Greetings Friends!

The Moebius Syndrome Foundation has had a fantastic year thanks to all of you.

Our 12th conference held July 15-17 in Long Beach, which you will read about in this newsletter, was a huge success with 375 people from 7 countries in attendance. For 116 people this was the first Moebius Syndrome Conference they had attended; 117 of the total attendees had Moebius syndrome. We extend our deepest thanks to the speakers, many of whom also offered one on one consults to individuals with Moebius Syndrome and their families for a total of 243 consultations. Many thanks also to the conference committee members who spent countless hours working on the conference.

This year the Moebius Syndrome Foundation awarded scholarships to 4 young adults with Moebius syndrome to help them with their college/university tuition – and to help them reach their professional goals. Congratulations to Sara Michell, Ben Preusser, Michael Mendenhall and Angel Cortes. You will see information on each of them in this newsletter.

Research continues! Our 5th Moebius Syndrome Research Symposium held July 14 brought together 15 world renowned researchers who presented their research on various aspects of Moebius syndrome including genetics, facial surgery, sleep disorders, psychological issues, development of the facial nerve, and Terminal Schwann cells. This year the Foundation has awarded three research grants; one to Ronald M. Zuker, MD; Gregory Borschel, MD; and Emily Ho at The Hospital for Sick Children in Toronto for their work in developing a ‘Paediatric Facial Palsy Patient Registry,’ one to Alan Tenney, PhD, at Boston Children’s Hospital, for his work in ‘Facial Motor Neuron and Axon Development,’ and to the National Human Genome Research Institute for Dr. Manoli’s research on the genetics of Moebius syndrome.

Thanks to the generosity of our donors, the Moebius Syndrome Foundation will have spent over $172,000 on research in 2016, including the Research Symposium. This year the Foundation has awarded three research grants; one to Ronald M. Zuker, MD; Gregory Borschel, MD; and Emily Ho at The Hospital for Sick Children in Toronto for their work in developing a ‘Paediatric Facial Palsy Patient Registry,’ one to Alan Tenney, PhD, at Boston Children’s Hospital, for his work in ‘Facial Motor Neuron and Axon Development,’ and to the National Human Genome Research Institute for Dr. Manoli’s research on the genetics of Moebius syndrome.

Under the leadership of executive director Kim Cunningham and board member Roland Bienvenu, Regional Coordinators are ramping up to host regional get-togethers. We’re looking forward to the get-togethers and photos from your events!

Moebius Syndrome Awareness Day will be held January 24, 2017. Be sure to wear purple, educate others about Moebius syndrome, and post your photos. Let’s once again light up Facebook, Twitter, Instagram, Snapchat around the world to educate people about Moebius Syndrome Awareness Day will be held January 24, 2017. Be sure to wear purple, educate others about Moebius syndrome, and post your photos. Let’s once again light up Facebook, Twitter, Instagram, Snapchat around the world to educate people about Moebius Syndrome Awareness Day will be held January 24, 2017. Be sure to wear purple, educate others about Moebius syndrome, and post your photos. Let’s once again light up Facebook, Twitter, Instagram, Snapchat around the world to educate people about ‘Smiles That Come From the Heart’

Best wishes for a safe, happy and healthy holiday season to all of you,

Vicki McCarrell
**A Letter from our Executive Director**

Dear Friends,

Happy Holidays! As I look back on the year, it truly was a successful time for the Moebius Syndrome Foundation. We have made great strides recently and it is because of the hard work of our many volunteers and supporters. There is a passion within our community that I have not seen within other organizations; and it makes my job so much easier.

In 2016, the Foundation supported more initiatives than ever before. We awarded educational scholarships for students entering college and post graduate studies. We increased our financial support for research being done on Moebius syndrome. We are launching the MSF Regions, which will allow us to host events around the country, especially in the "non-conference" years.

Speaking of the conference, I enjoyed meeting many of you this past summer in Long Beach, California. What an amazing experience! As I said during my closing remarks, with tears in my eyes, I am honored that I get to work with you all and represent the Moebius community. Watching new attendees meet others with Moebius, some for the first time, was inspiring. Seeing everyone connect and learn from each other gave me new energy. All of the hard work that went into the conference was suddenly worth it.

