2018 Moebius Syndrome Foundation Conference

Upcoming Events

Welcoming New Leadership
Moebius Syndrome Foundation Welcomes New Board of Directors Members

The Moebius Syndrome Foundation is pleased to announce that six new members have been added to the Board of Directors:

Bryn Webb, MD, New York City

Dr. Webb is Board Certified in Clinical Genetics and Pediatrics and is Assistant Professor in the Department of Genetics and Genomic Science & Pediatrics at the Ichan School of Medicine at Mt. Sinai Hospital in New York City. She is also the Co-Director of the Cleft & Craniofacial Clinic at Mt. Sinai Hospital, and is an active investigator in genetic research to better understand the etiology of Moebius syndrome and its associated conditions. She has presented at numerous Moebius Syndrome Foundation Scientific Symposiums and has worked with many individuals who have Moebius syndrome.

Paula Keebler Santana, Orinda, CA

Ms. Santana holds an MBA and Masters of Public Health from the University of California at Berkeley. She is currently a Marketing Director for Medivation, Inc., a large pharmaceutical company recently acquired by Pfizer, and has worked in the field for over 20 years. She is the mother of a young son who has Moebius syndrome.

Rebecca L. Maher, Wesley Chapel, FL

Ms. Maher has 22 years’ experience in sales and marketing for Novartis Pharmaceuticals Corporation and is a Senior Area Business Leader for the Southeast Region. She holds a Bachelor’s Degree from the University of Illinois Urbana-Champaign, has attended Moebius Syndrome Conferences since 2002 and is the mother of a teenaged daughter with Moebius syndrome. Rebecca is on the 2018 conference planning committee.

Kelsey Ferrill, Calgary, Alberta

Ms. Ferrill holds a Bachelor’s Degree in Communication Studies from the University of Calgary and earned a Journalism Diploma with Honors at SAIT Polytechnic in Calgary. She was a News Intern at Global News in Calgary and has appeared many times in various magazines, newspapers and television shows sharing her story of living with Moebius syndrome.

Nicolette Zeitler, JD, Hyattsville, MD

Ms. Zeitler is a Trial Attorney in the Disability rights Section of the Civil Rights Division at the US Department of Justice where she works exclusively on the Americans With Disabilities Act. She previously practiced campaign finance law at the Federal Election Commission. Ms. Zeitler holds a JD and BA in International Studies from the University of Washington in Seattle. She is the mother of a young son with Moebius syndrome.

Steven Maldonado MBA, Houston, TX

Mr. Maldonado holds a Bachelor’s Degree in Business Administration from the University of Houston and is completing his MBA at Texas A&M University. He currently is an Administrative Coordinator III in Immunology, Allergy and Rheumatology at Baylor College of Medicine where he is an administrator for NIH grants. Mr. Maldonado is a guest speaker in the Baylor College of Medicine, Compassion and the Art of Medicine Seminar Series, where he shares his life experiences as an adult with Moebius syndrome.
A Letter from our President

Dear Friends,

What a wonderful conference in St. Petersburg, Florida July 20-22!! Over 435 people attended, 25% who have Moebius syndrome ages 5 weeks to senior citizens, from 30 states and 8 countries. Amazing!! It was wonderful to see the beautiful faces of children playing together, teens hanging out together, and adults sharing life stories and successes. For us parents of children with Moebius syndrome, it was a very emotional experience as well.

The Moebius Syndrome Foundation held the 6th Moebius Syndrome Research Symposium on July 19, where 16 researchers shared the work that they are doing to unravel the mystery of the cause of Moebius syndrome and associated conditions. Two of the most incredible reports for me were the discovery that the cranial nerves DO attempt to develop, but sometime between the 10th and 20th weeks in development are calcified and thus do not further develop. Prior to this it was assumed the nerves did not develop between the 4th and 7th weeks. Also Dr. Gregory Borschel's work in transplanting nerves to develop blinking was fascinating.

Many thanks to all who attended, including our Scientific Advisory Board, which has grown from 8 to 14 physicians/researchers/therapists, and to outgoing Board members Marcia Abbott, Roland Bienvenu, Kathleen Bogart, PhD (who moved to the Scientific Advisory Board), and Matthew Joffe, MA. We greatly appreciate their years of service to the Moebius Syndrome Community.

Welcome to our new Executive Director, Dina Scalone, and new Board members Kelsey Ferrill, Steven Maldonado, Paula Santana, Bryn Webb, MD, Rebecca Maher and Nicole Zeitler. Together we are strong!

