role of President of the Moebius Syndrome Foundation effective January 1, 2020.

Jacob has a daughter with Moebius syndrome, and along with his wife hosted the 2016 Moebius Syndrome Conference in Bethesda, MD. Jacob lives and works in the Maryland suburbs of Washington, DC, and is a corporate development executive at a European vaccine company.

“My family has been associated with the Moebius Syndrome Foundation since our daughter’s birth seventeen years ago and have benefited greatly from the Foundation’s important work. It is an honor to lead the Foundation and I am excited to continue the work that Vicki began and to help the Foundation continue to be the premier resource for the global Moebius syndrome community.”

Vicki’s role as co-Founder of the Moebius Syndrome Foundation extended far beyond the Foundation, and she was a true global ambassador for Moebius syndrome. Vicki said, “I treasure the relationships I have developed with men, women and children worldwide who have Moebius syndrome and their families, researchers, physicians, therapists, MSF board members, donors and other Moebius Syndrome Support Groups around the world as well as Face Equality International, NORD, the NIH and other craniofacial support organizations.”

She will continue to play many of these roles and serve on the Board of the Moebius Syndrome Foundation.

Moebius Syndrome Foundation Conference 2021

Save the date!

The 14th Moebius Syndrome Foundation Conference in Minneapolis, Minnesota has been rescheduled.

We announced on March 31, 2020 that the 14th Moebius Syndrome Foundation Conference to be held in Minneapolis, Minnesota was being postponed.

Although this was the right decision to best protect the health of the Moebius community, we know that it was disappointing to many.

It is with great pleasure that the Moebius Syndrome Foundation announces that **the conference has been rescheduled in Minneapolis, Minnesota for July 23-25, 2021.** This will include a full weekend including a research symposium, family fun activities, educational and interesting sessions, and lots of opportunities to connect with other families and individuals within the Moebius community. This is our premier event, and you won't want to miss it!



The Moebius Syndrome Foundation is going virtual.

We don't need to wait until 2021 to connect! The Moebius Syndrome Foundation will be providing a week of virtual sessions this July to help inform, encourage, and connect better with each other.

These sessions will include:

- Moebius Syndrome Research updates
- Scientific Advisory Board Q&A session
- Uplifting and informative presentation by Susana Romero
- A Bright Future: Looking Beyond Moebius Syndrome
- Overcoming Life's Challenges and Obstacles
- Just for Sessions: Chat sessions between Moms, Dads, Men, Women, Teens, and more
- Coping strategies to get through pandemic and difficult times
- Fitness session
- Game Night
- Talent Show

...and more!

www.moebius syndrome.org/2020virtual



Research Summary: Facial Paralysis

Social-Emotional Survey by Dr. Kathleen Bogart, PhD

Each year, approximately 225,000 Americans develop facial paralysis. It can be congenital (present at birth) like Moebius syndrome, Hemifacial microsomia, or birth trauma. On the other hand, people can acquire facial paralysis at any point in their lives from an illness or an injury like Bell's palsy, acoustic neuroma, Lyme disease, or ear infections. Previous studies have reported high rates of anxiety and depression among people with a variety of types of facial paralysis, but most studies have been too small to compare different types of facial paralysis. In the largest psychological study of facial paralysis, recently published in *Health Psychology*, this research examined whether being born with facial paralysis or developing it later in life it is associated with different socio-emotional factors. This study also compared adults with facial paralysis to the general public on social-emotional factors.

What social-emotional factors were tested

Anxiety symptoms = worry and fear

Depression symptoms = sadness and hopelessness

Emotional clarity = recognizing and understanding one's own emotions

Attachment = whether one is comfortable and trusting in close relationships

Stigma = experiences of being avoided, bullied, or discriminated against

Methodology

Participants were contacted through facial paralysis organizations and social media. A total of 112 adults with congenital facial paralysis and 434 people with acquired facial paralysis filled out an online standardized survey screening for social-emotional factors. Participants were from 37 different countries, with 67% living in the United States and 16% living in the United Kingdom. Ages ranged from 18-82, and the average age was 45.

Findings

On average, people with any type of facial paralysis experienced more anxiety, depression, and stigma compared to the general public. 37% had moderate to severe anxiety symptoms and 34% had moderate to severe depression symptoms. People with acquired facial paralysis had more problems with anxiety, depression, emotional clarity, and attachment compared to people with congenital facial paralysis. The main factors that seemed to lead to anxiety and depression were stigma and emotional clarity problems.

