Our Mission
The Moebius Syndrome Foundation is a nonprofit organization founded by parents of children with Moebius syndrome. 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

Volume XXIII, Issue 2 • Summer 2014

Best Conference Ever

Our 11th Moebius Syndrome Conference took place July 18–20 in North Bethesda, MD, just outside of Washington, DC. As always, it was a phenomenal conference with many sessions for adults and parents as well as special events and activities for teens and children. There were 375 people attending the conference, from seven countries. Over 100 adults and teens came for the first time and there were over 120 people with Moebius of all ages.

The conference was opened by James Partridge of Changing Faces who presented “Looking Imperfect in a Look-Perfect World: Insights and Challenges.” The day before the conference researchers and members of our Scientific Advisory Board met for presentations on current research into Moebius syndrome. Articles on many of the sessions will be included in future newsletters and on our website. Some of the presentations will also be on our website. Be sure to watch the closing slideshow which can be found through a link on our website at http://www.moebiussyndrome.com/go/events/11th-moebius-syndrome-conference.

Quotes from our speakers:

“I was so sorry to have to leave you a week ago after such a short time but I was so uplifted by your conference. Thank you so much for your invitation, very warm welcome and wonderful hospitality. It all went to make for a very special trip...and I hoped I opened the event with the sort of utterance you had hoped for.....What an amazing organization you have created!”

~James Partridge, Founder & Chief Executive, Changing Faces, UK

“..Spectacular conference! I wanted to sincerely thank you for organizing this outstanding symposium and conference. I don’t know how you do it but it is always a perfect success. Everyone certainly enjoyed themselves, had a great educational experience and as always, the talent show was very special for everyone...Congratulations on a great symposium.”

~Ronald Zuker MD

“Once again thank you so much for all the organization done for Sara [Rosenfeld-Johnson] and I to be part of your conference! I learn so much every time and become more excited about what the children and adults we work with have achieved! I look forward to more years with all of you! Thank you again and see you in 2016!”

~Renee Roy Hill MS/CCC/SLP

“Thank you all so much for supporting my lab to attend the Moebius meeting. It was incredibly well organized and run, and the research set-up was the best yet. We enrolled about 50 families in collaboration with Dr. Jabs’ group...I hope the families are as excited about the...[NIH] grant as we all are...and we hope we have interesting findings to report two years from now. Thank you again for all the incredible work and dedication that went into planning and executing [the conference].

~Elizabeth Engle MD
Greetings!

The 11th Moebius Syndrome Conference in Bethesda was an outstanding success. Over 370 people from the United States (including Puerto Rico), Canada, Croatia, England, Germany, Guatemala, Nigeria and the Philippines attended the three-day event which featured over 50 speakers and 60 researchers dedicated to helping people with Moebius syndrome and their families. One hundred twenty people with Moebius syndrome from babies to adults attended the event. It was wonderful to see old friends connecting again and watch first time attendees being welcomed into our worldwide ‘Moebius Family.’

The day before the family conference began, 60 researchers from the US, Canada, Germany and Hungary came together to share the work they are doing to unravel the mystery of the causes of Moebius and share with each other the incredible strides they are making in helping people with Moebius in all aspects of the myriad ways that people are affected by this unique neurological condition.

We send a huge thanks to everyone who participated: people with Moebius syndrome and their families, researchers, physicians, therapists, financial experts, the stars of the talent show, panelists—the list goes on and on. To Jacob and Panina Licht and their family who chaired the conference, Marcia Abbott and Monica Woodall who handled registration and speaker coordination and numerous others who worked so hard to make the conference a success on behalf of the MSF Board of Directors, thank you from the bottom of our hearts.

Now on to the 12th conference which will be held in July of 2016 in Los Angeles.

Sincerely,

Vicki McCarrell
President
A Discussion of the Social Psychology of Moebius Syndrome
Dr. Kathleen Bogart

At the 2014 Moebius Syndrome Conference, I presented and led a discussion about the research I have been conducting on Moebius syndrome and facial paralysis for the past several years as Assistant Professor of Psychology at Oregon State University. The experience of Moebius syndrome is inherently a social one. Because of this, I focus both on the experience of the person with Moebius syndrome and the way other people form impressions about people with Moebius. The goal of my research is to facilitate interaction between people with and without Moebius.