As a parting note, the Moebius Syndrome Foundation and Community extend our deepest sympathy to the family of Michael Fuller Graham. Michael, who had Moebius syndrome, and his wife Melanie selflessly donated his body to research when he sadly passed away on July 28. He was only 49 years old. Their gift will help advance the study of Moebius syndrome. Melanie approved me sharing this news, and to her we send our love and appreciation at this very difficult time.

New individuals/families contact us weekly, adding over 100 new names from 5 continents yearly. They are sent packets of information about Moebius syndrome, t-shirts for children with Moebius syndrome, and we facilitate contact with others in their state/country so they realize they are not alone.

Thank you to our wonderful ‘family.’ Best wishes to all of the children/teens/young adults as you return to school/college/university this fall. You make the world a better place.

Sincerely,

Vicki McCarrell
President
Moebius Syndrome Foundation

A Letter from our Executive Director

Hello,

It was great to meet so many of you at the conference this summer! Thank you for your warm welcomes and patience while I acclimate to my new role. I am excited to work with you all to provide resources and support to our growing Moebius community.

Please mark your calendars for the 2020 MSF National conference, the 14th Moebius Syndrome Foundation Conference in Minneapolis, Minnesota, July 16-July 19, 2020. In the meantime, we have some exciting news! In 2019 we are excited to announce that we will be hosting 2 regional weekend conferences, Moebius Syndrome Foundation Mini-Conferences! One will be held in Portland, Oregon on April 5-7, and the other in Ft Worth, Texas on November 1-3. These events will be smaller than our national conference and enable regional communities to come together to connect with each other, explore resources closer to home and stay informed on the latest advancements in research and treatments for people living with Moebius Syndrome. We hope that everyone will be able to take advantage of these gatherings, especially those who are unable to travel to the bi-annual national events. We need your help to ensure the success of this new venture so if you live in the Portland or Ft Worth area and are able to help us with planning these conferences please let us know!

Did you know that the Moebius Syndrome Foundation awards three (3) educational scholarships of $2,000 each, to individuals who have Moebius syndrome and will be attending an undergraduate college/university/post-secondary vocational school? Look out for an announcement for the 2019 application in early 2019! Please help us spread the word to eligible college-bound friends.

I am looking forward to working with you all so please don’t be shy! Reach out to me directly at dina@moebiussyndrome.org

Sincerely,

Dina Scalone
Dina Scalone
Executive Director
MOEBIUS SYNDROME AWARENESS DAY
JANUARY 24, 2019

Celebrated globally each year on January 24th — the birth date of Professor Paul Julius Moebius, the doctor who first diagnosed the condition in 1888. The goal of Moebius Syndrome Awareness Day is to raise awareness about this rare condition and to educate the world. Each year participants are encouraged to wear purple and raise awareness through various means and channels.

MOEBIUS MINI CONFERENCES
APRIL 5-7, 2019 PORTLAND, OR
NOVEMBER 1-3, 2019 FT. WORTH, TX

A family friendly, meaningful weekend with one day of educational and networking sessions, and one day of optional activities; held in non-conference years in two different rotating cities.

Friday night: Optional Adult Meet-Up
Saturday: Family and Adult Educational and Networking Sessions
Sunday: Optional Outside Group Activities

RARE DISEASE DAY
FEBRUARY 28, 2019

Rare Disease Day takes place on the last day of February each year. The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

ARE YOU HOSTING AN EVENT FOR MSAD?
EMAIL US AT INFO@MOEBIUSSYNDROME.ORG OR VISIT HTTP://MOEBIUSSYNDROME.ORG/SUPPORT-RESOURCES/GET-TOGETHERS/.
Moebius Syndrome Awareness Day
by Kelsey Ferrill

Each year, January 24th is a day that is widely celebrated in the Moebius syndrome community, as it is the official Moebius Syndrome Awareness Day. This date is so meaningful to all of us because it is the one day that is set aside to celebrate Moebius, and also to educate our society about what it means (and doesn't mean) to live with this rare condition.

There are lots of different ways to raise awareness on this day, some in the community have chosen to hold walks or runs, been featured in the local news or have gone into schools to educate students about Moebius syndrome and diversity.

This day is so important to me, personally, because it is a day when I can go out into my community and raise the awareness that is so needed in our society today.

The life event that sparked my involvement in celebrating this day was attending my first ever Moebius syndrome conference in 2010. Before that conference, I didn't want to acknowledge my differences and I really could not even bring myself to say the name of the condition that I have. I took a leap and attended the conference in Broomfield, Colorado and it completely changed my life. In 2011, it was my idea to create a movement to encourage people to wear purple, which is the official color of the Moebius Syndrome Foundation, to show their support and raise awareness. I created the page on Facebook called I pledge to wear purple on January 24th and the rest is history. Wearing purple on that day is now an annual tradition that most in the community take part in.