Thank you to all of the researchers, consult staff, exhibitors, speakers, attendees, volunteers....it was a pleasure meeting and speaking with all of you. I left CA with many ideas for the coming year and for the 2018 conference. I am already looking forward to 2018 in St. Petersburg, Florida.

Our community is growing and we want to engage people from all parts of the world. If there are ideas you have, please reach out to me. One of the best parts of my job is when I get to talk and brainstorm with you. Thank you for all that you do!

Wishing you all a happy, healthy holiday season!

Kim Cunningham

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**Moebius Syndrome Foundation Scholarships Awarded**

The Moebius Syndrome Foundation is pleased to announce the winners of our first college scholarships for individuals with Moebius syndrome. Congratulations to all of you!

- **Sara Michell** of Lake Oswego, Oregon, majors in Biology at Oregon State University in Corvallis. Her goal is to attend dental school and become an orthodontist.
- **Michael Mendenhall** of Las Vegas, Nevada, earned his Bachelor's Degree in Communications from Brigham Young University, with a minor in Political Science. He is currently in law school at Gonzaga University in Spokane, Washington.
- **Benjamin Preusser** of Henderson, Minnesota, attends Saint Mary's University of Minnesota where he majors in Physics and Math. Ben graduated first in his high school class of 107 students with high honors. He was awarded the outstanding freshman math student award and has made the Saint Mary's Dean's List every semester.
- **Angel Cortes Gonzalez** of San Sebastian, Puerto Rico, is a student at the Interamerican University of Puerto Rico where he is working toward a Bachelor's Degree in Forensic Science. His goal is to be a forensic serologist.

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**Moebius Syndrome Foundation Regions**

The Moebius Syndrome Foundation is expanding its structure and creating chapters across the country. Please join us in welcoming our newly appointed Regional Coordinators:

- **Becky Becker**
  Midwest Region
  becky@moebiussyndrome.org

- **Kiowana Philips**
  Southeast Region
  Kiowana@moebiussyndrome.org

- **Tony Wilson**
  West Region
  Tony@moebiussyndrome.org

- **Jennifer Garvey**
  Northeast Region
  Jennifer@moebiussyndrome.org

- **Lisa Smant**
  Southwest Region
  Lisa@moebiussyndrome.org

If you are interested in hosting an event or assisting with event planning within your region, please reach out directly to your Regional Coordinator. We are excited about these events being planned around the country and need all the help we can get.

Follow us on Facebook or visit our Website to see what's being planned. We hope to see you at an upcoming event!

**Which region are you in?**
Thank You to all those who attended the 12th Moebius Syndrome Foundation Conference!

The 12th Moebius Syndrome Foundation Conference was held July 15-17 in Long Beach, California. Thank you to all those that attended! We had 375 people from 7 countries in attendance. For 116 people this was the first Moebius Syndrome Foundation Conference they had attended; 117 of the total attendees had Moebius syndrome. A total of 243 consultations happened at the event.

The 1st ever Movie Night was a great success, as was the Annual Talent Show! Many of our attendees got the chance to visit Disneyland and LA after the conference.

Thank You To Our Sponsors

- Global Genes - RARE Patient Impact Grant
- Dr. Brown’s Medical - Handi-Craft Company
- Facial Paralysis Center - Andre Panossian MD
- The Facial Paralysis Institute - Babak Azizzadeh MD
- Greystar
- Bobby and Chelle Medow / Bank of America
Save the Date
July 20, 21, 22, 2018
The Vinoy®Renaissance St. Petersburg Resort & Golf Club
St Petersburg
Florida

The Moebius Syndrome Foundation was honored to have photographer Rick Guidotti from Positive Exposure photograph the Conference. To see the full gallery: http://moebiussyndrome.org/events/conference2016/
My Internship at Global Calgary

By Kelsey Ferrill

As some of you know, I am a communications student at the University of Calgary. I am in my last year of the program and at this time next year will have my Bachelor’s degree in communication. This past summer, I landed an internship at Global Calgary, a national news company with stations all across Canada. They are undoubtedly one of the biggest stations in Calgary and I am incredibly lucky to have had the opportunity to intern there.

