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.

A Phenomenal Conference: From the Beginning to the End
By Matthew S. Joffe

So here we were. It was our 10th international conference, a milestone for our organization. We were very fortunate to have two very special guests as our opening and closing keynote speakers. On Friday afternoon, Dr. Francis S. Collins, director of the National Institutes for Health (NIH) christened our conference with an audio-visual presentation entitled, Seeking Molecular Answers to Moebius Syndrome. Dr. Collins, who holds both doctoral and medical degrees, took us on a journey through the amazing but often difficult to understand world of genetics.

While many in our community are both excited and eager to hear about the progress, few of us have the background to grasp its intricacies and vocabulary. Enter Dr. Collins, whose presentation framed the topic in understandable language and explained the progress made to date as well as outlining the work still to be done. But he saved the best for last. At the end of his talk, he brought out his guitar and played a song he had written just for us and the conference. A rousing song for all the work done in the name of the Moebius Syndrome community and family, it had the whole audience singing along and rising to their feet. One could say it was an anthem for all of us and our commitment to living in the presence of Moebius Syndrome (http://www.youtube.com/watch?v=jbbW2BHwTE&feature=youtu.be). It was hard to imagine a more emotionally powerful start to our conference!

Flash forward to Sunday afternoon. It was hard to fathom that the conference was coming to an end. Our closing keynote speaker was Rick Guidotti, director of Positive Exposure (http://www.positiveexposure.org/home.html), a New York City based non-profit organization, which Rick describes as, “Our programs support and promote human dignity through Positive Exposure’s Spirit of Difference photographic image data bank and video interviews of persons, particularly children, living with genetic conditions.”

Continued on page 3

Find us on Twitter and Facebook!

Join our Facebook Non-Profit Organization Page: Moebius Syndrome Foundation http://www.facebook.com/moebiussyndrome

Follow us on Twitter: @MoebiusSyndrome http://twitter.com/MoebiusSyndrome

Rick Guidotti, director of Positive Exposure and closing speaker, with good friend and vice president of the Moebius Syndrome Foundation, Matthew Joffe.

2012 Conference co-chair Dawn Ang with Kathleen Mc-Caughan, conference planning committee member and volunteer
Greetings! Our 10th conference in Philadelphia July 13-15, was a huge success with 425 people attending from 10 countries; 114 of the attendees had Moebius syndrome! For 111 attendees this was their first conference. Thirty-five speakers shared their knowledge with the participants (speakers came from the U.S., Canada, Saudi Arabia, England and Germany), and six physician/research teams held 193 consultations with conference attendees.

Dr. Francis Collins’ opening presentation gave us an overview of how genes work, as well as the work his lab at the National Institutes of Health is doing on the genetics of Moebius syndrome. His touching song written and performed specifically for our worldwide Moebius family was a special treat.

Two and one-half days of multiple sessions followed Dr. Collins’ opening presentation. It was wonderful to meet new families and individuals with Moebius syndrome, and to see so many old friends. I was especially touched seeing the babies, toddlers, children, teens and adults having fun with new friends and realizing that they are not alone. This was not the norm 20 years ago.

Chris Wazilewski opened the talent show on Saturday by dazzling us with his soccer skills. The show featured many talented young musicians, singers, dancers and even a magician! We are so proud of all of them. Susana Romero from Caracas, Venezuela closed the talent show with a dance proving that she is young at heart.

On behalf of the Moebius Syndrome Foundation Board of Directors, we extend our deep thanks to Dawn Ang and Emmet Joy Wennerholm and Diane Breton.

Continued from front page

The 2012 Moebius Syndrome Conference was our largest ever with 425 attendees (114 people with Moebius). That group included 275 adults, 30 teens, 80 children between 4 and 12 years old and 40 children under 4 years old. Ninety-six adults and five teens were attending for the first time. We gathered from across the globe representing 33 states, 1 territory (Puerto Rico), and 10 countries: Australia, Canada, Cyprus, Great Britain, Guatemala, Israel, South Africa, Sweden, United States and Venezuela.

