New Oral Placement Therapy Study
By Kevin Tunstall

The Foundation is excited to announce a new study to evaluate Oral Placement Therapy’s benefit to children with Moebius. A preliminary pilot study was conducted that warranted the formulation of a new study design that will focus on collecting empirical data for defined oral-motor therapy that facilitates strength, coordination, range of motion and tonal balance in the participants. The hypothesis is that it will show that OPT methods will help improve speech and swallowing abilities for people with Moebius syndrome.

Unlike the pilot study where all forms of OPT were utilized for the entire participants’ therapy regime, the new design will use separate OPT and conventional therapy methods across four independent groups. A baseline benchmark will be obtained on all participants at the start of the program and their progress graded as the therapy sessions progress through the study. The target participation group for this study is children between 5 and 18 years old with the medical diagnosis of Moebius syndrome.

The study will comprise of four separate therapy groups into which each participant will be randomly placed. The program will be quite intensive for the participants with the therapy sessions three times per week for a period of up to six months. The number of sessions and time period of six months will ensure that the effect of the therapy is measurable while limiting external influences.

Another good feature of the study is that the participant’s current speech therapist can be utilized for administering the study. All therapists who will be implementing the therapy techniques for the study will be trained in the specific therapy techniques and data recording such that uniform reliable data will be collected which will be used for statistical analysis. Independent third-party judges will also be utilized to ensure reliability of the data collected.

Principle Investigator Sara Rosenfeld-Johnson and Co-Principle Investigator Renee Roy Hill have assembled a Project Team to coordinate and implement the study. Sara and Renee will provide oversight, training and direction for the therapists that will be working with the children and documenting the protocol trials. The Project Team has created a website dedicated to the study that can be viewed at www.moebiusoptstudy.com. If you are interested in participating in the study, please visit the website to review the eligibility criteria and contact the Project Team if you wish to participate. In addition to the contact form on the website, the Project Team can be reached at info@moebiusoptstudy.com or 843-471-0882.
Summer Greetings!

Congratulations to all of the young people around the world who have Moebius syndrome and are graduating from elementary school, high school, vocational schools, colleges and universities this time of year. My son Sean graduated from a university with a degree in journalism with an emphasis in broadcasting on May 11. I was a very proud mom and kept thinking of all the other proud moms and dads around the world who spent years taking their children to speech and other therapies and are now watching their children cross a stage to receive a diploma and move on to the next stage of their lives. We are so proud of all of you!

Our hearts go out to parents who lost children and will not have the experience of watching their child receive a diploma. Our researchers are committed to finding the cause of Moebius syndrome and ways to help all people who were born with ‘smiles on the inside.’

We’re excited about the 11th Moebius Syndrome Conference which will be held July 18-20, 2014. In August our Board of Directors will meet at the Bethesda North Marriott Hotel & Conference Center, where the conference will be held, to determine which rooms to use for sessions, child care, meals, etc. Start planning now to attend and meet new friends, hear/meet fascinating speakers and participate in research. Kathleen Bogart, PhD, will be conducting sessions with teens/young adults who have Moebius syndrome and will share her own experiences of growing up with Moebius syndrome. We’ll have something for everyone! We hope to see all of you!

Warm wishes,

Vicki McCarrell
President

Letter from the President
Moebius Syndrome Foundation
Strategic Plan

The Board of the Moebius Syndrome Foundation adopted the following strategic plan to accomplish our mission. The Board is now involved in developing the activities that support these goals and objectives. Information on the activities will be included in a future newsletter and on our website.

The goals and objectives are permanent, thus are long term as well as immediate, short term. The activities that support those goals and objectives may or will change over time.

GOALS:

- INFORMATION
- NETWORKING
- CONFERENCES
- RESEARCH

OBJECTIVES:

- INFORMATION
  1. Establish a comprehensive, combined linked communication system;
  2. The Moebius Syndrome Foundation aspires to be the premier organization for Moebius syndrome and the leading definitive source for information on Moebius syndrome;
  3. The Moebius Syndrome Foundation aspires to be the leading definitive resource on Moebius syndrome.

- NETWORKING
  1. Enable global, regional and local networking within the Moebius community;
  2. Establish value added connections in the rare disease community and organizations dedicated to craniofacial disorders;
  3. Foster specific Moebius syndrome communities and networks (i.e. categories: parents, grandparents, adults);
  4. Create and maintain connections with medical and therapeutic community.

