MOEBIUS
SYNDROME
FOUNDATION

Moebius Syndrome News

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Winter 2011

Ian Linn, 10 – Teacher, Author, Humorist, Wii Master, Future Scientist, Poker Player, Deadpan Comedian

By Dawn Ang

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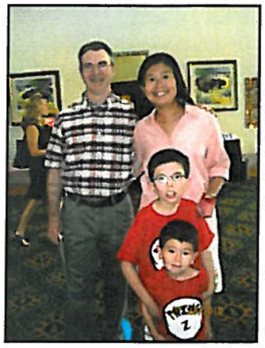

Everything happens for a reason, so I've come to believe.

Never in my wildest dreams could I have imagined that as I share my 10-year story with you, that I would be a mother of two beautiful children, have a loving and devoted husband, and have left my beloved journalism profession. More important, that I would have learned so much about Moebius syndrome, a syndrome so rare there are only an estimated 1,000 documented cases in the country.

My son Ian Linn, who was born with Moebius syndrome, has led me on this tremendous educational journey.

Not enough is known about Moebius, which manifests itself primarily in facial paralysis. Many individuals with Moebius have additional challenges. Ian also has Poland syndrome.

So, in Ian's case, he does not smile the way we do, he does not frown, and he does not have lateral eye movement. Articulation is difficult, because with the paralysis, words that begin with B, P, and M are hard to form. He was also born without his left pectoral muscle, and has a smaller left hand. He has overall low tone.

In a world where appearances seem to matter so much, where we respond to the slightest smile, wink, frown, it was terrifying to new parents like me and my husband, Emmet, that we could not tell if our baby was happy or sad or angry.

So we adopted the philosophy that he was happy, and we would smile at him all the time. We began to recognize the cries of frustration and anger. We managed.

When Ian was born, we were living in Philadelphia. We could not have been at a better place.

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Hecho en Argentina -- Made in Argentina. That's what we like to tell Ian.

It was October 2000. Emmet and I were living in Buenos Aires, where he was a financial journalist. The local economy was in shambles. In the few months we were there, we had experienced two attempted pocket-pickings. Emmet had been mugged, and many of our friends had been held up at gunpoint and robbed. I was sick as a dog, and ended up in the hospital, where we were told I was pregnant.

It was time to cut our losses and return home to Philadelphia.

I spent the remaining six months of my pregnancy planning for our future as a family. Aside from being really, really sick in my first three months, the pregnancy was uneventful. I planned to stay home for six months after the birth, then return to work as a journalist.

Inexperienced as I was, I walked to the oldest hospital in the country, Pennsylvania Hospital, three times, pillow tucked under my arm, thinking each time I was in labor. Ha! When labor truly began, I was in no position to walk those four blocks to the hospital. My total labor and delivery took about five hours. Ian was anxious to join us.

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When they placed this 6 lb 9 oz baby on me, I noticed his left hand was webbed and his index finger had no nail. No one else had noticed it. I asked Emmet to point it out to the doctor. I recalled the science classes I was

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The newsletter is on the web site in color at: www.moebiussyndrome.com

NORD
National Organization for Rare Disorders
2011 National Organization Member

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.

The Kids' Page will return in the Spring 2012 Newsletter

Letter from the President

Fall 2011

Warm Greetings,

As we draw near the end of the year, we are so grateful to all of you for your support of the Moebius Syndrome Foundation. With your support, we are able to reach people with Moebius syndrome around the world via our website, newsletters and emails. We mail an average of 200 packets of information per year to people affected by Moebius syndrome and professionals. We have funded over $150,000 for five research projects, hosted nine conferences attended by over 3,000 people in total, hosted a research conference and a scientific symposium, all with no administrative overhead.

The Foundation is pleased to announce that we will award twenty $500 scholarships to adults attending a Moebius Syndrome Foundation Conference for the first time (either an adult with Moebius or the parent of a child with Moebius) with financial need for the 10th conference to be held in Philadelphia next July. The scholarship will consist of the waiver of the $200 adult conference registration fee and a $300 debit card to be used toward transportation or hotel expenses.

The MSF Board is currently reviewing additional research grant requests to be announced soon. We are extremely grateful to our Scientific Advisory Board for their unwavering support of the Foundation. They speak at our conferences, answer questions from people with Moebius and their families throughout the year, as well as conduct research and share their findings at our scientific symposiums.

