Moebius Syndrome Awareness Day!

Moebius Syndrome Awareness Day (MSAD) was celebrated on Saturday January 24, the birthday of Dr. Paul Julius Möbius, across the country and internationally. Get-togethers, walks, gatherings of family and friends, and presentations took place—often with our signature purple, in t-shirts, balloons and even purple pancakes. Many people posted their activities in Facebook groups and shared their experiences. Our new Moebius Syndrome Awareness Day logo is courtesy of Beau Bogart.

Look for MSAD next year, including new purple MSAD t-shirts for the family from the Moebius Syndrome Foundation, on Sunday January 24, 2016 and plan what you will do to increase awareness of Moebius syndrome.

More photos on page 4.

Look Beyond Face Value by Raising Awareness

By James Gaither, Sara McCracken and Kathleen Bogart, PhD
Disability and Social Interaction Lab, Oregon State University

Research in our Disability and Social Interaction Lab finds that greater public awareness results in more positive first impressions of people with Moebius syndrome. In an attempt to apply this research and to decrease stigma around social interactions regarding Moebius syndrome and other disabilities, Oregon State University’s Disability and Social Interaction Lab developed a pilot educational campaign that took place over the
Greetings!

It is wonderful this time of year to see photos on social media of all the young people with Moebius syndrome who are graduating from high school and college with exciting lives ahead, as well as prom pictures and photos of young children who are moving through elementary and preschool. We are proud of all of you. We also will never forget the children and adults with Moebius syndrome who are no longer with us; our hearts go out to their families.

These are exciting times for the Moebius Syndrome Foundation as we plan the July 2016 conference to be held in Long Beach—we hope you are making plans to attend. The NIH research grant that Drs. Jabs, Engle and Manoli secured to work toward finding the genes that cause Moebius syndrome continues to provide hope for all with Moebius syndrome. We greatly appreciate their support and that of our dear friend Dr. Francis Collins, Director of the National Institutes of Health.

Thanks to the never ending generosity of each of you, we have been able to hire our first ever paid part time Executive Director! Kimberley Cunningham will begin working with us on June 8 and we are thrilled that she will bring her experience with the Children’s Well-Being Foundation, American Medical Student Association and American Heart Association to the Moebius Syndrome Foundation. In her new role Kim will lead us through strategic planning, and will take on some of the duties that Marcia Abbott has done so professionally for the past 13 years including the newsletter, our ever growing database of members, and will help design a new and improved website. Marcia has done an outstanding job and will remain on the Board as Secretary.

On behalf of the MSF Board of Directors, we thank you for your continued support. Keep those photos and letters coming. You are members of a dynamic, well respected Foundation.

Warm wishes,

Vicki McCarrell
President
Moebius Syndrome Foundation Selects First Executive Director To Lead Organization

The Moebius Syndrome Foundation, the nation’s largest organization dedicated to the support of individuals and families with Moebius syndrome, is proud to announce Kim Cunningham as its new executive director. She began her new position on June 8, 2015.

Cunningham brings to the organization more than 15 years of executive leadership, communications and development experience in the nonprofit sector. Previously, she served as Executive Director for the Children’s Well-Being Foundation and as Director of Public Relations and Managing Director of Development for the American Medical Student Association, the oldest and largest independent organization of physicians-in-training in the United States. Cunningham has extensive experience in the healthcare industry and with patient advocacy organizations.

“We are happy to have Kim on board to take the Moebius Syndrome Foundation to the next level,” says Vicki McCarrell, President and Co-Founder. “Kim’s experience in communications, development, and leadership will help raise awareness of this rare neurological congenital condition which renders those affected with ‘smiles that come from the heart.’”

“The Moebius Syndrome Foundation has a powerful mission and I am honored to have been selected to serve the organization and work with this amazing community,” says Cunningham. “As the first executive director, this is an exciting time for the Foundation. I look forward to this new challenge and will dedicate myself to raising awareness and understanding of Moebius syndrome.”

About the Moebius Syndrome Foundation

Founded in 1994, the Moebius Syndrome Foundation provides information and support to individuals with Moebius syndrome and their families. The Foundation promotes greater awareness and understanding of Moebius syndrome and advocates for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions. For more information on Moebius syndrome, the Foundation or becoming a member, please visit www.moebiussyndrome.com.
The Moebius Syndrome Foundation created four designs of our Moebius Syndrome Awareness Posters with the words “look beyond face value” or “our smiles come from our hearts” especially for MSAD and Rare Disease Day. They were offered free of charge, and there are a limited number of the 19 x 13 posters left.

If you would like a poster sent to you, send an email to marcia@moebiussyndrome.com. Specify which poster you would like, and your mailing address. Sorry, we are out of poster 1 (the two girls!).

All posters are on our website and can be downloaded in the 8.5 x 11 inch size at http://www.moebiussyndrome.com/go/news/free-moebius-syndrome-awareness-posters-available-in-the-moebius-marketplace.

Moebius Syndrome Awareness Posters
“What Are You Looking At?” is an acrylic painting that I entered and won by an online popular vote into the 6th Annual RareArtists art contest for persons with rare diseases. The painting is a self portrait. When you draw your attention to the eyes, curiosity strikes you as to what is she looking at. Clearly she is looking at you and your inner imperfections as a mirrored image of judgment that I or others with Moebius experience regularly.

I had achieved my dream and won a lifetime opportunity to have my painting displayed on Capitol Hill in Washington D.C. during the Rare Disease Legislative Advocates’ Rare Disease week in February.