- CONFERENCES
  1. Host national conference every two years;
  2. Board members attend conferences hosted by other organizations.

- RESEARCH
  1. Support research financially and in access to Moebius community;
  2. Build and expand research community.

New Survey and Research on the Orthopedic Manifestations of Moebius Syndrome

Dear Friends and Members of the Moebius Syndrome Foundation:

Please help us gain further understanding about Moebius syndrome and associations with musculoskeletal problems in the spine, hips, and extremities. A research study is being conducted by Dr. Craig Eberson, the principal investigator on the study at Rhode Island Hospital, in conjunction with Brown University.

For all those affected by Moebius syndrome, there may be many areas of uncertainty and anxiety: physicians who treat patients with Moebius syndrome may not have a complete understanding of the spectrum of problems that may occur in this special population. A survey has been developed to collect specific information about the association of musculoskeletal problems and Moebius syndrome. If enough data can be collected, we are hoping to increase our understanding of this area of Moebius syndrome.

It is very important that as many individuals as possible participate in the research to help give better estimates of the frequency of each problem. Everyone’s input is valuable. The survey is simple to complete, and should take only 10-20 minutes, depending on the length of your responses. Your participation in this study may not benefit you personally; however the information gathered is intended to improve the care of all patients with Moebius syndrome. The survey is available on the internet at http://www.surveymonkey.com/s/Mobius_MSK.

This survey is anonymous and there will be no way to link the survey to you. None of the information you provide will have your name or any number on it that will identify you personally. If you have any questions about your rights as a research subject please call the Office of Research Administration manager, Patricia Houser, at 401-444-2099.

The survey focuses on some of the known associations in an effort to more clearly define incidence, and also includes opportunities for patients/families to inform the study group of less commonly known aspects of Moebius syndrome. We are hoping that this effort will increase the understanding of Moebius syndrome and advance the care of affected patients/families. Thank you for all your help in this very important project. We hope that we can share the results with everyone at the 2014 Moebius Syndrome Foundation conference.

This research study is voluntary. You have the choice not to take part in it. Thank you for your participation. If you have any questions, please contact one of the following:

Kathy Kraus, MD 724-827-2048 or trynny@aol.com
Philip McClure, MD 724-312-7615 or phil@brown.edu
Craig Eberson, MD 401-457-1550 or ceberson@lifespan.org

Again, THANKS to EVERYONE! Together we can learn more.
At the 2012 Moebius Syndrome conference in Philadelphia, I was fortunate enough to moderate a panel entitled “Moebius Syndrome: Triumphs Through the Years.” On the panel with me were several of my friends with Moebius, including Chelsey Thomas, Roland Bienvenu, Christa Trelenberg and Henrietta Spalding. Our goals were to talk about our lives dealing with Moebius syndrome; focus on how we’ve been able to handle the challenges we’ve faced; and how we have achieved success in our lives. Everyone did that very well. And in listening to what my fellow panelists had to say, there were several commonalities that we shared.

First, we all for sure HAVE faced challenges. Often, doctors told our parents that we might not live, or that we wouldn’t be able to function well in society when we grew up. We were at times teased and bullied when we were kids and teenagers. When I was in graduate school, one of the professors in my program suggested to me that, due to my condition, I’d probably never be able to teach, and so instead I should look into going into archival work (presumably, that would be good because I’d rarely come in contact with people). I did not listen; I became a teacher anyway and have been doing it for over 20 years, winning teaching awards to boot.

But then, that’s been the case for everyone on the panel. Roland has been working for years in a very important position with the city of Houston. Chelsey is about to graduate from San Francisco State University. Christa is just beginning a new job of her own, and she’s thrilled with it. Henrietta has also been a teacher, and has a prominent role with the outstanding organization in the UK called Changing Faces. And I know many other adults with Moebius, so many of whom have success stories of their own they could tell.

So if you’re out there, and you’re someone who has Moebius syndrome, or you’re a mom or a dad whose child has Moebius syndrome, then always know this: take heart. Be strong.
At the Moebius Syndrome Conference in 2012, Dr. Kathleen Bogart presented about the research in our Disability and Social Interaction Lab, which she directs. We study the psychology behind living with Moebius syndrome, including the social perception of people with facial paralysis and how to improve interpersonal understanding. Facial expression is important to social interactions because it communicates emotion and helps develop social connectedness between individuals. Although facial expression is a main way people share information, there are other ways that people communicate, for example with body language and tone of voice.