We want to thank several families that have held fundraisers this year, including Kacie and Carlos Nievesmassol in Colorado who hosted the motorcycle 'Ride for Moebius;' The Cheyenne Mountain and Schriever Colorado Fire Departments' Firefighter Ball; Brian and Stephanie Ramseier in California who hosted the Sandford Invitational Golf Tournament in honor of their son Triton, and the wonderful families who suggest donations in memory or honor of their loved ones to the Foundation.

Warm wishes to all of you as the holiday season approaches. May your holidays be filled with the love of family and friends. Best wishes for a happy, healthy, peaceful new year. We look forward to seeing you in Philadelphia next summer!

Sincerely,

Vicki McCarrell

Vicki McCarrell, President

vickimc@iland.net
www.moebiussyndrome.com

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Ian Linn, 10 – Teacher, Author, Humorist, Wii Master, Future Scientist, Poker Player…

in as a child, where the tadpoles' tail and webbed feet eventually evolved. I thought maybe as Ian grew, the webbing would go away.

I wasn't even worried when our pediatrician came into the delivery room to tell us that Ian had Poland syndrome. We were told it was merely cosmetic, that it wouldn't really affect his functioning. No biggie.

In the course of the morning, I attempted to bond with Ian, to nurse him periodically. Each time I did, he would gag, and I would call the nurses over. After about three times, a nurse came in and told me they wanted to take him to the NICU to observe him.

By mid-afternoon, a team of doctors descended on our room, and delivered the news. They thought Ian had Moebius syndrome. They wanted to send him over to Children's Hospital of Philadelphia, less than three miles away.

That's where we spent our first week.

We took turns to stay with Ian, wanting him to see one of us every time he opened his eyes. We held him as much as we could. We learned to intubate him. We were trained in CPR.

We were terrified. In the research we had done, much of what we learned portrayed the more severe cases of Moebius syndrome.

We already knew that without surgery, he would never be able to smile. What else? Would he be able to eat normally? Would he walk? Would he talk? What were his cognitive skills going to be like?

What did our future hold? More important, what was in store for Ian's future?

It broke my heart – still does – to think of the challenges Ian will face throughout his life.

But humor can break through many barriers, right?

So maybe his facial paralysis will serve him well – future poker player, or better yet, perhaps he could give deadpan comedian Steven Wright a run for his money.

****

That is why meeting so many of you at this past June's retreat made such an impression on me. Your resilience inspires me.

Our personal journey has been one of triumph, perseverance, exasperation, exhilaration, frustration, sadness, joy, and, sometimes, anger.

I am angry with anyone who dares to limit Ian's abilities. I am angry with bureaucracy – with individuals who favor job preservation over the developmental progress of any child with identified needs.

Ian has worked hard to be where he is today. At 10, he is a straight-A student, and has entered the most prestigious public middle school in Philadelphia – Julia R. Masterman School. Besides working hard at school, he still has two sessions each of occupational therapy, physical therapy, and speech therapy a week. He also takes swimming and karate. He continues to see a wonderful team of doctors at Children's Hospital of Philadelphia.

We celebrate his successes: at age 2, he took his first steps; at age 3, he was humming Beethoven's Ode to Joy; at age 8, he read a book on the periodic table of elements and decided his favorite element is beryllium; at age 9, he read Homer's The Odyssey, unabridged. Ian has also decided he enjoys the music of Electric Light Orchestra.

Don't get me wrong – he's still a kid, who enjoys tormenting his little brother. Lego Harry Potter and Star Wars on the Wii are his first choice for fun activities. Cookies and cream is his ice cream flavor du jour.

We continue to work on overcoming his visual and physical limitations. We also continue to wrack our brains to understand and forgive the bullies who exist in our world. At this point, that is our greatest challenge.

It is amazing how the ignorance of these cowards can so easily strip a child of self-esteem.

"Ian, it's not you, it's them," we have said repeatedly.

I continue to struggle to overcome this anger, and focus on the positive.

So much is possible.

We do what little we can to educate the public about Moebius syndrome and craniofacial challenges.

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I work to surround our family with friends who continually champion Ian's accomplishments.

The support we have from friends, from the Moebius syndrome community, and, now, from the Children's Craniofacial Association (CCA) have been invaluable. As much as it can sometimes feel like it, we know we are not alone. We felt that at the CCA retreat and we feel it with each Moebius Syndrome Foundation Conference. (Emmet and I are hosting the next Moebius conference in Philadelphia in July 2012, and expect 500 people to attend.)

Everyone goes through challenges. Ours is just a little different. Ian has come a long way, and for that, we are grateful.