My mother and I had ventured down together in Washington to attend the 1st Rare Artists Reception where I had the opportunity to meet, display my art, and share my personal story about Moebius syndrome with more than 200 fellow rare disease advocates, industry partners, Members of Congress, and Congressional Staff. It was truly an honor and privilege to not only represent “What are you looking at?,” but to represent Moebius syndrome in the fight for spreading awareness and recognition for funding of all rare diseases. I would like to thank the Moebius Syndrome Foundation for helping my mom and I attend this opportunity of a lifetime.

I would also like to thank the Moebius syndrome community for all your loving support, voting, and warm comments. I wouldn’t have been able to experience this moment without you all! 😊

Como é ter Síndrome de Moebius?

Amanda Nascimento of Brazil has published a book about Moebius syndrome. The book is written in Portuguese, has 96 pages and can be ordered by the following email: amandanovonascimento@hotmail.com. Information about the cost will be provided in the email response. Part of the proceeds will be donated to the Brazil Moebius Association.

There is a very interesting image in the back cover: a drawing Amanda made when she was eight years old. The caption below the drawing says: Amanda always liked to scribble on papers with her pencils and pens. More than the expression of her childhood’s creativity, the colorful and effusive image in the drawing is indicative of the feeling of happiness that she wanted to show in her face, but overflowed in her heart. 😊

Como é ter Síndrome de Moebius?

Amanda Nascimento with her new book in Brazil.
Following Moebius Syndrome Awareness Day on January 24, the international Rare Disease Day took place on the last day of February, Saturday February 28. The purpose is to raise awareness of all rare conditions, and we in the Moebius syndrome community may use it as an opportunity to again raise awareness of Moebius syndrome and the other 7,000 rare conditions. NORD (National Organization of Rare Disorders) and Global Genes sponsored many activities throughout the country including NORD’s state house events with presentations by families impacted by rare conditions in 32 states. Governors in 36 states issued Rare Disease Day proclamations, and the US Senate passed a resolution designating February 28 as Rare Disease Day.

One of the Rare Disease Day events was the Rare Artist Reception and Gallery in Washington DC, sponsored by www.rareartist.org from the EveryLife Foundation for Rare Diseases. As one of the 2015 award recipients, Tracy Harper, an adult with Moebius syndrome from Canada, was one of the artists featured in the exhibit.

GIVE RARE was established as a single day for the world to give to rare diseases. It took place on the first Tuesday of March as a 24-hour online event to encourage people to donate to rare disease organizations. The Moebius Syndrome Foundation had our own page on the website— www.giverare.org.

In 2016, Rare Disease Day will take place on the rarest day ever, Monday, February 29, and Give Rare will take place on Tuesday March 1. We hope that everyone will participate in some way.

Dear Moebius Syndrome Foundation,

I am writing to you today to say “thank you!” Thank you for making the transition from “new mom” to “special needs mom” a little less scary. Thank you for sending me email addresses for Moebius moms in MN so I could be in contact with them after our son Liam was born. Thank you for sending Liam a “Moebius Syndrome” t-shirt to help spread awareness. Thank you for accepting our application for the scholarship to go to the conference in Washington DC this past summer!

The amount of information, love and support we received there was invaluable! Not only did we receive the scholarship through the Moebius Syndrome Foundation but we also received a scholarship through Miracle Flights which paid for our entire family to fly to Washington DC. Without your knowledge and resources this never would have been possible—so thank you!

While at the conference we had a consultation with Dr. Zuker and Sarah Rosenfeld-Johnson. Because you provided these resources at the conference Liam has started a new speech therapy regimen and has made tremendous improvement! Because of you we have made life-long friends which we never would have met otherwise. Because of you we know that we are providing our child with the best support and resources there are—in the world!

Those who help us most often go unrecognized and I would like to take this opportunity to thank you from the bottom of our hearts for all that you’ve done for our family and the entire Moebius community!

Sincerely,

The Kraushaar’s
This question was posed on the Moebius Moms closed Facebook group.

Q: How many parents have a child on a ventilator? Has anyone had a doctor suggest that your child just has a lack of effort? What are some of the suggestions doctors have made for respiratory issues?

The following answer was posted in the Moebius Moms Facebook group.

A: My son is on a vent for central sleep apnea and alveolar hypoventilation. We didn’t get the hypoventilation put in there until some sleep studies were done when he was two, but now he is back on the vent 24/7. When he is off the vent he breathes very fast, about 60+ breaths per minute. For him it is all neuromuscular so they don’t really know exactly what is going on. Hypoventilation doesn’t seem common but goes with CO2 build ups and shallow fast breathing as well as having central sleep apnea under the umbrella. CCHS (Congenital central hypoventilation syndrome) is a different type of hypoventilation where some people do not have a drive to breath at all when they are asleep and it varies as some are on vents 24/7 and some are not on vents at all. His hypoventilation issues stem from a neurological source. As Moebius is a neurological condition and all of this stuff happens in the same area of the brain it makes sense. I don’t like it but I see how it happens.

The following response was provided by Dr. Hollis Chaney:

A: Moebius syndrome generally affects the cranial nerves, commonly limiting the movement of the face and eyes. Because it can lead to difficulties swallowing, food might be aspirated into the lungs, causing significant lung disease. Also, sometimes there is hypotonia, or weakness, which affects the ability to take deep breaths and cough.