At the 2010 and 2012 MSF conferences, I conducted focus group studies of adults and teenagers with Moebius. These studies have since been published in the Journal of Health Psychology. We discussed the way Moebius affects social interactions. The groups agreed that Moebius is usually the first thing that people notice, and that strangers might be confused by one’s appearance or the way one talks. However, the teenagers were very insightful on this issue and pointed out that once people get to know the person with Moebius, their personality becomes more important than their appearance. Facial expression is a very important part of socializing, but people with Moebius reported many ways of compensating such as tone of voice, gestures, humor, and even clothing to express themselves.

Adults and teens alike brought up the need for better awareness about Moebius so that others would be more likely to understand them. Participants noted that they were sometimes mistaken for being unhappy, unfriendly, or even intellectually disabled because people were not familiar with the condition. One teenager explained that a child was concerned about Moebius and thought it was painful or dangerous, and the child was relieved when it was explained to him. People with Moebius often feel the need to explain Moebius to others so they will understand why they look and speak differently. At the same time, it is unreasonable to explain Moebius to every person they encounter. Greater awareness would make it so that people with Moebius would not have to explain their conditions and reassure people as frequently. Moebius Syndrome Awareness Day is an excellent opportunity to educate others about Moebius syndrome and celebrate pride for the Moebius Syndrome community!

In one study, my lab tested whether educating people about facial paralysis led to better first impressions of them. We gave participants a short written description of the common causes and symptoms of facial paralysis. We also explained that people naturally tend to pay attention to the face when talking with someone, but in the case of people with facial paralysis, it is most effective to focus on the other ways they express themselves such as their bodies and voices. Participants then watched videos of people with facial paralysis. Compared to participants who did not receive education about facial paralysis, participants who did rated the people in the videos more positively.

I have several other studies underway now. In one, we are examining the differences in experiences of people who do and do not attend the Moebius syndrome conference. In a second, we are testing the effectiveness of a social skills workshop for teens. Once we finish analyzing the results of the study, we would like to offer this workshop to more people at future conferences.

If you would like to learn more about my research or sign up to be contacted about future research participation opportunities, please visit my website: http://liberalarts.oregonstate.edu/users/kathleen-bogart

Corneal Anesthesia Repair

Corneal anesthesia is a rare condition that can be found in conjunction with Moebius syndrome. A patient with this condition cannot feel any foreign object, such as a grain of sand, in the affected eye. This often leads to cloudiness in the eye and finally to loss of vision. There are currently A patient with this condition cannot feel any foreign object, such as a grain of sand, in the affected eye.

Corneal Anesthesia Repair, continued page 4
no treatments to correct this, only the use of eye drops to alleviate the condition.

In 2009, Terzis and Bodner reported a dramatic procedure. This involved an incision across the head from eye to eye, with the attachment of a nerve graft. Although the patient benefited from this procedure, because it was such a major operation, it has not been performed by other surgeons.

A less invasive procedure has been used in Toronto with promising results. The incision is only from eye to eye instead of across the head as above. For this operation, a nerve is taken from the leg (this does not affect the leg). This nerve graft is connected to the donor nerve in the unaffected eye, then run across the lower forehead and connected to the nerve to the retina in the affected eye. Most patients regain significant sensitivity in the affected eye. Vision is the same or better after the operation.

In Moebius syndrome patients, certain cells did not grow in the brain stem. The cause for this is still unknown. If a nerve does not grow out of the brain stem, the nerve does not connect with the muscle, and the muscle, in turn, fails to develop. This can be true for eye muscles. Without the nerve, the specific cells that would have been muscle do not develop. Therefore, new muscle tissue is needed (via a transplant) to respond to the new nerve.

Stimulating Axon Regeneration

Many nerve transplants seem to be positively affected by stimulating the nerve with electricity. It has been found that one hour is the maximum optimum time with 20 to 30 volts and 20 cycles per second. Electrical stimulation also helps patients suffering from carpel tunnel syndrome. This treatment is now used in Toronto.

-Reported by Katherine McCaughan

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Corneal Anesthesia Repair, continued

Los Angeles

July 2016

Watch for details about the 2016 conference on our website and in the next newsletter.
Old Friends & New Friends Connect at Moebius Syndrome Conference

Ado Muktar, Ahmad Ado and Ibrahim Moussa Fatouma from Nigeria.