10th Moebius Syndrome Conference

2012 Moebius Syndrome Conference

Friday July 13 – Sunday July 15, 2012

Sheraton Philadelphia Downtown Hotel

Hotel room rate valid: July 10 – July 18, 2012

Please be sure to join us for our 10th Moebius Syndrome Conference next July in Philadelphia. Information on the speakers and sessions is being updated frequently on the Moebius Syndrome Foundation website, and will be in the Spring Newsletter. The Conference Brochure will be posted online on our website and mailed to everyone in the U.S. and Canada in February. Be sure to keep checking www.moebiussyndrome.com for conference updates as well as information on registration costs, scholarships, and other important information.

Hotel Reservations

You can reserve your room now at the reduced hotel conference rate of $119 ($137.09 including Philadelphia hotel tax). Reserve your room early! Rooms are subject to availability. To receive the reduced conference rate you must reserve your room by June 15, 2012. You can reserve your hotel room online by following the link to the hotel from the conference web site (click on 'read more' about the conference from the home page of www.moebiussyndrome.com and select 'conference web site.' Or, click here for the hotel conference website. You also may phone the Sheraton Philadelphia Downtown Hotel at 215 448-2000, and be sure to request the special rate for the Moebius Syndrome Conference.

Baskets for Conference Raffle

We are trying something new at the upcoming conference. In addition to the usual raffle, we will have a raffle of baskets of items that reflect the cities, towns and regions where you live. We are inviting you to consider bringing a basket for the raffle, with items that reflect where you come from. This is optional, but everyone is encouraged to participate. These baskets can include souvenirs from your hometown, local and professional sports teams, wine from your local winery, or foods that are representative of your region. When you register at the conference, bring your Raffle Basket to the table next to Registration identified as Raffle Basket Drop-Off.

Important information: Please note that the Moebius Syndrome Association of Canada will no longer pay registration fees for Canada residents to attend Moebius Syndrome conferences.

Questions? Contact 2012 Conference Chair Dawn Ang at dawnang@moebiussyndrome.com.

Remembering Marion Meyerson

Dr. Marion Meyerson, a great friend of the Moebius Syndrome Foundation, passed away in August. Dr. Meyerson presented at several Moebius Syndrome Foundation conferences, and kept in contact with numerous members of our Foundation. She published an early article on speech, language and hearing with Moebius syndrome in 1978, and more recently published an article in a medical journal on adults with Moebius syndrome. Dr. Meyerson began working as a speech and language pathologist, and was a Professor and Lecturer in Communicative Disorders at several state universities in California for many years.

Several members of the Moebius Syndrome Foundation remember Dr. Marion Meyerson:

I met Marion in Memphis, Tennessee in 1978 when I was moving my family to California. She was one of the reasons we moved to California. She had used data about my daughter in a paper she had published about Moebius. Throughout my life Marion was a steady source of wisdom about the Moebius condition. I told her this and thanked her in a card I sent in the last of her days. I hope and trust that she heard my appreciation.
Bob Towler

I remember fondly my chatting with Marion on the phone. She was warm and supportive, offering great insight into our lives and challenges. She made us feel important and accepted as adults, and in my case, it came at a time when I was learning more about Moebius syndrome and myself. In many ways, she was one of the earliest "friends" to the foundation. Thanks for letting me share.
Matthew Joffe

I was one of approximately 18 Moebius adults she interviewed telephonically for a journal article. I recall at least one lengthy conversation with her about 12 years ago, during which she raised many probing questions. I appreciated her direct but professional approach, and was happy to have participated, especially after reading the "final product." I mourn her passing.
Roland Bienvenu

I met Marion Meyerson at the first Moebius conference I attended, and she served as a friend and mentor for my Moebius research for the last several years of her life. We visited numerous times when we were both living in San Francisco. She was very devoted to working with and researching people with Moebius syndrome. She published one of the first papers on the speech of individuals with Moebius. She also published a wonderful qualitative paper highlighting the resiliency and strength of adults with Moebius. The Moebius community has lost a great advocate.
Kathleen Bogart

Moebius Syndrome Foundation Board Meets

The Board of Directors of the Moebius Syndrome Foundation met with 2012 Conference Co-chairs Dawn Ang and Emmet Linn at the Sheraton Philadelphia Downtown Hotel in July for our annual face-to-face board meeting. The Sheraton Philadelphia Downtown Hotel is the site of our upcoming conference next summer. The hotel is situated very close to and walking distance to many city and historical attractions in Philadelphia.