Dr. Bogart organized a focus group of 12 adults with Moebius where the participants discussed their experiences of having Moebius syndrome and its effects on their social interaction. Her findings include that people with this condition have difficulty being understood and others sometimes stereotype people with it. It can be challenging meeting new people because Moebius is often noticeable to strangers. Most people are unfamiliar with the condition and may not know how to approach a person with Moebius and do not know if it is acceptable to talk about their condition. People can make unfair assumptions about a person’s capabilities, which can affect people’s careers and relationships with other people.

Many people report being stared at and bullied at some point in their lives. However, many people with Moebius thrive with their differences. Other studies from our lab suggest that people with Moebius are just as happy and well adjusted as a person without this condition. Many people with the symptoms of Moebius can learn how to proactively manage others’ reactions by letting people know that they are just like them in many ways. Some people choose to address their disability directly when meeting someone new, while others make jokes to help new people relax and feel comfortable around them. People with Moebius are adapted to using other ways to communicate by voice, gestures, touch, humor, and clothing.

Research in our lab has found that people without Moebius perceive people who have difficulty making facial expressions as being less happy and less friendly. This perception is not true. People with Moebius can be just as happy as people without the condition. Just because some people are unable to create facial expressions themselves, it does not prevent them from recognizing facial expressions in other people, making friends, or experiencing emotions. Research in social psychology has found that people cannot accurately predict what will make someone happy. After a year, people who have won the lottery and people who become paralyzed report the same levels of happiness, although many would incorrectly predict that they would be happier winning the lottery. People are a lot more resilient to life-changing events than they think they are. Fortunately, although people with Moebius can be perceived incorrectly, research finds that others can learn to see beyond facial paralysis. Our lab is working on applying our findings with informational pamphlets and training for educators and healthcare workers who work with people with Moebius syndrome.

People with Moebius are part of a small community because Moebius syndrome is a rare condition with only 3,410 to 8,960 cases of congenital facial paralysis reported each year in the United States. Although there are challenges to living with Moebius syndrome, there are some positive sides to having this condition. People with Moebius can live their whole life never being able to make facial expressions, so they do not feel the sense of loss that many people with acquired facial paralysis struggle with. Having facial paralysis is just part of who they are because they have not experienced life without it. They learn to express themselves in other ways besides just relying on facial cues and can become very skilled at communicating and interacting with other people. They adapt with their condition and learn how to flourish with the differences that they have.

In 2014, we are conducting several studies with people with Moebius syndrome and their families, some of which will be held at the next conference. If you would like to be contacted about future studies, please e-mail Dr. Bogart at Kathleen.bogart@oregonstate.edu.
After Emily Rapp’s 9-month-old son Ronan is diagnosed with Tay-Sachs disease, she searches for ways to cope with raising a child with an illness, a child who will most likely die by the time he is three years old. Her beautiful, heartbreaking memoir “The Still Point of the Turning World” is Rapp’s way of working through her grief, of being a fierce “dragon mom,” of giving the world her son’s story. She writes, “The more I wrote about Ronan, the more I understood that the only way grief would not take me down completely was to greet his diagnosis head-on and make my world big, make his story known. His myth [...] is about the joys and costs of refusing to look away, of diving into the abyss and kicking around in it....”

Although others often try to help her with words of “encouragement” about her sick child, Rapp finds many of the salutations she receives to be most unhelpful. Ultimately, she finds the only thing that helps her are honest expressions of rage, of utter grief, and no platitudes: “[As] those of us who have or have had sick kids know, some situations can’t be fixed. Instead they must be borne in whatever ways we can manage. I decided that I was not responsible for managing other people’s rude reactions of misconceptions. I was unable to mitigate other people’s fears, but I could certainly love Ronan.” She takes others’ reactions to her child to conclude, “[What] people view as the ‘tragedies’ of others makes them feel better about themselves. If somebody else has it worse than you, you can walk around feeling lucky for a few minutes.”