Conclusions

This study found that adults with facial paralysis, especially those with acquired facial paralysis, are at a greater risk of social-emotional problems. Although more than 1/3 of adults with facial paralysis had significant anxiety or depression symptoms, it should be noted that the majority of people with facial paralysis do not have these symptoms. Why? It seems that people who've experienced less stigma and have more emotional clarity as less likely to have anxiety or depression.

Recommendations

- Stigma is the main source of distress for people with Facial paralysis. Public awareness campaigns and trainings for healthcare providers, employers, and teachers are needed.
- Everyone with facial paralysis should be routinely screened for anxiety and depression and provided mental health services when needed, such as cognitive behavioral therapy or acceptance and commitment therapy.
- There are no specialized mental health therapies for people with facial paralysis. These must be developed and should address experiences unique to facial paralysis, including emotional communication, stigma, self advocacy, employment, and relationships. Support groups and conferences and communication skills training could be part of a therapeutic plan.
- If you or someone you know is experiencing emotional distress or suicidal thoughts, please call the 24 hour National Suicide Prevention Lifeline, 1-800-273-TALK (8255)

Reference

Bogart, K. R., (2019). Socioemotional Functioning with Facial Paralysis: Is There a Congenital or Acquired Advantage? *Health Psychology*. Advance online publication. <https://doi.org/10.1037/hea0000838>

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Thank you -to all of our donors!

Thank you to all of our donors! Because of your generous contributions, the Moebius Syndrome Foundation was able to award six educational scholarships in 2019, 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 through February 28, 2020.

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 Molly Bielesch
Tammy and Reinhold Bielesch

In Memory of Hannah Jade Devine
Mark & Susan Knox

In Memory of Ed McDaid, Bill McDaid
& Terry Garbuzinski
Jane McDaid

In Memory of Bill McCaid and
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In Honor of Marian Setzman's 70th Birthday
The Levine, Snyderman, Carlton,
Sumpter, and Guttman families.

In Honor of Pierce Zeitler
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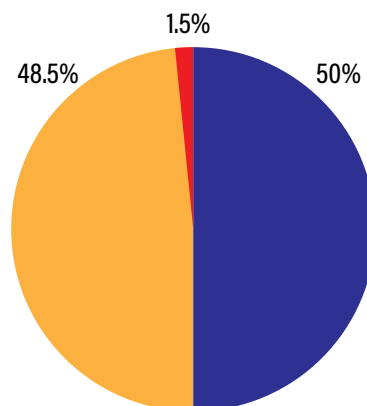
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Moebius Syndrome 2019 Financial Summary

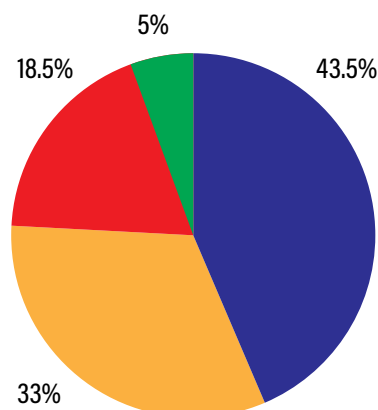
INCOME

	Donations	\$189,213.12
	Investments	\$183,183.51
	Conference Income	\$5,049.54
	Total Income 2019	\$377,446.17



EXPENSES

	Programs: College Scholarships, Conference, Membership	\$147,999.91
	Research	\$111,000.00
	Management & Operations	\$62,827.53
	Board	\$17,376.07
	Total Expenses 2019	\$339,203.51



Moebius Syndrome Foundation

The Home for the Moebius Community™

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Vicki McCarrell leaves NORD Board of Directors

Vicki McCarrell, co-founder and president of the MSF for 25 years, represented the Moebius syndrome community by serving on the NORD Board of Directors (National Organization for Rare Disorders) from 2011-2019. Vicki was also the chair of the membership committee for three years and served on the executive committee.

NORD supports 30 million Americans affected by 7,000 rare disorders. Founded 35 years ago, NORD is very active at the national level advocating for people in the rare disorder community, and is responsible for the Orphan Drug Act, among other rare disorder legislation.

Vicki learned a great deal from the experts in the NORD community and in terms of the future for the Moebius Syndrome Foundation, thanks to NORD, the MSF is developing a bioregistry. “Another thing I hope the MSF follows through on is obtaining our own ICD10 code so that physicians code people with Moebius syndrome *specifically as having Moebius syndrome*. Physicians currently use a craniofacial term to describe Moebius syndrome, but being more specific would help those with Moebius syndrome get the care that they require.”

Vicki says that her favorite memory of being involved with NORD was “learning from experts in the rare disorder community and attending outstanding summits/meetings.”



Vicki with Peter Saltonstall, CEO of NORD and Debbie Drell, Director of Membership.