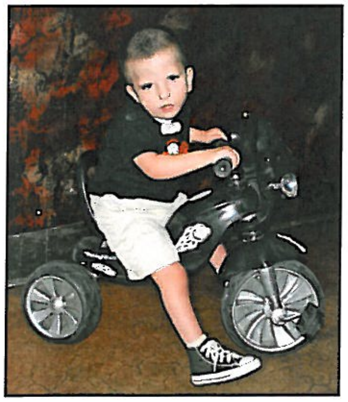
8th Annual Front Range Firefighter Ball

Pictured above: Monica Woodall, Anthony Flowers, Shandy Staggs, David Arcella and Kacie Nievesmassol

By Monica Woodall

The 8th Annual Front Range Firefighter Ball & Silent Auction was hosted by the Cheyenne Mountain and Schriever Fire Departments in Colorado Springs, Colorado on the evening of Saturday October 8th. They held several fundraisers throughout the year, culminating in this formal event, to benefit the Moebius Syndrome Foundation as the designated charity for the year. Presentations on Moebius syndrome and the Foundation were made by Monica Woodall, Shandy Staggs, and Kacie Nievesmassol. The Moebius Syndrome Foundation was presented with $6,000 (see check above!) from the Cheyenne Mountain and Schriever Fire Departments.

Riders for Moebius Fundraiser



By Kacie Nievesmassol

The second "Riders for Moebius" event took place in Colorado Springs, Colorado on July 16, 2011. We had a wonderful turn out of thirty-five Bikers: last year we had ten, so we are getting bigger. We are "Riders for Moebius" and this was our second motorcycle ride. We put together a $250 Poker Run where the bikers ride around collecting cards and we met at an ending point and had raffles, prizes, food and cake. This year we put together a wonderful slide show letting everyone know our experience with Moebius and our journey we have been on. We raised over $1000 and had lots of family and friends supporting us. My husband Carlos and I will continue to do what we can for the Moebius Syndrome Foundation. I have new shirts (last year's shirts were a huge hit at the conference) and I have a CD we put together.

I Have a Disability. So What!

By Aidan Lucid

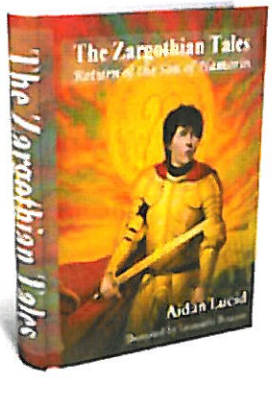
Imagine a beauty queen standing proud on a stage, flashing her pearly whites and looking glamorous. She thinks about pursuing a career as a model one day and with her stunning good looks, this girl would probably be very successful. Now imagine what life would be like if that same beauty queen suddenly woke up one morning to find that she could no longer smile? The poor girl would probably be overcome with great sadness and instantly know that her career as a model has now gone down the proverbial drain. For some people with Moebius syndrome, living without a smile is a reality they face every day.

Like most people I have encountered, there's a high probability that you have never heard of Moebius syndrome before. Then you're not alone; most people in the medical profession have not encountered many patients with Moebius because it is so rare. In fact, it's estimated that one in 10,000,000 are born with it. So what exactly is Moebius syndrome, I hear you ask? Well, it's not like Down syndrome. No two Moebius sufferers are alike. Some may be missing a few digits or a limb, while others may be missing an ear. The one characteristic that is common amongst most Moebiusians is that they can't smile or move their eyes due to some facial nerves being dormant since birth. Sometimes an individual may also be partially deaf. In my case, I had to have a few operations as a child to correct some deformities and had to overcome some learning difficulties.

After reading the above most people might say, "Oh my gosh, the poor things. Why do they have to suffer like that?" Well please don't pity us. I, like most Moebiusians, have lived a full life. Some have gone on to college, like me, and are holding down full-time jobs. In my case, I have received diplomas of distinction in writing for TV and radio, freelance journalism and creative writing. I've been published in many magazines, e-zines and a few poetry anthologies. Last December my young adult fantasy novel, *The Zargothian Tales: Return of the Son of Hamorin* (www.thezargothiantales.com) was published in ebook format after three years of searching for a publisher, and it is now also available in paperback. In June 2011, I received my second degree in Reiki so now I'm able to practice as a Reiki healer and heal people, which is something I've always wanted to do, as well as my first love - writing. Having a supportive family is also essential when one has Moebius syndrome and I'm blessed with my family. They have supported me in all my pursuits and were there when things got a little tough when I was in my teens and early 20s.