Rapp meditates on the idea of luck, in life and in genetics. When she was pregnant with Ronan, she got tested for Tay-Sachs, but received a negative result (having a very rare form of the gene). A geneticist later tells her, “We really don’t know who we are, how old these genes are, or where they come from.” It reminds her that although most people walk around thinking they know their fate, or that they are “lucky,” nobody really knows what’s in store for them.

Rapp had her leg amputated at a young age, and wrote movingly about her experiences as a March of Dimes poster child in her previous memoir. In a way, Ronan’s diagnosis helps her to revisit her ideas of what it means to have a disability: “Ronan helped teach me a lesson I had long been resisting: this world belongs to everyone. We all have a place in it, no matter how long we live and no matter what we look like, how we move or don’t move, how we exist. What matters is that we lived.”

The book is ultimately a call for everyone, but especially parents, to live in the present. This is, after all, all any of us have. “It was difficult—maybe even impossible for me to imagine that Ronan was not, in his own way, perfect, if only because he was living the only way he could. There was a great deal of perfection—and rare innocence—in that.”

—Reviewed by Kate Abbott

Kate Abbott is the author of the new middle school novel, “Disneylanders.”

I love photography. I find it simple yet beautiful. I wrote my master’s thesis on the Positive Exposure™ photography project, and I love seeing photographers exploring differences.

Photographer Sage Sohier spent time at the Facial Nerve Center at the Massachusetts Eye and Ear Infirmary in Boston, photographing patients—most before surgery. I appreciated how frank these photographs were, not that they glorified distinctive-looking faces, but that they didn’t try to hide or camouflage anything. I found them simple and beautiful.

Facial difference is a strange disability to have, in that it is not in the public’s consciousness. I love that the world—at least the art/academic world—is paying attention to, even highlighting, them. For both people with congenital or acquired conditions (I would have loved this book as a child!), it’s a remarkably powerful thing to be exposed to people who look like you.

Overall, I highly recommend this book for anyone affected by or interested in facial differences.

—Reviewed by Natalie Abbott

More information on Sage Sohier can be found at www.sagesohier.com. Proceeds from the sale of “About Face” will be donated to the HUGS Foundation (Help Us Give Smiles).
If you have an answer and/or information about one of the questions in this newsletter, you can respond to the e-mail address from the writer. Also, please copy Newsletter@moebiussyndrome.com on all responses so that your letter can be printed in a future newsletter. Thank you.

VERTIGO & MOEBIUS SYNDROME
Q. Does anyone have any knowledge of people with Moebius syndrome experiencing issues with vertigo? I was diagnosed with benign positional vertigo several years back. The vertigo is mild and does not impact me very much. The symptoms will fade then return at odd times. I am curious if others have experienced this as well.
Mark J. Sullivan
mjs@rwsullivan.com

EATING REGULAR FOODS
Q. I’m looking for some ideas to help our 2 ½ year old son move from purees to regular foods. What has been some of your experiences? Our current occupational therapist is great, but she has never had a child with Moebius before (naturally) and so she’s just doing what she would do with any other kid with feeding delays. He has a smallish asymmetrical tongue. We are trying to get him to use his teeth when eating, but he just keeps mashing food on the top of his mouth with his tongue, which works fine for bananas, not so great for everything else. Any ideas would be appreciated.
Laura Harms
lauraharmz@gmail.com

TONGUE BITING & MOEBIUS SYNDROME
Q. Last year my wife and I attended the 2012 Moebius Conference in Philadelphia. It was our first conference and we learned so much from the experience. Meeting others with Moebius and learning from their experiences was one of the most valuable benefits we received from the conference. The additional knowledge has really helped us further advocate for our daughter at school and in the medical clinics. Recently our daughter has experienced some additional challenges. Her adult teeth have been coming in and it has caused some tongue biting issues within her mouth. We have seen a series of doctors and dentists, looking for options. Unfortunately, many of the options being presented are rather severe including tongue reduction and jaw extraction. Currently she is trying to use mouth guards, but it has not resolved the situation. I’m hoping through the Moebius community I will be able to discover things that have worked for others. Has anyone had a similar experience? How was it resolved? Thank you.
Gary Dressel
gdressel@tds.net

A: Many children with Moebius require orthodonture work to get their teeth to match up. My son had braces for three years in middle school/high school and it worked wonderfully. Prior to that his top and bottom teeth did not match up when he chewed and it took him forever to eat. He is now 22 and we are so glad we did that. Many children with Moebius have small mouths and when their adult teeth come in there is not enough room. Sometimes it requires extracting several teeth.
Vicki McCarrrell
vicki@moebiussyndrome.com

The book “undesirable elements: Real People, Real Lives, Real Theater” by Ping Chong documents the “undesirable elements” performances that have taken place in many parts of the US and internationally. It describes the undesirable elements theatre performances with essays as well as presenting the scripts of four performances, including “Inside/Out...voices from the disability community.”