The first Moebius Syndrome Awareness Day that I officially held an event for was in 2014. It was my first year of the journalism program at SAIT (the Southern Alberta Institute of Technology) and with the help of one of my best friends and my roommate at the time, we set up a table outside the student association room. At that table, we encouraged people to come up and talk to us, so we could educate them about Moebius and pass out brochures. The next year, while still at SAIT, I held the same kind of event but this time my friends from the journalism program helped out. We asked people passing by to fill out signs that asked how they expressed themselves. That event was a giant success, and we ended up with an entire wall covered in those signs and we passed out hundreds of brochures. I also got a lot of media coverage that year too. Two local news stations came to cover the day and both the SAIT newspaper and journalism student paper covered it as well.

In the two years that followed, I was a student at the University of Calgary and both of my years there, I held the same kind of awareness events, thanks to the help of some amazing friends. Both of those events also got massive media coverage which got the word out not only to students at the U of C, but also the larger community and city.

Planning an awareness day event takes a lot of time and organization, but I do it because I know the importance and it means a lot to me to be able to raise awareness on that day. I have witnessed firsthand the comments, stares and general prejudice that we with Moebius are prone to. I truly believe that the way to combat these things is through education and awareness. It is so important to show people that having Moebius does not define us, nor does it make us less worthy of respect or opportunity. We all have the power to make a huge difference and by holding these awareness day events, I truly believe that is what we are doing.
Once again, the Moebius Syndrome Foundation Conference did not disappoint. This year attendees traveled to St. Petersburg, Florida for the 13th year to partake of 4 days of learning, sharing, inspiration, and of course, lots of key lime pie.

Over 435 people from 7 different countries were at conference. Let’s just stop and revel in how much diversity was present—diversity in thought, company, job profession and world views! But everyone had at least one thing in common, and that is that they have, or love someone, with Moebius syndrome.

Some of the most prominent themes from the entire conference were: overcoming challenges, treating everyone with love, respect, and kindness, and sharing triumphs and positivity. Seemingly, the most meaningful sessions for many were the “Just For” sessions where groups of moms, dads, grandparents, men, women, and teens discussed their challenges, heartaches, fears, successes, and real-life situations together in safe environments. We heard repeatedly how therapeutic it was to be able to share these things with others that truly understood.

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Photos taken by Rick Guidotti will be available soon on our website!
Hi everyone, I'm home and finally starting to process all the incredible, emotional feelings I have right now. I want to say a massive thank you to every single one of you for making me feel so welcome, filling me up with love and positive energy.

I also want to share something that I wrote too. Over this week, there have been a few tears to say the least. But those tears haven't come from staring...

None have come from hurtful comments.

None of have come from a jealous bully

And most of all none have come from hate

WE have created an environment where we have had tears of relief, understanding and love.

TOGETHER we have created an environment where all of us felt empowered and free to be ourselves.

It truly is life changing.

But what's next?

What can we do now?

The aim now is to create our homes, our community's, our schools, even our world. To be like the weekend we have just shared.

Full of people that are empowered to be themselves and most of all free from hate.

Because if not us, then who??

Whilst our world leaders argue amongst them selves and their toys, We can make it A better place for us all.

I'm not asking you to go on a crusade (although I know many will happily do so)

I'm not even ask you to do anything you don't want to do.

I'm asking you to be your amazing beautiful self Raw, open and as we sang - this is me!

We can do this, we can change the world.

Love your self and the rest will follow!

Love 'a jetlagged' happy Jono

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Life is a Puzzle with a Missing Piece
By Valerie Garcia - Valy

Life is a puzzle with a missing piece,
Everyone tries to fill the empty spot,
Some people think that the piece can be bought,
Others think that the piece can be cheated.
But at the end their efforts are always defeated,
Some people search all their lives,
But the missing piece never arrives,
Very few find what they are looking for,
But even if they do, they'll always want more.

Life is a puzzle with a missing piece,
Some people put it together with love and admiration,
While others rush with desperation,
If you're lucky it will take you days or maybe weeks,
But for most it will take a lifetime to build,
When you're done you'll feel wise and skilled,
It will take a lot of dedication,
You will want to give up because of all your frustration,
And you will realize some pieces just don't fit.
You will even debate breaking the puzzle in half,
Or maybe it will be easier to toss it in the trash,
But you have to think of all the time it took,
And of how beautiful it will look.

Life is a puzzle with a missing piece,
When you are done you will look at your masterpiece,
That is, until you realize there is one piece missing.
You will look under the covers
Below the sofa
But you won't find that piece,
Because that piece is something hidden deeply underneath.
The missing piece is what makes you happy.
It might be a place or maybe a thing.
That piece could truly be anything.