Many of us know Rick through our calendar with his photos a few years back and for those of us lucky enough to visit his studio for a photo shoot of a lifetime. A world famous fashion photographer, Rick is truly a magician whose art is in revealing the beauty that is in all of us. His presentation, Positive Exposure, The Spirit of Difference, was chock full of pictures and videos which took aim at the standard notions of beauty and helped us see how we can transform ourselves to see our own beauty and then show it to the world. It was also an oral history of his work and organization. Here difference was a badge of honor for us to embrace with pride and dignity.

Dr. Collins and Rick Guidotti framed the conference in their own unique styles, bookends for what was a special three days.

Photos taken by Rick Guidotti at the conference may now be viewed on a password protected website. Go to http://ricknycc.exposuremanager.com/g/moebius_2012, and use the password philly. Photos may also be ordered from this site.

Moebius Syndrome News
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Summer 2012

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Reflections from Speakers, Researchers & Attendees

“The Moebius Syndrome Conference was truly inspiring, and I wish I could have stayed for the whole thing! Lori [Bonnycastle PhD] told me how much she had gained by being there and meeting so many families. Your help has been central to our own efforts, and your offer to continue that assistance is much appreciated. I think progress in understanding the genetic factors will be pretty interesting in the next couple of years!”
—Francis S Collins MD, PhD, Director, National Institutes of Health

“Thanks very much. It was a pleasure and an honor to participate. I have marked my calendar!”
—David Hunter MD

“The conference was fantastic as usual. The talent show incredible. I was so happy to be there with Greg [Borschel MD] and Alison [Snyder-Warwick MD]. They will be great supporters of the organization. It was a true joy for me to take part. Hope we meet again soon.”
—Ron Zuker MD

“It was so nice to meet you [Vicki McCarrell] in person at the Moebius event on Saturday. It was an extraordinary conference—I can’t stop thinking about the people I met, the conversations I had, etc. Here is the first of at least two posts I plan to write about the conference: http://e-patients.net/archives/2012/07/facial-paralysis-not-personality-paralysis.html. Please share it widely, within your network via email if appropriate since I know not everyone is on Twitter and Facebook.”
—Susannah Fox, Associate Director, Pew Research Center’s Internet & American Life Project

“And from a few of our conference attendees:

“Amazing.”
—Henrietta Spalding

“What a wonderful time I had in Philadelphia. The conference was brilliant—you and your whole committee should be so proud of what you’ve achieved for the Moebius community around the world. I really enjoyed myself and it was all just so stimulating. I came home with my head buzzing with ideas. Many thanks for your kind words—I’m so pleased that I hit the mark!”
—Henrietta Spalding

“Amazing.”
—Having Dr. Collins open the conference was fantastic.”
—Thank you to everyone who worked so hard to make this possible.”

“Meeting other parents and talking one on one was the most beneficial to me. My daughter with Moebius enjoyed meeting and playing with other kids.”
—Denise Ray Hill (oral motor) was very informative. She gave us great suggestions to bring back to our therapist.”

“Presentations led by Matthew Joffs and Kathleen Bogart were excellent.”

“Kudos to all involved in organizing this great event!”
—Online registration was user friendly and the email confirmation was thoughtful.”
—We appreciated name tags with ‘First Time Attendee’ and other special designations.”

“I found the nerve regeneration and personal stories most helpful.”
—Being positive with Susana Romero was the best! She is funny and outgoing!”

“Talent show and dancing were great!”

“It’s been very informative. People have been very warm and welcoming.”
—Incredible • Inspiring • Stimulating • Helpful • Outstanding

Extraordinary • Informative • Fantastic • Uplifting • Great

The Colchado family: Cody Colchado Jr. and Albie, with their children Tabatha and Cody III on the Monday excursion around Philadelphia.

The Gradillas children Matix and his sister Olivia.

Joy Wennergren, Karin Sandberg, and Caroline Askardot, all from Sweden.

The Lockwood family: Kevin and Sarah with daughters Samantha and Erin.

The Goodwin children Mako and his sister Olivia.
Q: SCOLIOSIS AND MOEBIUS SYNDROME
Have you heard of any other Moebius patients developing scoliosis? My daughter is and developed this additional condition at age 10, yet another problem for us to worry about and deal with! It might be interesting to see whether it features regularly or whether it is just bad luck! Unfortunately, hers is getting worse as she grows so we are heading towards surgery, and trying to avoid it at all costs.

