

Moebius Syndrome Foundation Announces First Ever Research Conference

For Immediate Release

February 3, 2007 - With tenacity, initiative and in keeping with the goal of finding the cause of a mysterious neurological condition which leaves people unable to smile from birth, the Moebius Syndrome Foundation is pleased to announce its first research conference to be held in Bethesda, MD April 24 & 25, 2007.

Moebius syndrome is a rare neurological disorder which affects primarily the 6th and 7th cranial nerves, leaving those with the condition unable to move their faces (they can't smile, frown, suck, grimace or blink their eyes) and they are also unable to move their eyes laterally. Other cranial nerves may be affected causing hand/feet anomalies, respiratory problems, speech problems, sensory issues and weak upper body strength. Approximately 30-40% of children with Moebius syndrome are on the autism spectrum.

The Moebius Syndrome Scientific Conference, funded by a grant from the NIH, will be held April 24 & 25, 2007 in Bethesda, Maryland. The conference is being organized by Moebius Syndrome Foundation board members Vicki McCarrell, Co-founder and President of the Foundation, and Jacob Licht. McCarrell and Licht, parents of children with Moebius syndrome, submitted the grant to the NIH to bring together physicians and researchers from around the world to share their research on Moebius syndrome. "Moebius syndrome is a complicated disorder and we are grateful that several NIH Institutes and Centers have joined together to fund this first ever conference," said McCarrell. The Conference is being funded by grants from the following NIH branches: The National Institute of Neurological Disorders and Stroke, The National Institute of Dental and Craniofacial Research, The National Institute of Child Health and Human Development, and the NIH Office of Rare Diseases.

The research conference will be held at the Clark Building, 7500 Old Georgetown Road, Bethesda. "We're excited about this conference, which will bring together researchers from around the world for the first time to share their work with each other," said McCarrell. "All of our scientific advisory board members have been instrumental in helping us with this conference, which we hope will bring us closer to understanding the factors responsible for this life altering condition." Moebius syndrome touches on several medical specialties, including neurology, opthalmology, genetics and dentistry and this conference will be the first time specialists from across the Moebius syndrome scientific community will be able to share their findings with each other. The Moebius Syndrome Foundation is a 501c 3 organization founded in 1994 by parents of children with Moebius Syndrome. There are currently approximately 2000 cases of Moebius syndrome identified worldwide. The Foundation has no paid staff; all work is done by volunteers who want to help those whose 'Smiles Come From Their Hearts.' Many of the volunteers are adults with Moebius syndrome as well as parents of children with Moebius syndrome.

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