A small percentage of children also have brain stem hypoplasia, meaning that the part of the brain that drives breathing doesn’t work properly. The more severely affected will have inadequate breathing in the first days of life. They may have shallow breathing, pauses in their breathing (apnea), and turn blue. Children with a milder form may have difficulty to the point where it makes them cough, but he will need to be careful not to trigger asthma. The other reason for mucus in the throat could be post nasal drainage. If he has much nasal congestion, particularly if the mucus is colored, he should try exercising to the point where it makes him cough, but he will need a new symptom. Is there something I can do to reduce the need to clear my throat so often?

Q: As an adult with Moebius syndrome, I manage asthma symptoms daily with Singulair and a Q-VAR inhaler, with albuterol occasionally, when needed. For a number of months now I have so much phlegm in my throat I have to clear my throat often, a new symptom. Is there something I can do to reduce the need to clear my throat so often?

A: From Dr. Hollis Chaney

Frequent throat clearing means there is a lot of mucus in the lungs that is coming out and getting stuck in the throat. If he can actually cough any of it out and it is colored, he should get an antibiotic. Two things that could help would be Chest PT (have someone cup their hand and clap on his chest), and, if possible, get a nebulizer from his doctor and put hypertonic saline 3 percent in it. After breathing in the saline, it will loosen up the mucus and help him cough it out. This is the best time to get some chest PT. If there is no one to do the CPT, he could try exercising to the point where it makes him cough, but he will need to be careful not to trigger asthma. The other reason for mucus in the throat could be post nasal drainage. If he has much nasal congestion, particularly if the mucus is colored, he could have a sinus infection and need an antibiotic.

Hollis (Holly) Chaney MD is an Assistant Professor in Pediatrics at the George Washington University School of Medicine and Health Sciences. Dr. Chaney is the Vice Chair of the Division of Pulmonary Medicine at Children’s National Health System in Washington, DC. She is board certified in pediatric pulmonology. Dr. Chaney has been practicing in Children’s Division of Pulmonary Medicine for over 15 years. She has a special interest in rare congenital diseases. Send questions for Dr. Chaney to Newsletter@moebiussyndrome.com.
The ADA and Disability Discrimination—An Overview

By Roland Bienvenu

Twenty five years ago, President George H. W. Bush signed the landmark Americans With Disabilities ACT (ADA) into law. The ADA prohibits discrimination against people with disabilities in employment, transportation, public accommodations, communications, and governmental activities. Five federal agencies enforce the provisions of the ADA. The Equal Employment Opportunity Commission (EEOC) enforces the regulations regarding employment. Employment issues appear to be of large concern to those of us with Moebius syndrome who are about to enter the workforce (or are already in it). This article will focus on the ADA’s provisions regarding employment.

In addition to the ADA, there are other legal protections from discrimination based on disability. For example, Executive Order 11478 prohibits employment discrimination and requires affirmative action on various bases, including disability, by the federal government. Also, some state and local governments have their own anti-discrimination statutes regarding disability.

Employment discrimination is prohibited against “qualified individuals with disabilities.” This includes applicants for employment and employees. An individual is considered to have a disability if he/she has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment. The important part of this for many of us with Moebius syndrome is that this definition protects individuals who are regarded as having a substantially limiting impairment, even though they may not have such an impairment.

ADA has provisions about employers providing “reasonable accommodations” for people with disabilities who either seek employment or may already be employed. A job accommodation is a reasonable adjustment to a job or work environment that makes it possible for an individual with a disability to perform job duties. Accommodations may include specialized equipment, facility modifications, adjustment to work schedule or job duties, as well as a range of other creative solutions.

Employers are only required to accommodate a “known” disability of a qualified applicant or employee. This requirement will generally be triggered by a request from an individual with a disability who may be able to suggest an appropriate accommodation. When applying for employment, you are not required to disclose the fact that you have a disability. It is also a violation of the ADA for an employer to ask you if you have a disability. However, they may ask you if you are able to perform certain essential functions of a job and may even ask you to demonstrate this ability.

The scope of the ADA was broadened with the passage of the ADA Amendments Act (ADAA) in 2008. The ADAA overturned a series of Supreme Court decisions that interpreted the ADA in a way that made it difficult to prove that an impairment is a “disability.” For additional information on the ADA, visit the U. S. Department of Labor website (www.dol.gov) and go to “disability resources.” You can also call the ADA Information Line at 800 514 0301.

Roland Bienvenu retired from the human resources field in 2013 and resides in Sugar Land, Texas, just outside of Houston. He currently serves on the board of the Moebius Syndrome Foundation.

Legacy Gifts

Do you want to be able to do more for the Moebius Syndrome Foundation? Would you like to help enhance research, development and therapies? Then remember us with a legacy gift from your IRA or Estate. It’s really easy: for your IRA, just add us in as one of your beneficiaries. It takes one signature on a change of beneficiary form from your provider. Or, if you choose to leave part of your estate to The Foundation, call your attorney to add an amendment to your Will or Trust. What we plan for today can make a great difference for the future of our loved ones tomorrow.
Updates on Moebius Syndrome and Other Congenital Facial Weakness Disorders
Research Study on Moebius Syndrome

Greetings from the Study on Moebius Syndrome and other Congenital Facial Weakness disorders.