Shelby Kennedy and Emma Turner

Dr Ronald Zuker with Chelsey Thomas and Chris Wasilewski

Lauren Deveney and Austin Halls

Kevin Nieves-Brailsford and his mother, Kacie Nievesmassol

Jensen Jennings and Patrice Jennings-Rado

Some members of the Moebius Syndrome Foundation Board

Shelby Kennedy and Emma Turner
We are so grateful to have been a part of your recent conference. We would like to see if any of this year’s attendees would be interested in becoming PEARLS Ambassadors for Positive Exposure. Positive Exposure’s PEARLS Project is a ground-breaking educational tool which invites students to learn about their peers living with genetic, physical and behavioral differences through an image gallery and safe online blog.

As a PEARLS Ambassador, you would have the opportunity to blog about your day-to-day experiences with the world. Our Ambassadors are able to freely express themselves, as well as create an atmosphere of honesty and openness.

For more information, you can view our sample page on the Positive Exposure website, by visiting positive-exposure.org, and clicking on the PEARLS Project tab on the upper-right hand corner. Once you’re on the PEARLS Project page, use the username pearlsprojectsample and password pe2014 to get into the blog. From there, you can view a video where Rick Guidotti explains the expectations of a PEARLS Ambassador, and even see some sample blogs by clicking on the names on the right-hand side!

The PEARLS Project Application and Waiver are on the Moebius Syndrome Foundation website (Go to ‘News & Events,’ and select ‘Pearls Project’). You can also contact us to have the forms emailed to you. Thanks again for your interest in Positive Exposure, and we look forward to working with you in the future!

FRAME—Faces Redefining the Art of Medical Education

Positive Exposure is engaged in creating video vignettes of individuals with a variety of genetic conditions in which they teach about the basic aspects of their various conditions.

They allow health care providers to learn about the different aspects of a disease or disorder from the perspective of an individual actually living with a certain condition. We were very fortunate to have Rick Guidotti and the other FRAME staff, Shabbi Asgari, Tabha Joshi and Erik Spink, videotape people at the recent conference for a FRAME video on Moebius syndrome. When it is complete, a link to the video will be added to the website of the Moebius Syndrome Foundation as well as offering it to health care providers. Special thanks to those of you who participated in the videotaping at the conference. We will see many familiar faces when the FRAME video on Moebius syndrome is completed.
READERS TO READERS

If you have an answer and/or information about one of the questions in this newsletter, please respond to newsletter@moebiussyndrome.com so your letter can be printed in a future newsletter. Thank you.

The following questions and answers were originally posted on the ‘Moebius Moms’ Facebook Group and compiled by Lori Thomas. To join ‘Moebius Moms’ or ‘Moebius Friends 2,’ go to the group and request to join. Both are closed groups.

Q: DIGESTIVE ISSUES
How many mothers have children with Moebius who have digestive issues or smaller than normal organs? My son has a smaller sized bladder and stomach. He has a slow digestive tract also. Is this common with Moebius?

A:
- My daughter has Crohn’s. She also has small kidneys. After a bronchoscope, we were told that our son’s airways are a little smaller than normal.
- My daughter has digestive issues and constantly has either diarrhea or constipation. I was told a few years ago that she had a small bladder. She has had over 60 urinary track infections and I’ve stopped counting.
- My daughter had similar issues. Her urinary track infections did get better as she got older.
- Does she have reflux that is causing them? My daughter’s reflux resolved without surgery. Her urologist also had her on daily preventative antibiotics. Have you tried that?
- My daughter was born with gastroschisis, which has given her slow bowels. She also had reflux disease and had a fundoplication done when they put her g-tube in. She has a smaller lower jaw and had sleep apnea for a few years.

Q: ARE FEEDING TUBES PORTABLE?
Those of you with kids with feeding tubes, and with older children, do you find it hard to get out with your child with Moebius?