Of course, there are those ignorant individuals who wish to stand, stare or laugh at us because we're "different" but this doesn't bother me anymore. I don't hate these people; instead I hope they may see sense some day. Yes, life may not be easy for a person with Moebius but so what if I have a disability! I'm damn proud of who I am and what I've achieved so far in my life and there's not a thing that I would change.

So for those of you with disabilities, don't be afraid to live your life and chase your dreams. You only live once so make your life count and show the world your inner beauty and true magnificence. You're not a "retard" like some callous people like to label us. Instead you are special and ***can*** make a true difference to the world, so don't ever forget that.



By Aidan Lucid

A new breed of fantasy has arrived. Don't miss out and join in the adventure today! For more info. go to: www.thezargothiantales.com or to purchase a copy, go to www.wordtechs.com/ztlucid.html. Some of the royalties will go towards helping an organization in Ireland called Friends of ABLE. ABLE (A Better Life for Everyone) helps people with disabilities gain new skills and assists them in seeking employment.

Questions & Answers

A: A Question was asked in the Summer 2011 Newsletter about Behavioral Issues & Moebius

I have had issues with my 6-year old son's behavior. You didn't go into detail about your daughter's behavior so I will just tell you what is going on with my son's behavior. This only started when he went to kindergarten at a new school. He is in a regular classroom where the kids really don't have any problems like he does. He started doing a lot of annoying behaviors like touching people a lot and saying things that weren't nice. I didn't know how bad the behavior was until about six months into school when I decided to observe for a day. He was not connecting with anyone and he wasn't communicating with anyone other than the annoying behavior.

After getting with the counselor and talking to other friends who had children with behavior problems we started trying different things. We found a therapist who helped me put the behavior issues on the Exceptional Learning Plan that the school has for him. So the school is required to help me with this. The therapist also ruled out any other issues by evaluating him.

I also read a book at the advice of a friend called "Transforming the Difficult Child - the Nurtured Heart Approach." It helped a lot. Some kids are looking for a "reaction" from their behavior, even though the behavior may be negative. They need to get more attention from positive behavior. Also I felt that my son is shy to begin with and can't speak as clearly as other kids so he tried to communicate with them in other ways even though it was negative. This obviously isolated him and made his behavior even worse. He did have to deal with kids saying that he looked weird which made his behavior bad too.

Finally we started this token plan where my son gets tokens for good behavior. He "cashes" in his tokens at the end of the day for a TV show or popsicle. He is not perfect but the behavior has greatly improved. He became much happier too. I started going to lunch with him at school and showing him how to talk to the other kids.

Also, the book said that when the child does something wrong or bad that the parent or teacher needs to keep the emotion out of it when they are put into timeout or something. Emotion is the reaction that the child may unconsciously be seeking. Your reaction needs to be matter-of-fact.

I really hopes this helps.

Alexa Graf
alexabillgraf@yahoo.com

A: A Question was asked in the Summer 2011 Newsletter about dry eyes and watering eyes.

This is in response to the question regarding "Watering & Dry Eyes". My husband has Moebius and he also has difficulties with dry eyes and also suffers from seasonal allergies which irritate his eyes. Our daughter is an optometrist, and to help with the dry eyes she inserted punctal plugs in his tear ducts. These plugs force the tears to remain in the eye longer and have really helped. I spoke with her about your question and she advises against the surgery. She said the main issue is the lack of blinking which causes the eyes to dry out and as a defensive mechanism they water. It is not because the tear ducts are not draining the tears properly.

For her dad's allergies she recommended an allergy drop called "Pat a Day" and to further help with the dry eye the routine use of eye drops (such as Sustane Balance) several times a day, and finally an eye ointment (such as Genteal Gel or Refresh PM) at night. Another helpful tip - warm compresses on the eyes for several minutes as needed. The warmth is very soothing.

Our daughter also suggested that if this doesn't help you should seek a second opinion from an optometrist or ophthalmologist. Best of luck,

Nancy Moore

Please copy Newsletter@moebiussyndrome.com on all responses so that your letter can be printed in a future newsletter. Thank you.

Rare Disease Day—Wednesday February 29, 2012

'Rare but strong together'

Rare Disease Day

Rare Disease Day is now celebrated around the world, sponsored by the National Organization for Rare Disorders (NORD) in the US and by EURODIS in Europe. According to NORD, "Rare Disease Day is about realizing the similarities among all individuals impacted by rare diseases. By working together we can raise awareness and create a global impact."