Thank you to all of you who have participated or contacted us with regards to this wonderful collaborative effort between Mount Sinai Health Systems, Boston Children’s Hospital and the National Institutes of Health. We have some brief updates with regards to the study:

- Seventeen participants affected with Moebius syndrome or other Congenital Weakness disorders (and their family members) have been evaluated at the National Institutes of Health (NIH) clinical Center in Bethesda, Maryland
- Fifteen additional participants and their family members are scheduled to be seen this spring/summer
- A secure database system has been set up to share data that has been collected at other sites. Close to 300 people have been entered into the database system.
- Monthly teleconferences have been held amongst the collaborators to discuss the study’s progress and plans going forward
- Our 2nd in-person meeting will be held at the NIH this summer

It has been quite a successful year of collaboration and we will continue to maximize our efforts to make new discoveries and advances toward a better understanding of Moebius syndrome and other congenital facial weakness disorders.

If you would like to have more information about the study please contact Carol Van Ryzin, RN, CPNP by phone at 301-827-1071 or by e-mail at moebius@mail.nih.gov. More information at: http://www.moebiuussyndrome.com/go/news.nih-moebius-research-study.

Oral Placement Therapy Study Discontinued

I am writing this letter with deep regrets regarding the oral motor treatment study “Alternating Treatment Design with Multiple Probes across Behaviors and Groups of Children with the Diagnosis of Moebius syndrome,” that was initially developed two years ago, in cooperation with Dr. James Dworkin from the Detroit Medical Center. My sincerest and unavoidable apologies are expressed to all of you as a result of the decision to terminate this investigation. Over the past two years we have been unable to recruit a sufficient number of participants and their families to proceed with this important study. I do want to thank all of the parents, therapists and of course the children who were involved with the study as each of you made a big commitment in both time and energy.

~Sara Rosenfeld-Johnson

Webinars
Recent webinars of interest to people with Moebius syndrome are now online for viewing:

**Congenital Facial Paralysis**
by Bryn Webb MD
http://www.facialparalysisfoundation.org/webinars/

**Facial Neuromuscular Retaining**
by Jacqueline Diels OT
http://www.facialparalysisfoundation.org/webinars/

**Facial Paralysis**
by Andre Panossian MD
https://plus.google.com/u/0/s/dr%20panossian

Young Adult Advisory Board

The Moebius Syndrome Foundation has created a Young Adult Advisory Board, which will report to the Board of Directors regarding issues relevant to their age group. Our first young adult advisory board members are Jeanne Dyer, Gavin Gardner, Austin Halls, Allie Johnson, and Madison Woodall. The group will meet approximately twice per year via videochat. Upcoming agenda items include ideas for conferences and social media campaigns. If you are between the ages of 16 and 21 and would like to apply for the board, please email: Kathleen.bogart@oregonstate.edu.
Tell Your Story and Own Your ‘Self’
By Tim McCaughan

To my kids, I’m just “Dad.” They’re eight and six now. A boy, Jackson, and girl, Sophia. They’re much closer to being teenagers than I am from having been a teenager. Exponentially closer! Sigh!

But my youth doesn’t seem all that long ago to me. The secret you realize when you become an adult is that you never feel as old as you are. (Except when you get out of bed in the morning—but that’s different.)

Also, that “adult” word. There are no “adults.” Everyone’s just making up life as we go. If someone tells you otherwise they’re kidding you or themselves. But that’s also an aside.

So back to the kids. “Dad” is just who I am to my kids. They know when I’m happy and they know when I’m distracted, and they certainly know when they’ve done something to tick me off.

Since becoming an “adult” Moebius syndrome has only been an issue when I’ve made it one. And I intentionally bring it up. As in polite society we don’t generally ask when someone appears different. But that doesn’t mean folks don’t think about it.

I’ve always been ready to explain. Quickly. Happily. It’s no big deal: “You’ve probably noticed. I have something called Moebius syndrome. Basically, it’s a facial paralysis. I tell you so there’s no mystery and also because I may appear more serious than I really am. In fact, I’m quite the opposite…”

And then—if that opens a conversation up about it—there’s a funny story about my wife thinking I was a jerk when we first met.

You’d be surprised how quickly people warm up to you when—as a gentleman who attended my talk for teenagers at the last Moebius Conference put it—“you own your SELF.”

It shows confidence. It shows you’re secure. It shows there’s no mystery. It answers the questions that are unasked. It works in social situations. It works in work situations. I’ve never had a moment where it did not work.

Really? Something this heavy you can talk about in a social situation? To that I reply: it’s only heavy if you make it heavy.

I can remember Moebius always being in the forefront of my mind when I was a teenager and when I was just out of college. Especially in social situations. How could it not be? But once I learned to use it as a (pardon the Washington inside-the-beltway talk) “talking point” I became more at ease. And quickly found that it was a non-issue for almost all people.

I encourage you to practice talking about it with parents, with friends, with uncles, aunts, cousin, your dog, cat, goldfish, iguana… whatever makes you comfortable and MORE comfortable with what you want to say. The easier it is for you the easier it is for others.

And for those people who are still standoffish? I’ve stopped having the time or patience for them. Always be nice. But don’t be offended by their oafish behavior. Just walk away. It’s them not you.

I have had the honor of meeting and talking to the last three US presidents as I produced television coverage of them. I can report that President Clinton, President Bush and President Obama and their staffs have all treated me as they would any other. That’s what you should expect.

You are stronger for having Moebius syndrome. It has given you a better empathy towards the human condition earlier in life. Don’t discount that. And don’t discount the credit those you meet will give you for having overcome the additional challenges it has presented you. You should tell that story. Communicating who you are helps others meet you where you are.