Many thanks,
Kathryn Tait, Ktait@blinernet.com

Q: STOMACH PROBLEMS AND MOEBIUS
I have a 13-year-old son with Moebius syndrome. He has had a Trach tube and G-tube since he was three months old. He has had ongoing stomach problems for seven years now. He complains about feeling full, constipated and possibly having a slow digestion process. Because of these issues, he refuses to eat regularly according to his schedule. Does anyone know of a specialist/doctor or have suggestions that may help? Thank you.

Davinda Black, davinda.black@gmail.com

Q: EYE GLASS SHIELDS
Does anyone have information about Eye Shields to protect the eyes of adults or children with Moebius?

A: Recently a couple of engineers have graciously given my daughter Tessa their time and talent to create custom made side shields for her eye glasses using high-tech equipment. Through trial and error we are getting close to having comfortable and appropriate fit for Tessa. This firm is interested in writing about this project in their internal news and I wonder if the Moebius community would also be interested. Perhaps there is someone in a similar field that would benefit from this whole process. There may be others who need the same type of protection as Tessa.

Michelle Turtle, cturtlehome@bigpond.com

Q: HEALTHCARE SPENDING ACCOUNT
Can Moebius Conference fees be submitted & reimbursed through a Healthcare Spending Account?

A: Great Question! Many people don’t realize that costs associated with medical conferences can be reimbursed through a Healthcare Spending Account. For example, many people contribute “pre-tax” dollars from their paycheck into a Healthcare Spending Account and get reimbursed for office co-payments, dental expenses, etc. Since Medical Conferences are “Eligible Covered Expenses,” you can also submit the receipts and documentation for attending the Moebius Conference and get reimbursed for the conference fees and transportation costs. If there was airfare and hotel costs incurred, you would most likely be asked for a “statement of medical necessity” (signed by your doctor or pediatrician). For more information you can visit http://www.yourspendingaccount.com/.

There is a spot on the website where you can input your employer’s name and it will provide you a link to the Benefits Directory for that employer. You can also contact the Benefits Department within your company to learn more.

Debbica Mahar, debbica.mahar@gmail.com

Q: OSTEOPOROSIS, ARTHRITIS, AND REFLEX SYMPATHETIC DYSTROPHY
Over the last 12-18 months my 12-year-old daughter has been diagnosed with significant osteoporosis, arthritis and reflex sympathetic dystrophy. Her rheumatologist thought it was not unexpected because of her limb deformity, even though her osteoporosis is systemic. I wondered if anyone knows of many, or any, kids with Moebius who suffer with the same? Her eyesight has also deteriorated fairly rapidly, and now she only has 15 percent vision in her right eye and 30 percent in her left (her right side is more affected with Moebius). Again I can’t see how it ties in with Moebius, but there aren’t many people I can ask here in Australia.

Michelle Turtle, cturtlehome@bigpond.com

Q: EYE GLASS SHIELDS
Does anyone have information about Eye Shields to protect the eyes of adults or children with Moebius?

A: Recently a couple of engineers have graciously given my daughter Tessa their time and talent to create custom made side shields for her eye glasses using high-tech equipment. Through trial and error we are getting close to having comfortable and appropriate fit for Tessa. This firm is interested in writing about this project in their internal news and I wonder if the Moebius community would also be interested. Perhaps there is someone in a similar field that would benefit from this whole process. There may be others who need the same type of protection as Tessa.

My daughter has had eye muscle and eyelid surgeries making her eye movements very limited and her ability to close her eyes impossible. The shields help to protect her from wind and dust which could lead to corneal scars and abrasions. How many others in the Moebius community have such eye limitations? Can most roll their eyes and/or have partial closure at night? What are others doing for protection?

There are some glasses on the market that offer wind protection but don’t allow for Rx lenses. Tessa’s new glasses with the clear shields should go fairly unnoticed as they are standard frames. Up to this point we tried using plastics manufactured by Eagle Vision that were fit around her lenses and face then secured in wire-framed glasses. Our last attempt at eye protection was packaging tape that was sized to fit over the tops and bottoms of Tessa’s frames and molded to the curvature of her face. While fairly easy to fit and replace, the tape is not washable or extremely durable. These new shields are sturdy plastic and should last the life of her frames.

If you know of other eye concerns, needs, or folks in engineering/design fields that would like more information please contact me.

