



For Release—February 2, 2016

Media Contact:

Kim Cunningham

E: kim@moebiusyndrome.org

P: 844-MOEBIUS (844-663-2487)

Moebius Syndrome Foundation Receives Global Genes RARE Patient Impact Grant

Pilot Grove, MO — The Moebius Syndrome Foundation, the nation's largest organization dedicated to the support of individuals and families with Moebius syndrome, is proud to announce it is a recipient of the [Global Genes RARE Patient Impact Grant](#). The grant support will educate the Moebius community about Oral Placement Therapy at the upcoming [Moebius Syndrome Foundation Conference](#). For the first time, Feeding and Speech Clarity consultations will be offered free of charge.

A critical area for those with Moebius syndrome is speech clarity. For children and infants, the same problems that can cause speech issues impact feeding safety (swallowing) as well. These are due to reduced oral sensitivity, incomplete lip closure, reduced tongue mobility/grading, and weak jaw musculature. Many people with Moebius syndrome have paresis, a partial paralysis where muscles can improve with appropriate exercise and practice in a speech therapy setting, called Oral Placement Therapy.

Two therapists will provide individual speech & feeding consultations. Each is a 45 minute evaluation which provides an overview of the muscle based activities that can be used by both therapists and parents to improve verbal communications and feeding safety. In the past, individuals were charged \$75 for this consultation. For the first time, with this generous grant support, the consultations will be offered free of charge.

There are two sessions at the Moebius Syndrome Foundation Conference which address Oral Placement Therapy:

- **Feeding for Infants and Toddlers:** Renee Roy Hill, MS, CCC-SLP
- **Speech Clarity for 3 Years of Age through Adults: It's Never Too Late:** Sara Rosenfeld-Johnson, MS, CCC-SLP

"We are honored to receive this grant funding from Global Genes," says Kim Cunningham, Moebius Syndrome Foundation executive director. "It is our hope that more families will be able to benefit from the feeding and speech clarity consultations, now being offered at no charge. Parents of children with Moebius syndrome will leave our conference with techniques that may assist their kids to eat well and gain an understanding of the connection to later speech development."

The RARE Patient Impact Grant Program offers support groups and nonprofits that care for patients affected by rare diseases the opportunity to secure funding for projects that will make a tangible difference to patient and caregivers' lives. To see a list of 2016 awardees and a summary of their projects, [click here](#).

For more information on the 12th Moebius Syndrome Foundation Conference, [click here](#).
Registration is now open!

About Global Genes – Allies in Rare Disease

[Global Genes](#) is a leading rare disease patient advocacy organization. The group's mission is to eliminate the challenges of rare disease, by providing patients with educational tools, building awareness, providing critical connections to people and resources, and through investment in technologies that will positively impact affected patients and families. Recognized worldwide by the Blue Denim Genes Ribbon™, Global Genes unites experts, advocates and patients of all ages to stand together in hope for treatments and cures for the estimated 7,000 rare and genetic diseases that impact approximately 30 million Americans and over 350 million people worldwide.

About the Moebius Syndrome Foundation

The Moebius Syndrome Foundation is the Home for the Moebius Community™. Founded in 1994, the Moebius Syndrome Foundation provides information and support to individuals with Moebius syndrome and their families. The Foundation promotes greater awareness and understanding of Moebius syndrome and advocates for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions. For more information on Moebius syndrome, the Foundation or becoming a member, please visit www.moebius syndrome.org.

#