My kids never had to figure out who I was—they’re growing up knowing. They show how social behavior is learned and how quickly and readily anyone and everyone can adapt to new circumstances. I look at them—they were unaffected by my Moebius—and I know they will be better people as they grow up having accepted differences from the beginning of their lives.

As you continue on your life’s journey, intertwine Moebius syndrome with that story. Tell the story of your “self.” Make it about Moebius but make it more than that. Make it bigger than that. Moebius is a part of you. But only one part. Tell them that.

Tim had a 20-year career with CNN in Washington, DC. Eleven of those years were spent in the network’s White House Unit covering the last three US presidents in more than 40 countries and all 50 states. He is currently starting his own company—outside the media world—developing a new mobile app. Stay tuned for details.
Hi!

We are so thankful for this opportunity to address you. Our son/daughter, (child’s name here), will be in (number) grade with your child, and we are hopeful that they will all have a great experience and build strong friendships that become the cornerstone of a positive academic career.

All children have strengths and weaknesses, challenges and differences. Our son/daughter (child’s name here) has some physical differences that may be something your children notice and speak with you about. We hope that with this heads-up, we can reduce any awkwardness or discomfort for the kids.

(Child’s name here) has Moebius syndrome (pronounced “mo-bee-us”). It’s a very rare disorder that affects facial movement and some muscle function. The main feature of this condition is facial paralysis, due to missing nerves. (Child’s name here) cannot blink or squint, and cannot move her eyes left to right. She cannot frown, and because her top lip does not move, she cannot smile like you and I, or fully close her mouth. At times her speech can be difficult to understand also.

This is (child’s name), smiling her biggest smile… (attach a photo here)

Moebius syndrome is not progressive, but new challenges arise with age and new social situations. (Child’s name here) does have some muscle weakness and may not keep up with the other kids easily on the playground or in gym class. She gets physical therapy in school to help with this. Other than these differences, (Child’s name here) is a typical (number)-year-old. She is outgoing and friendly, she wants to have friends, join in with her peers and learn new things each day.

In our experience, some children, and adults, may avoid her or stare at (child’s name here). We know they are just unsure, but it can be upsetting. If they ask her about her differences, she may be willing to answer questions. Other children may prefer to ask their parents about it, and we are asking for your support in reassuring them that she is not intellectually disabled, not unhappy, not “pulling a face,” and the syndrome is not “catching.”

We are not asking for (child’s name here) to get special treatment, but hope that we can all encourage every child to be friendly, include others and be sensitive in the things we say. If you have any questions, we will be happy to answer them. Even “Does she have feeling in her face if it’s paralyzed?” to which the answer is yes! Please don’t hesitate to contact us. Our email address is (your email address).

Many thanks for taking the time to read this, and we hope all the children feel valued and important!

(Signed by parents)
Moebius Syndrome Conferences take place every two years, and our next one will be July 15–17, 2016. This will give everyone time to make plans to attend, and fundraise if needed so that you and your family may attend. Conferences are a significant part of the programs the Moebius Syndrome Foundation provides and are costly to hold. We are committed to offering the best conferences we can, and ask for your help in supporting them.

Our last conference, held in July of 2014, cost the Foundation $62,000, even taking in to account the sponsorships, donations, registration fees, raffle and sales we received. With 375 people attending, that means the Foundation spent $165 per attendee. We encourage your sponsorship or donations for our next conference, and have decided to take a new approach. Conference sponsorships and donations received or pledged during both 2015 and 2016 will be combined to determine your sponsorship or donation level. That way you can contribute in either or both years to the upcoming conference, and your donation level will reflect your donations from both 2015 and 2016. Sponsors will receive acknowledgment at the conference and a full page color ad in the Conference Journal. We will be able to identify early sponsors in our conference materials including our brochure and website.

Donations for the 2016 conference will be accepted in any amount, and we are very appreciative of any donation we receive. When you donate in 2015, please let us know if you are also pledging to donate in 2016.

Support the 12th Moebius Syndrome Conference!

Moebius Syndrome Conferences take place every two years, and our next one will be July 15–17, 2016. This will give everyone time to make plans to attend, and fundraise if needed so that you and your family may attend. Conferences are a significant part of the programs the Moebius Syndrome Foundation provides and are costly to hold. We are committed to offering the best conferences we can, and ask for your help in supporting them.

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Support the 12th Moebius Syndrome Conference!
Moebius Syndrome Conference
Sponsorship Opportunities

Please support the 2016 Moebius Syndrome Conference with a sponsorship. Your generous contribution will help with the cost of the conference or the conference scholarship fund. The Moebius Syndrome Foundation is a 501 c (3) charitable organization, and your sponsorship will be tax-deductible to the fullest extent of the law. EIN is 13-3753992.

DIAMOND SPONSOR - $10,000 and above
As a diamond sponsor you will receive:
✓ Full page (7” x 9.5”) color Journal Ad in the Conference Journal
✓ Your name and logo on the inside front cover of the Journal
✓ Be acknowledged as a diamond sponsor at the conference
✓ Your name or company’s logo will be featured on the back of our conference t-shirts

Amount: $ ___________

GOLD SPONSOR - $5,000 - $9,999
As a gold sponsor you will receive:
✓ Full page (7” x 9.5”) color Journal Ad in the Conference Journal
✓ Your name and logo on the inside front cover of the Journal
✓ Be acknowledged as a gold sponsor at the conference
✓ Your name or company’s logo will be featured on the back of our conference t-shirts

Amount: $ ___________

SILVER SPONSOR - $1,000 - $4,999
As a silver sponsor you will receive:
✓ Full page (7” x 9.5”) color Journal Ad in the Conference Journal
✓ Your name and logo on the inside front cover of the Journal
✓ Be acknowledged as a silver sponsor at the conference

Amount: $ ___________

SPONSOR - $500 - $999
As a sponsor you will receive:
✓ A full page (7” x 9.5”) color Journal Ad in the Conference Journal
✓ Your name and logo on the inside front cover of the Journal
✓ Be acknowledged as a sponsor at the conference

Amount: $ ___________

OTHER DONATION
✓ You will be acknowledged in the Conference Journal.