“Undesirable elements” began with themes of cultural and national identities, and has evolved and expanded to include many different types of differences, all with the theme of otherness. The structure of all the performances is the same: The performers are in a semi-circle, with chairs, scripts and music stands. There are sequences of claps as well as graceful gestures by the performers and unusual music, called a haunting Norwegian incantation. In all the performances, historical events, such as the Americans with Disabilities Act, are mentioned by the performers along with their own stories. All are honest, brave, personal stories, with many performers explaining how they learned to stand up for themselves.

The “Inside/Out...voices from the disability community” performance includes seven actors, ages 23 to 60, with different disabilities and experiences. This piece has been identified as the first oral history theatre project on disability. It is storytelling at its most powerful since it is real people telling their own stories.

The personal essay and participant information background form at the end of the book is that of Matthew Joffe. Here, readers learn more about Moebius syndrome and Matthew’s personal experiences.

Reading “undesirable elements” is the first step in the process; the second is to experience a performance.
**Power Up! Apps for Kids with Special Needs and Learning Differences**

Power Up! provides information on apps for children with special needs and learning differences by Common Sense Media. They are listed by level (beginner, intermediate and advanced) and by category (communication, social interaction, organization, reading, mathematics, and motor skills). Check out the apps at [www.commonsensemedia.org/guide/special-needs](http://www.commonsensemedia.org/guide/special-needs).

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**Moebius Syndrome Friends & Family Get-Together in the UK**

Emma Turner is organizing an informal get together in Reading, just outside London for the weekend of Friday August 23 – Saturday August 24, 2013. There may be an organized day trip on Saturday with everyone meeting up at the end of the day for a meal/drinks/natter. For more information, please contact Emma Turner at emja77@ntlworld.com or through Facebook (search on Emma Jayne Turner).

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**Disease InfoSearch**

The Genetic Alliance recently launched a new website, [www.DiseaseInfoSearch.org](http://www.DiseaseInfoSearch.org), with information on more than 15,000 conditions. In addition to information on conditions and diseases, there is information on advocacy and support groups and clinical trials for specific conditions as well as links to recent scientific literature.

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**A Mother’s Dilemma**

By Katherine McCaughan

As we approached the stop, I was devastated to hear a chant, ‘Here comes funny face. Here comes funny face,’ which was repeated by several older boys already there waiting. My heart lurched and all my protective mother instincts flooded my heart and my mouth. I heard a loud voice much like my own announcing loudly, ‘His name is Timothy and you’ll call him that or have me to answer to.’ A few curtains in nearby houses parted and a couple of mother’s faces peered out quickly. As I glanced at Tim, I realized he was trying to hide behind a telephone pole. What had I done? A steely silence ensued until the bus appeared and the children rode away.

Takings a deep breath, I approached one of the houses where a mother’s face had earlier appeared at a window. Firstly, I apologized for raising my voice at the children, and then I explained Moebius syndrome to her. After repeating the explanation at the other two houses where the children lived, I returned home and called the school. Tim’s teacher reported that Tim seemed unusually quiet that morning, but there was no need to pick him up.

The next morning I insisted on walking the children to the bus stop. As we approached, a different chant greeted us. ‘Good morning, Tim-O-Thy.’ Well, it was still a chant, but it was certainly better. Had I done the right thing in facing down these young kids? Thirty five years later, I am still not sure. Today there are many books on dealing with bullying, but way back then, I was on my own. However, I learned a valuable lesson from this episode—if I did not stand up for my child, who would? My neighbor had obviously ignored the mean greeting, and the kids were probably emboldened as a result.

It is interesting that although Tim remembers other difficult episodes in his life, he does not remember this one. Tim is now an adult of whom I am very proud. He is married to a wonderful woman and has given me two grandchildren I love to pieces. He is a strong and confident man, so at least my response to the bullying did him no harm.