The communications field is hard for anyone to break into, let alone someone with Moebius syndrome who has problems with speech and being understood sometimes. This field is based on oral communication and I know that can be difficult for us sometimes. There is, however, more than one way to communicate with people and this industry is shifting. It is moving online and to digitalization which is perfect for me and what I love working on.

At Global, I ended up writing a lot of stories for online which I absolutely loved. I went out and shadowed reporters, I shadowed the graphic designer, I did some producing on the evening shows and helped draft scripts. I was able to follow my passion and do exactly what I love to do, which is write and tell peoples’ stories. I went into communications because I see the value in telling stories and giving a voice to those who otherwise might not have one.

Two of my favorite stories that I worked on this summer were based on raising awareness. One was about a therapeutic horseback riding facility that needs to find a new barn to operate out of, or else they might have to close down which would be absolutely devastating for all who use their services. The other story that I loved doing was about a mother who has a daughter with Down syndrome who makes baskets for other parents of babies with Down syndrome. It was so uplifting to be able to tell these stories.

What I loved even more than getting to write stories was the atmosphere at Global. It was phenomenal, everyone there is so incredibly lovely. It was such a fun, accepting environment and I met some truly inspiring people. I never felt different or judged there, I just felt one of the crew. I would walk into the newsroom at the beginning of my shift and everyone would greet me with a smile and a “hey, Kelsey!” A few of the anchors even met me for coffee outside of work time one day to talk about my future in the business. They are all truly beautiful souls.

I became close with the evening shift crew, and worked on their show a lot. They became like an extended family to me, as did everyone at Global. The evening crew even got me a cake on my last shift before I came back to school. That’s just the kind of people they were though, so full of kindness and acceptance.

I really could not have asked for a better summer. The experience that I got, the contacts I made and the friends that became like family are something that I would not have traded for absolutely anything.

Sometimes having Moebius makes us question ourselves and if we are worthy, if we are able. After the truly uplifting experience that I had this summer, I am here to tell you all to never stop accomplishing your goals and never stop chasing your dreams. We are all able and honestly, I see having Moebius as a blessing, not a curse. It has made me who I am today and I wouldn't have the outlook on life that I have without it. I also wouldn't have met so many truly amazing people if not for having Moebius. Never for a second think that you are less of a person because of Moebius. You are all truly inspiring.
Thank you to all of our donors!

Your generous support is greatly appreciated! Donations listed here have been received since the last newsletter was published. If we have missed you, please let us know so that we can acknowledge your generous gifts.

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The Moebius Syndrome Foundation
CafePress Shop is up and running just in time for the holidays, Moebius Syndrome Awareness Day and Rare Disease Day! Get your Moebius Syndrome Foundation logo gear, Moebius Home products and other unique designs and spread Moebius awareness!

http://www.cafepress.com/moebiussyndromefoundation
2016 was an amazing year for the Moebius Community! We began by celebrating Moebius Syndrome Awareness Day on January 24, 2016 and have continued the momentum throughout the year. Here’s a look at the year by the numbers...

- **400** people attended the 2016 Moebius Syndrome Foundation Conference in Long Beach, California. 117 with Moebius syndrome. Individuals and families participated in **243** consultations with physicians and experts. 23 financial scholarships helped families attend the Long Beach conference.

- **Funded more than $100,000** in research projects which will help identify the Moebius syndrome gene.

- Launched 5 Moebius Syndrome Foundation Regions - we expect numerous gatherings across the country in the coming months so keep an eye out for an event near you!

- More than **60** New member packets mailed out to those just diagnosed or finding the Foundation.

- Awarded **4** college scholarships amounting to **$7,000** to 4 students with Moebius syndrome attending college and post-secondary schools.

Your donation supports all of these endeavors and more. And in 2017, we hope to expand upon all of these projects! Thank you for your generous support - any amount helps us move our mission forward!