Amount: $ ___________

JOURNAL AD
✓ Your black & white Ad will be featured in the Conference Journal
✓ Your donation will be acknowledged in the Journal

Full Page (7” x 9.5”) $400
Half Page (7” x 4.75”) $200
Quarter Page (3.5” x 4.75”) $100
Business Card (3.5” x 2.5”) $ 50
Listing of Friends: $ 25
(Name & 1-Line Message)

Name: _____________________________

Message (90 characters maximum):

_______________________________

Conference Donations received or pledged in 2015 and 2016 will be combined to determine your sponsorship level.

I pledge to donate $ __________ in 2016.

This fund will be used to provide conference scholarships to waive registration fees and fund travel expenses for adults and families with Moebius syndrome who are attending a conference for the first time and have a financial need. You will be acknowledged in the Conference Journal.
WAYS TO SUBMIT YOUR DONATION

1. Mail form (at left) and your donation by check (made out to Moebius Syndrome Foundation) to:
   Moebius Syndrome Conference
   PO Box 20354
   Oakland CA 94620-0354

2. Make your donation through www.moebiussyndrome.com by clicking the DONATE button.
   If donating online, please complete the form (at left) and either mail it to the address above, or attach via email to Marcia@moebiussyndrome.com.
   Online payments are made through PayPal via the Moebius Syndrome Foundation website:
   Date: _____________________ 16 Digit Receipt Number: _____________________

3. If you are registering for the Moebius Syndrome Conference, you may make your donation at the time of your registration through the Conference Website. If donating online, please complete the form (at left) and either mail it to the address above, or attach via email to Marcia@moebiussyndrome.com.
   Payment made through the Conference Website with my Conference Registration
   Date Registered: ________________________
   Registration ID Number: ________________________
   Paid Online OR Paid by check (check number: ___________ and date: ___________ ).

HOW TO GET YOUR JOURNAL AD TO US

You may email your completed Journal Ad to Marcia@moebiussyndrome.com. Acceptable file formats include: PDF and JPG. You may email this form with your Journal Ad. If you need to have your Journal Ad designed, you may email or mail us your text and photos along with this form and the payment.

COMPANY OR INDIVIDUAL NAME: ____________________________________________
ADDRESS: _________________________________________________________________
CITY: __________________________ ST: __________ ZIP: __________
EMAIL: __________________________________________ PHONE: ___________________

PLEASE SUBMIT YOUR DONATIONS BY MAY 15, 2016 SO THAT WE CAN BE SURE TO INCLUDE YOUR JOURNAL AD AND ACKNOWLEDGE YOUR DONATION IN THE CONFERENCE JOURNAL.

Thank you!

Questions? Email Marcia@moebiussyndrome.com or phone 510 304-2302
Greetings. We would like to introduce you to the Moebius Syndrome Foundation, a national organization for children and adults with Moebius syndrome, their families, and professionals. We are the oldest and most experienced nonprofit dedicated to Moebius syndrome and are a 501(c)(3) nonprofit organization. Our mission is to provide information and support, 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.

Moebius syndrome is a rare neurological, craniofacial disorder that manifests itself primarily in facial paralysis. Individuals with Moebius syndrome cannot smile or frown, and do not have lateral eye movements. Many people with Moebius syndrome also have limb abnormalities, respiratory problems, speech and swallowing disorders, and other complications that impact health and well being.

Our organization holds conferences every two years. The 12th Moebius Syndrome Conference will take place Friday July 15 through Sunday July 17, 2016 in Los Angeles. The national conference is a place for people with Moebius syndrome to learn about treatments and the latest research, and is also a social outlet for those with Moebius. It reminds these individuals that they are not alone in confronting their challenges.

We would like to ask you as an individual, company or another organization to consider sponsoring or donating towards the Moebius Syndrome Conference. We suggest support in any of three ways: Sponsoring the conference, purchasing an Ad in the Conference Journal, or donating towards the scholarship fund that will enable families attending the conference for the first time with financial need to attend. All sponsors receive a complimentary Journal Ad. Donations and pledges of donations in 2015 and 2016 will be combined to arrive at your sponsorship or donation level.

Donation information is on the following pages. Please contact the Moebius Syndrome Foundation Conference co-chair, Marcia Abbott, at 510 304-2302 or marcia@moebiussyndrome.com with any questions or comments you may have. On behalf of the Moebius Syndrome Foundation, I thank you in advance for your consideration for our request.

Sincerely,

Member, Moebius Syndrome Foundation
www.moebiussyndrome.com
Moebius Syndrome News

ADULTS WITH MOEBIUS
Moebius Syndrome Foundation Board Member Kevin Smant will moderate periodic conference calls for all adults with Moebius. This is a forum for adults with Moebius to get together, chat, brainstorm ideas and to discuss issues and concerns with each other. The next call is scheduled for Wednesday August 5th at 8 pm Eastern/ 7 pm Central / 5 pm Pacific. To sign up to join the call or for more information call Kevin Smant at 682 228-9018 or email: ksmant@gmail.com.