A:
- They are portable, even if you have to be on a pump. My daughter has had hers since she was born and it doesn’t stop her. She only needed a pump when she was little, now we just bolus feed.
- Yes it was difficult. It is good to find another person to go with you and help with an older child. My son was on 23 hour feeds and I have an older son as well.
- When we first came home, I was a wreck trying to be out and about with my child with her being on the pump for three hours on and two hours off around the clock. I learned little tricks to make it easier and with time it did get a lot easier. The problem now as she has gotten older is keeping her still during her feeding and not pulling her button out.
- My daughter was only on a pump a night. We mostly did gravity feeds, often a bolus, until she was almost four. We just got used to it, though I’m sure it grossed some people out because we had to let gas out of the tube, and at times it sounded like a burp or would spit milk.
- At first with our pump, it was difficult to go out but we did anyway. I was determined to give my son as typical a life as possible and that meant leaving the house. It got easier with time, especially once it got to bolus feeds that we could do with a string we just slipped in our bag. It just took a little bit of planning before going out. The one thing that helped was when our feeding team told us it is just like his mouth, yes we should try to be as sterile as possible but we are not very super sterile with what we put in our mouths daily and it was the same with his tube. That took a lot of pressure off. We have traveled internationally with his tube with no problems; again, it just took a little bit of pre-planning.
- We are really mobile. We don’t have a pump but do bolus feeds. We get some strange looks and little kids that come up and ask questions but it has not been a big problem for us, but then I have been doing this for five years now so it may just be my perspective.
- My son has a pump and has a feed four times a day. It is very portable, we have a little backpack that the pump goes in and we just attach it to his buggy. It takes a bit of organization at the start, but you get used to it. We had to; he had so many appointments when he was tiny that we were always on the move. He’s very tolerant, so we can feed him in the car on long journeys if we need to. Today, the only chance I had to do grocery shopping was during his feed, so he sat in the seat in the trolley, with the pump in the trolley. Our biggest problem now is that he is constantly trying to eat his tube.
- We get out a lot, when he was ng fed it was much harder when we were out and about, but when he got the g-tube it was so much easier.
- It a bit of organization but totally possible! Make a packing list. We once forgot an extension tube or water to flush and rinse the bag. But go out! Life is already hard with a medically complex baby so don’t stay home. Enjoy!
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. If we have missed you, please let us know so that we can acknowledge your generous gifts.

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New Books for Kids

Counting by 7’s
By Holly Goldberg Sloan
Dial; 384 pages; ages 10-up
“Counting by 7’s” is about 12-year old Willow Chance who has a terrible tragedy occur in her life. This is the story of how she manages after it. Counting by 7’s refers to what she does to relax.

Smile For Me
By Linda Lawrance
16 pages; for primary school aged children
This is a children’s book about Moebius syndrome written by a mother in Australia. Go to http://www.facebook.com/#!/MoebiusSyndromeSmileForMe for more information or email at lindaglawrance@mail.com.

Fundraising for the Moebius Syndrome Foundation
We are very proud of two boys who have just completed fundraisers for the Moebius Syndrome Foundation.

Matix Gradillas, six years old, of North Carolina donated $1,000 to the Moebius Syndrome Foundation for conference expenses. He earned much of the funds by collecting and recycling cans (check out the photo!). Matix also was selected as a local winner in the Kohl’s Cares® Scholarship Program.

Willem Wuebben, nine years old, of New Jersey donated $370 to the Moebius Syndrome Foundation at the conference in July. He created a fundraiser at his school. All of the students in his class made items out of duct tape and sold them for $1.

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.

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Mitchell L. Washer

Mary Jo Robbins, a mother of a child with Moebius, has created practical infant/toddler apparel with removable matching bibs. Check out the adorable outfits from Three Angels LLC at www.SwitchABibs.com. You can also contact Mary Jo by email ajcsm@yahoo.com, or call 978 815-0670 for more information. A portion of her sales will be donated to the Moebius Syndrome Foundation.

Switch-a-Bib™
Practical infant/toddler apparel

Spring 2014 9
**Moebius Syndrome Awareness Day**
Moebius Syndrome Awareness Day will be here before we know it, to be celebrated on Saturday January 24, 2015. Moebius Syndrome Awareness Day is a day of advocacy and outreach, to explain and educate the public, friends and family, and professionals about Moebius syndrome. Ideas on what you can do will be on our website and on our Facebook page soon. The Moebius Syndrome Foundation will not have new t-shirts, but check out those at [www.freshprinz.com/moebius](http://www.freshprinz.com/moebius) which are offered through the Many Faces of Moebius Syndrome website. We do have new Moebius syndrome jewelry and other items for sale. Go to the Moebius Marketplace on page 11 to order. And repeat your efforts on Rare Disease Day, celebrated globally on Saturday February 28, 2015 to bring attention to all rare conditions including Moebius syndrome. Check out [www.rarediseaseday.us](http://www.rarediseaseday.us) and [www.rarediseaseday.org](http://www.rarediseaseday.org) for more information on the 2015 celebrations.