My life is a puzzle with a missing piece,
Of the smile in my face that I will never see,
But my puzzle looks beautiful without it,
So it doesn't matter if the pieces don't fit,
Because my puzzle was not cut the same,
And for that, there is no one to blame.

When God designed my puzzle he meant for it to be seen with beauty,
And I believe he did his duty.

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thoughts from the Conference
Surgical and Postmortem Tissue Donation: Advancing Moebius Syndrome Research

Analysis of tissue samples and blood samples is a vital part of genetic research for complex conditions like Moebius syndrome. Unfortunately, the limited supply of tissues is a barrier to progress in understanding the causes and improving the diagnosis and treatment of this rare disorder. Tissue donation includes discarded tissues from surgery, as well as postmortem (after-death) donations of brain and other organs. If someone with Moebius syndrome is undergoing a surgical procedure of any kind (including, but not limited to, orthopedic, abdominal or thoracic, ophthalmological, or smile procedures), small pieces of tissue that the surgeon would normally discard could instead be donated to research. Agreeing to donation would not change the medical procedure or amount of tissue removed by the surgeon, and would not cost participants anything. Additionally, abnormalities of the brainstem, cranial nerves, and muscles are suspected to be the source of the eye, face, and limb and other complications experienced by individuals with Moebius syndrome. Therefore, postmortem donation to research teams of nervous system, muscles, and potentially other tissues from individuals with Moebius syndrome when they pass away is exceedingly valuable.

If you are interested in learning more about tissue donation, please contact Vicki McCarrell (vicki@moebiussyndrome.com), President and Co-Founder of the Moebius Syndrome Foundation. It is important to keep in mind that tissue can be fragile, so timing around tissue donation can be critical. Therefore, making decisions and arrangements in advance, whenever possible, helps ensure your donation will have the greatest value to Moebius Syndrome research.

Elizabeth Engle, MD, Boston Children's Hospital

Moebius Syndrome Foundation Scientific Advisory Board

The Moebius Syndrome Foundation would like to thank our friends at Music with Friends, Hotel Zaza in Houston, and The Palm restaurant for their generous raffle donations for the 13th Moebius Syndrome Foundation Conference in St. Petersburg, Florida. This "Experience Houston" package is valued at $2500! Congratulations to Julie Leahy for winning this amazing package! Please take a moment to check out their websites and tell your friends!

www.musicwithfriends.com
www.hotelzaza.com/m/houston
www.thepalm.com/restaurants
Moebius Syndrome Foundation Financial Summary 2017 (as of Dec 31, 2017)

Income
Donations $167,382.59
Investment Income $107,195
Interest $4,290.29
Other Income $1,218.73
$280,086.61

Expenses
Research $156,000.00
Foundation Staff & Consultants $42,763.79
MSF Conference Expenses $43,295.49
College Scholarships Awarded $6,000.00
Marketing, Web & Database $11,108.63
Meeting & Travel Expenses $11,811.74
Tax Preparation $2,450.00
D&O Insurance $1,584.00
Phone lines $212.19
Regional Events $2,000.00
Discretionary Medical Fund $500.00
Other Expenses, Supplies & Dues $957.92
$277,725.84

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With a speaker lineup including Jono Lancaster, Rick Guidotti, Dr. Elizabeth Engle, Dr. Irini Manoli, Dr. Azizzadeh, Dr. Leah Stock-Holmes, Dr. Ronald Zuker, and Vicki McCarrell, to name a few, just by attending the keynotes and some of the “Just For” sharing sessions, the attendee experience was meaningful and inspiring. Then, adding on the many options for more concentrated learning experiences in breakouts sessions topics ranging from Orthopedics, Dentistry, Autism, Trach and Ventilators, Alternative Medical Care, Respiratory Treatment, Smile and Hand Surgeries, Speech and Feeding, Optometry, Bullying, Social Skills, Employment Specialty, Self Esteem, Mental Health, Research, and so much more, the overall attendee experience reported in survey feedback was phenomenal. There were also several social events such as the Welcome Reception, Moebius Movie Night, Talent Show, Teen Scavenger Hunt, and a trip to the Aquarium. Wow. The #MSFCon18 was hands down one of the best conferences out there. We are looking forward to beginning plans for the 2020 Conference in Minneapolis, Minnesota.
Thank you to all of our donors! Because of your generous contributions, the Moebius Syndrome Foundation was able to award several educational scholarships in 2018, fund more than $156,000 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.

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.
Happy fall to our Moebius syndrome family. We loved seeing your back to school photos!