MOEBIUS FAMILY ON TV!
In March a program on The Doctors featured a North Carolina family, Danielle Temple and Charlie Perales with their son Maddox. They discussed Moebius syndrome, how it affects Maddox, and how he wanted to have smile surgery. On the program Dr. Andre Panossian offered to do the surgery, and shortly thereafter, Maddox had his long-awaited smile surgery! You can watch the TV program at: http://www.thedoctorstv.com/videos/smile-reanimation-surgery-explained.

MOEBIUS GET-TOGETHERS
A Moebius Syndrome Get Together took place in Texas in May. Another is planned for Virginia in June. Riders for Moebius fundraiser is scheduled for June in Colorado. Other get togethers are in the planning stages for southern California, San Francisco Bay Area, and Canada. Check Facebook posts and our website for updates.

ON BEAUTY
The documentary On Beauty about Rick Guidotti and Positive Exposure is now being shown across the country in film festivals and other venues, and has won several awards. Watch for more showings in your area at: http://iambeauty.me/

FRAME – FACES REDEFINING THE ART OF MEDICAL EDUCATION
A short video on people with Moebius syndrome is in the works as part of the FRAME effort by Rick Guidotti and Positive Exposure. FRAME is an online library resource for health care providers in training, practitioners, teachers, students and families. Many people participated in the project at the last conference. The completed video on Moebius syndrome will be available online to view.

MOEBIUS NECKLACES
You can create your own Moebius syndrome awareness necklace and choose the text and charms at Origami Owl. A portion of the sale of each necklace will be donated to the Moebius Syndrome Foundation. Go to: www.erikabrown.origamiowl.com to check out how to create a necklace and to order.

NEW WEBSITE COMING!
The Moebius Syndrome Foundation will have a new website before the end of the year. Check our Facebook page for updates and information.

NAME THIS NEWSLETTER
Do you have a suggestion for a new name for the Moebius Syndrome News? Send it to: newsletter@moebiussyndrome.com.

Not on our mailing list?
If you are not on the mailing list for the Moebius Syndrome Foundation, please join us. You can complete the ‘contact us’ on our website or email kim@moebiussyndrome.com for an informational packet and to receive our newsletters twice a year in the mail. If you have a baby or toddler with Moebius syndrome, we will also send you a purple t-shirt that says “My smile comes from my heart!”
I Can See Just Fine
By Eric Barclay
 Abrams Appleseed
32 pages, Hardcover

It appears obvious that Page needs to go to the eye doctor to have her eyes tested. She protests, but her parents insist, and she quickly realizes that with glasses she WILL see fine. She particularly enjoys finding new eyeglass frames, and especially, finally seeing clearly with those new glasses!

2015 Schneider Family Book Awards
These books were selected for their portrayal of the disability experience:

A Boy and a Jaguar
By Alan Rabinowitz
Illustrated by Catia Chien,
Children up to age 8

This book is about a boy who stutters except when he talks to animals.

Rain Reign
By Ann M. Martin
Ages 9 – 13
About a young girl on the Autism spectrum

Girls Like Us
By Gail Giles
Teens
About two young women with intellectual disabilities

Super Power Baby Project
Written & Photographed by Rachel Callander
Mary Egan Publishing, Evie’s Book Club LLD
201 Pages

Super Power Baby Project is a fabulous new book by Rachel Callander with large, beautiful, superb photos of 72 children with genetic conditions, inspired by her daughter Evie’s life. It won the Outstanding Book of the Year Award for Independent Spirit, an Independent Publisher Book Award. It is a large, coffee table size book with narratives that accompany the photos of each child.

Rachel and Sam Callander visited with parents and children throughout New Zealand as they photographed them, and spent time finding out about the personalities and qualities of the children.

Each page begins with the child’s first name, then the syndrome they have is listed, followed by words from the parents as well as the author’s about the child, and ends with a listing of the child’s “super powers”: positive attributes—their abilities, strengths and likes.

Parents often mentioned that because of their child their priorities changed (for the better), they felt less judgmental and were more patient than they used to be. Many children were described as happy, loving, caring, and curious. Some parents emphasized that they now live in the moment and are more appreciative of the small things their child does. Parents not only celebrate their children but also are happy to part of the community that supports and embraces their children. Be sure to check page 68 for Mela, who has Moebius syndrome.

Support organizations are listed at the end of the book. While most are based in New Zealand, the Moebius Syndrome Foundation was also listed (thank you!). Books can be ordered from their website, or ask your local library to purchase the book.

There is an excellent talk by Rachel Callander from TEDxAuckland on the book’s website at http://www.superpowerbabyproject.org.
We greatly appreciate the generosity of all our supporters/donors. Many thanks to everyone for your ongoing support. All donations are used to further the mission of the Moebius Syndrome Foundation. The Moebius Syndrome Foundation would like to thank the individuals listed here for their generous donations. Donations listed here have been received since the last newsletter was published. If we have missed you, please let us know so that we can acknowledge your generous gifts.