In the US, there are 30 million people affected by rare conditions. NORD asks those of us who are touched by a rare condition to join in creating awareness for Rare Disease Day. The Moebius Syndrome Foundation is proud to be a participant with many other organizations in the annual Rare Disease Day. Everyone is encouraged to support the theme of Rare Disease Day, that rare diseases are an important public health issue. The special website for Rare Disease Day details how you can get involved and lists events occurring in different states and regions. Equivalent activities will take place in many countries around the world, with international efforts to raise awareness led by EURODIS.

Check out www.rarediseaseday.us for NORD and other organizations' efforts in the US, and www.raredisease.org for international efforts sponsored by EURORDIS.

COMING SOON: Online Rare Disease Community for Moebius syndrome. A special rare disease community will be launched soon for Moebius syndrome. Its purpose is to help patients to understand their condition, connect with others and provides tools for living with their diseases. It will provide a forum to add your story, ask questions and provide input to others on your experiences with Moebius syndrome. Check for its launch at www.rarediseasecommunities.org.

Moebius Syndrome Foundation

2010 Financial Overview

Revenue		**Expenses**	
Donations	$159,810	Postage	$ 2,615
Interest Income	$ 6,379	Newsletter expenses	$ 9,101
Fundraiser Income	$ 4,774	Website expenses	$ 3,670
Conference Income	$ 56,230	Research expenses	$ 20,962
		Conference expenses	$120,770
		Miscellaneous (insurance, tax preparation, envelopes, CDs, dues)	$ 2,716
Total Revenue	**$227,193**	**Total Expenses**	**$159,834**
Revenue less Expenses	**$ 67,359**		

Thank You

The Moebius Syndrome Foundation would like to thank the following 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.

In Memory of Hannah Devine
Susan Knox
In Memory of Jason Duarte &
In Honor of Morgan Rowe
Cindy Duarte & Dave LaDuca
In Memory of Mary Wasilewski
Stephen & Jennifer Toth
In Honor of Samantha Jezowski
Lori Grossbert
In Honor of the Licht Family
Bobby & Chelle Medow
In Honor of Jacob Middendorf
St Bernard Catholic School, 7th Grade
In Honor of Kevin Osowski
Marissa Osowski
In Honor of Triton Ramselier
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Stacy Elia
Flatiron West, Inc.
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Don Sandford / Riverway Properties
Joann Steinegeweg
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Daryl & Karen Annis
In Honor of Kasey Wessel
Elizabeth Wessel

Cheyenne Mountain & Schriever Fire Departments' Ball
Computershare
Fidelity National Information Services
Susan Isaacson
Steve Knight
Marshall Gerstein Borun LLP
Merck Partnership for Giving
Steven Miller
Moebius Syndrome Association of Canada
Network for Good
Stephen Szemenyei
Linda Tate
United Way Greater Lehigh Valley

For 2012 Conference:
In Honor of Ian Linn
Colleen Gallagher & Bruce Morris
GR & Roberta Shell

Build-A-Bear Workshop Foundation
Kacie & Carlos Nievesmassol

For 2012 Conference Scholarship Fund:

In Memory of Katherine Weishiet
Elizabeth Mayfield
In Honor of Natalie Abbott
Bette Baker
In Honor of Kimberly Banning
Dave & Cheryl Banning
In Honor of Leslie Dhaseleer
Louise & James Hilligan
Marsha Steward
Carl Romanik
In Honor of Ian Linn
Douglas & Jennifer LeMire

Samir Asaad
Charlevoix Lions Club
Nancy Gibbons

Moebius Syndrome Foundation Sales

Watches To order a watch with the MSF logo, send a check for $30 (made out to the Moebius Syndrome Foundation) and indicate if you want a women's or men's watch. Send your order with payment to:

Moebius Syndrome Foundation
PO Box 147
Pilot Grove, MO 65276

Pendants
Sterling silver pendants with the Moebius Syndrome Foundation logo circled with crystals are available through Sticky Jewelry. The cost is $39.95 plus shipping. To order a pendant, click on the link from the home page of the Moebius Syndrome Foundation website or call 727-823-9500.

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Will you contribute to the Moebius Syndrome Foundation?

Your support is always appreciated, and will help the Moebius Syndrome Foundation fund important activities such as the conferences and research grants. The Moebius Syndrome Foundation is a 501(c)(3) non-profit 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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