**FREE CHILDREN’S BOOK ON MOEBIUS SYNDROME**
Order for your child’s class or for Moebius Syndrome Awareness Day! The Moebius Syndrome Foundation is offering free copies of ‘My Face’ at no charge. US residents may request up to 35 copies, and international addresses two copies. They may be used for your child’s school, friends and relatives, or the professionals who work with your child. Send your name, mailing address and the number of copies you would like to marcia@moebiussyndrome.com.

**NEW BOOK**

**FIRST MOEBIUS SYNDROME CONFERENCE IN THE UK!**
Called “Un-masking Moebius Syndrome & Facial Palsy,” the conference will take place on October 25, 2014 in Liverpool. For information, contact ceri@moebiusresearchtrust.org, call 01875 819822, or check [www.moebiusresearchtrust.org](http://www.moebiusresearchtrust.org).

**WELCOMING A CHILD BACK TO SCHOOL AFTER SURGERY**

**NEW ACCESSIBLE ICON**
A new, revamped version of the accessible icon is available courtesy of [www.accessibleicon.org](http://www.accessibleicon.org). It now is approved in New York State as well as other localities and is on display at the Museum of Modern Art in New York City. According to disabilityscoop.com, it is a “more active, in-motion image of a person using a wheelchair.”

**MR. STRONG FOUNDATION**
The Mr. Strong Foundation was founded to help children with special needs to receive occupational, speech and physical therapy that is not covered by insurance. The grant application may be downloaded and submitted with other documentation to the address on the application form. For more information, go to [http://mrstrongfoundation.org/need-help/](http://mrstrongfoundation.org/need-help/).

**SHOP & GIVE**
When you shop at Amazon.com or Goodshop.com, a portion of your purchase will go to the Moebius Syndrome Foundation! Use GoodSearch as your search engine. Designate the Moebius Syndrome Foundation. GoodSearch will donate ONE CENT for each search to MSF.
Children’s T-Shirts – $10
“I’m smiling on the inside.”
Very Limited Quantities
Call for sizes and colors

Purple Dog Tag – $7
Aluminum, 1 1/8 on 18” Ball Chain

Jewelry with Moebius Syndrome Foundation Logo – $15
Dangling Pendant Necklace
Stainless steel charm with amethyst on 18” chain
Dangling Charm Bracelet
Stainless steel charm bracelet with amethyst, 7”

Wristbands – $2
Our purple wristbands are designed with the words “I’m smiling on the inside” on one side, and the Moebius Syndrome website on the other.

Paracord Bracelet – $5
S, M, or L

Children’s Sunglasses – $5

Jewelry with Moebius Syndrome Foundation Logo – $15
Dangling Pendant Necklace
Stainless steel charm with amethyst on 18” chain
Dangling Charm Bracelet
Stainless steel charm bracelet with amethyst, 7”

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:

Dangling Pendant Necklace ___ @ $15 __________
Dangling Charm Bracelet ___ @ $15 __________
Purple Dog Tag ___ @ $7 __________
Paracord Bracelet (Circle size) S M L ___ @ $5 __________
Awareness Wristbands ___ @ $2 __________
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Donation __________
Shipping (US addresses) __________

TOTAL ENCLOSED __________

INTERNATIONAL SHIPPING: Call for price

Please make checks payable to:
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Mail form and payment to:
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PO Box 20354
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Questions?
Questions or to order and pay online, E-mail us at marcia@moebiussyndrome.com or call 510 304-2302.
This is a natural history study at the National Institutes of Health (NIH) in collaboration with Mount Sinai School of Medicine and Boston Children’s Hospital.

For more information about the study please contact the study coordinator: Carol Van Ryzin RN, CPNP by phone at 301-827-1071 or email at: moebius@mail.nih.gov

More information at:
http://www.moebiussyndrome.com/go/news/nih-moebius-research-study

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.

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