IN MEMORY OF
Grace Susan Akers
Abigail Fulmore
Hannah Jade Devine
Suzan Knox
Christine Dowdle
Ruth T. Dowdle
Fletcher Evans
Judith Guffey
Therese Siemianas
Vern Lueders
Thomas Wagner
William J. McDaid
Fred Allen
William Allen
Aon Umbrella & Excess Casually
Ellen Bell
Edward Bernazzani
Richard & Mary Buckley
Dan & Ellen Carter
Rita Cohen
Marcia J. Crossman
Kathleen Currar
Marilyn & Michael Currar
Trudy Deane
Joanne Doherty
Jill Duggan
Edgewood Club
Geraldine Fanwell
Frasu, Previt, Kernay, Wadman,
Goyette, Ennis, DeMaria & Burke
Families
Henry Jr & Sandra Garbuzinski
John Green
Robin & Jeff Harris
Michael & Joanne Joyce
Michael Keenan & Roberta Conuel
Kathleen Kelly
Andrew & Eveline Kemalian
Charlene Kinneavy
Frank & Peg Labollita
Mary Lavelle
Nancy Lavelle
John & Patricia Malloy
Marsh NY Excess Casually Group
Colm & Marion McDaaid
James & Jacqueline McDaaid
Linda McDaaid
William McDaaid Jr
William McPherson
John & Sheila McSweeney
Angela Menino
Walter & Virginia Oleary
Sherriane Pechie
Terry Perkins

IN HONOR OF
Natalie Abbott
Marcia Abbott
Atheist Family & Friends Quote Bot
Bruce Freeman
Dawson Barnett
Truman Elementary School
Ben Becker
Juanita Becker
Zora & Nick Cholakova
Corrine Cooper
Amy, Anders, Skylar & Samantha Farr
Mark & Susan Knapp
Julie Sloncen
Reinhard Krestel
Sarah Nichols
Amy Twardowski
All Wright
Roland Bienvenu
Anne Bienvenu Brossard
Anna Cheney
Chuck & Becky Cheney
Faith Dressel & all with Moebius
Gary Dressel
MCM Insurance Co.
MCM Insurance Co. Associates
Abigail Fulmore
Sylvia & Gerlad Bondanese
Laura Chaucon & Anne Caniglia
Dawn & Donnie Dobbins
Debbie & Scott Fulmore
Xander & Branson Graham & Family
Cal & Caleb Hague & Family
Shanna Milton
Tom & Cathy Street
Amber & Kyle Toth
Ryan Dylan Gibbons
Nancy Gibbons
Michael Garbuzinski
Trudy Deane
Austin Halls
Sandyston Walpack Education
Association
Nicholas Jennison
Cella & Daniel Lucas
Amy Jo & Jeffrey Luna
John & Suzan Nassab
Anneliese Odeh
Anthony & Kathleen Paukstis
Christine Puzauskas
Suda Tadros
Mary & Bernard Vitchens
Nicolas Jennison & Lisa Odeh
Toni Shewell
Adeline Kathryn Jones
Kathryn Lee Clemens
Miriam Licht
Jacob & Panina Licht
Jessica Maher
Rebecca Maher
Novartis & ‘Dollars for Doers’
Lisa Odeh
Cella & Daniel Lucas
Anthony & Kathleen Paukstis
Vicki L Tamoush
Katherine Zucca
Khaleb Phillips
Kiowana Phillips
Joseph Michael Pierre
Linda M Pierre
Kylie Vander Veer
Carleen Wargowsky
2nd Lt Kyle David Ward
John & Sharon Ward

‘GIVE RARE DAY’ DONATIONS
Marcia Abbott
Natalie Abbott
Alice O Goeldner
Chelle & Bobby Medow
Karen Weber

On Thanksgiving of this past year, a devoted friend of the Moebius cause was taken from us—Benay Hecker. In her honor, friends and family generously contributed funds to help support a cause that was very important to her. Benay would have been greatly touched by the outpouring of support in remembrance of her, but also would have been quick to remind us that supporting the cause was never about her.

~Mike and Jeff Hecker
**Moebius Marketplace Order Form**

Name: 
Address: 
City:  
State:  
Zip:  
Telephone:  (We will contact you only if we have a question.)
E-mail: 

Ship to same address  
□ Ship to different address:

Name: 
Address: 
City:  
State:  
Zip:  

□ This is a gift. Please include the following note:  

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<tr>
<td>Dangling Charm Bracelet</td>
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<td>$</td>
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<tr>
<td>Purple Dog Tag</td>
<td>@ $7</td>
<td>$</td>
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<tr>
<td>Paracord Bracelet (Circle size) S, M or L</td>
<td>@ $5</td>
<td>$</td>
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<tr>
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<td>@ $2</td>
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<td>Awareness Wristbands Orders of 25 or more</td>
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<td>Children’s Sunglasses</td>
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TOTAL ENCLOSED $ 

INTERNATIONAL SHIPPING: Call for price 

**Please make checks payable to:**
Moebius Syndrome Foundation

**Mail form and payment to:**
Moebius Syndrome Foundation  
PO Box 20354  
Oakland CA 94620-0354 

**Questions?**  
Questions or to order and pay online,  
E-mail us at marcia@moebiussyndrome.com  
or call 510 304-2302.
Will YOU contribute to the Moebius Syndrome Foundation?

Your support is always appreciated, and will help the Moebius Syndrome Foundation fund important efforts such as the conferences and research grants.

The Moebius Syndrome Foundation is a 501(c) (3) nonprofit organization.

Please use the enclosed envelope to donate. Contributions are also accepted online at www.moebiussyndrome.com.

Please call us at 660 834-3406 with any questions.

EIN # 13-3753992