Katherine McCaughan is the author of Moonbeam Award winning young adult novel, “Natasha Lands Down Under.”

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Moebius Syndrome News
IN MEMORY OF
Frank Agar Sr.
Douglas & Suzanne Koch
Hannah Devine
Susan Knox
James Drugg
Accounting Department
Mr. & Mrs. William Baker
Verna Boudreau
Brine Family
Capone Iron Corp
Elaine & Bill Copithorne
Linda Dubeau
Judith Goggin
Elaine & Bill Copithorne
Linda Dubeau
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Pamela Uccello Green
Jennifer & Chris Jones
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Vincent & Lois Maddon III
Rose Magliozzi
Sunshine Memorial School
Wayne & Karen Morgan
Joseph & Kathleen Mullen
Victoria & Richard Olken
Palace Construction Inc
Wendy & Gene Peterson & family
Lawrence & Donna Pope
Elizabeth Powers
Ptimum Building Systems & Management Inc.
Sally Stebbins
Deborah & Linda Thompson
IN HONOR OF
Natalie Abbott
Marcia & Wayne Abbott
Kimberly Banning
Dave & Cheryl Banning
Luke Calhoon
Nancy Legurzamon
Lauren Deveney
Laura Dean
Abigail Fulmore
Debbie Fulmore
Debbie & Abigail Fulmore
Sally Clark
Clayton Hoffman
Mathea Salas, DO
Dave Sprecher
Samantha Jezowski
Lori Jezowski
Alyssa Lueckhoff
Nancy Lueckhoff
Sean McCarrell
Jerry, Paula & Kellie Dilliner
Vicki McCarrell
California Federated
Women’s Club
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Mark J. Sullivan
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Eric A Washer
Chris Washer & Holly Kahle
In Honor of
Natalie Abbott
Loretta Lisowski
Benjamin Graf
Aralia, Hazori, Weinstein & Graf families

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 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.

kids’ PAGE will return in the next newsletter
Plan to attend the 11th Moebius Syndrome Conference in Washington, DC!

Mark your calendars to attend the 11th Moebius Syndrome Conference. Board as well as many speakers from the Washington, DC area. We also will offer consult and research opportunities for people with Moebius syndrome and their families. Support sessions will take place for parents, grandparents, and for adults with Moebius syndrome. The conference will offer an incredible opportunity for people with Moebius syndrome to meet others with the same condition. People who have attended previous conferences will be able to connect with old friends as well as new, and those attending for the first time will be able to make new, lifelong friends.

Here's the scoop—
✓ Friday July 18, 2014 through Sunday July 20, 2014
✓ Bethesda North Marriott Hotel & Conference Center
  5701 Martinelli Rd
  Bethesda, MD
✓ The hotel rate will be $109 plus tax; the registration fees are not yet confirmed
✓ A number of scholarships for first time attendees with financial need will be offered

Contact conference chairs Jacob and Panina Licht at plicht@yahoo.com.
Moebius Marketplace Order Form

Name: _______________________________________________________________
Address: ___________________________________________________________
City: ____________________________ State: __________ Zip: ________________
Telephone: ______________________ (We will contact you only if we have a question.)  E-mail: ______________________

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☐ This is a gift. Please include the following note: ______________________

Complimentary copies of “My Face”

You may request up to 35 copies of the children’s book “My Face” from the Moebius Syndrome Foundation.  
(Mailed to US addresses only.  International residents may request 2 complimentary copies.)

The books can be for your child’s class, your friends & relatives, and the professionals who work with your child.

The books are complimentary, but donations are always welcome.

Please send me __________ copies of “My Face”

How to order:
To receive your complimentary copies of “My Face” complete and return this order form to the address below, or send an e-mail to marcia@moebiussyndrome.com.

Be sure to include the number of copies you would like.

NEW Moebius Syndrome Teddy Bear (I’m smiling on the inside)  ____ @ $12  $ ______

Awareness Wristbands
One size  ____ @ $2  $ ______

NEW T-shirt Check Size and circle color:
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   PINK  BLUE  WHITE

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TOTAL ENCLOSED:  $ ______

NO CHARGE FOR SHIPPING IN US:

INTERNATIONAL SHIPPING: $10 on any order

Please make checks payable to: Moebius Syndrome Foundation

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

Questions? 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](http://www.moebiussyndrome.com).

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

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