Donna Kremer, donna.kremer@gmail.com
“Wonder” – A Book Review

“Rich and memorable...It’s Auggie and the rest of the children who are the real heart of ‘Wonder,’ and Palacio captures the voices of girls and boys, fifth graders and teenagers, with equal skill.”

–The New York Times

Wonder
By R.J. Palacio

CHOOSE KIND
A New Anti-Bullying Initiative by Random House
Random House has created a new blog to help raise awareness about some of the issues in “Wonder” and as an anti-bullying initiative. You can find the blog at: http://choosekind.tumblr.com

ASSISTANCE DOG AND HEARING AID FOR DOLLS
A merican Girl now has an assistance dog! The service dog, named Chocolate Chip, comes with a handle and “treats.” They also have hearing aids that fit all the American Girl dolls. The hearing aids must be fitted at an American Girl retail location, but they are removable. More information on both can be found at www.americangirl.com.

FROM OUR donors
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 gift.

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ASSISTANCE DOG AND HEARING AID FOR DOLLS
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.

Moebius Marketplace Order Form

Name: ____________________________
Address: ____________________________
City: ____________________________ State: __________ Zip: __________
Telephone: ____________________________ (We will contact you only if we have a question.) Email: ____________________________

☐ Ship to same address
☐ Ship to different address:
Name: ____________________________
Address: ____________________________
City: ____________________________ State: __________ Zip: __________

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

TOTAL ENCLOSED: ____________________________

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<th>Item</th>
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<tr>
<td>T-shirt</td>
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INTERNATIONAL SHIPPING:

For questions/costs, Email us at marcia@moebiussyndrome.com or call 510 304-2302.

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 email to marcia@moebiussyndrome.com.

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

“I Am Smiling” Bears

Cost is $8 each, plus shipping.

Necklaces

<table>
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<th>Item</th>
<th>Rate</th>
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<tr>
<td>Heart Necklace on purple ribbon</td>
<td>$10</td>
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<tr>
<td>Round Silver Necklace</td>
<td>$30</td>
</tr>
</tbody>
</table>

Shipping (per box, any number ordered) $2

PARACORD BRACELETS

Purple & White Paracord bracelets still available! Cost is $5 each, plus shipping.

Please specify which size you need: Small, Medium, or Large (adults) or one “child” size available as well. The bracelets are made by 11 year old Jessica Maher who sold them at the recent conference. Email your request for paracord bracelets directly to Jessica at rebecca.maher@ymail.com.

All proceeds from wristbands will be donated to the Moebius Syndrome Foundation.

Necklaces

Heart necklace on purple ribbon @ $10
Round Silver Necklace @ $30

Shipping (per box, any number ordered) $2

2012 Conference T-shirt — Check Size:

☐ Youth Medium @ $5
☐ Youth Large @ $5
☐ Adult Small @ $5
☐ Adult Large @ $5
☐ Shipping (per box) $2

Wristbands — sizes are limited (includes shipping)

☐ Small (older children & small adults) @ $2

TOTAL ENCLOSED: ____________________________

Moebius Syndrome News

T-SHIRTS

2012 Conference T-shirts
Sizes are limited, order quickly.
Cost is $5 each.
If ordering with a teddy bear or necklace, no additional postage.
If ordering separately, postage is $2.

TEDDY BEARS

Our adorable Moebius Syndrome Teddy Bears are wearing a purple t-shirt with the words “I’m smiling on the inside” on one side, and the Moebius Syndrome website on the other.
Cost is $2 each and includes shipping.

WRISTBANDS

Our purple wristbands are designed with the words “I’m smiling on the inside” along with a little heart in the logo. They measure 1” tall.
Cost is $5 each, plus shipping.

NECKLACES

Heart necklaces (shown at right) are sterling silver with the MSF logo, on a light purple ribbon.
Cost is $10 each, plus shipping.

Round sterling silver necklaces (shown at left) are on an 18” chain.
Cost is $30 each, plus shipping.

COMPLIMENTARY COPIES OF CHILDREN’S BOOK “MY FACE”

Up to 35 copies of the children’s book “My Face” may be requested 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. See ordering information on Order Form to the right.

The books and shipping are complimentary, but donations are always welcome.

Moebius Marketplace

Fall 2012
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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