

MOEBIUS SYNDROME AWARENESS DAY 2023 PRESS RELEASE



Many Faces of Moebius Syndrome

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FOR IMMEDIATE RELEASE

We Are the World!

Remington, Virginia - The Many Faces of Moebius Syndrome (manyfacesofmoebius.com), the Children's Craniofacial Association (ccakids.org), Face Equality International (faceequalityinternational.org), and our global partners, join together in announcing the 13th annual Moebius Syndrome Awareness Day which will be celebrated worldwide on Tuesday the 24th of January 2023.

This event will occur in real-time -celebrated online- as people around the world hold a wide variety of special events in multiple locations to honor the critical significance of those families and friends whose respect, validation, support, honesty, love, and vocal advocacy builds an ever-growing world-wide community for all affected by Moebius syndrome.

Phyllida Swift, CEO of Face Equality International writes –

"Here at Face Equality International, we advocate to end the discrimination and indignity experienced by the global facial difference community. We often speak to our community about how talking to family and friends about personal experiences can be the hardest audience to open up to. But advocacy starts at home and having a supportive network around you of friends and family, whether from birth or chosen, is vital to thriving in society."

Erica Klauber, Executive Director of Children's Craniofacial Association writes –

"We recognize our family as our fiercest advocates and first friends. They are on the journey of living with a facial difference along with us, albeit a different journey. CCA seeks to nurture and support the entire family - from the affected individual to the parents, siblings, grandparents, to life partners. We offer support groups, trainings, and networking to build confidence, learn effective mental wellness strategies, and practice positive interactions. Together, we can support one another, empower each other to reach our full potential, and to work to widen the circle of acceptance."

Sandy Goodwick, Educator and individual with Moebius Syndrome writes –

“Not all families value kindness or support. But all of us do need validation to hold the challenges we experience. When families or communities ignore one another’s challenges, it is as though that pain continues within - as silent screams. In honoring all with Moebius syndrome, we hope to bring healing to those whose families or communities who don’t know how to care. When we feel together, we heal together.”

We look beyond the rarity of Moebius Syndrome when we mutually strive to build a kinder world that recognizes the worthiness of all – such as those affected by facial paralysis and other facial differences. When we see beyond each other’s visible differences – (for those of us with Moebius syndrome - of facial paralysis, speech differences, or any of several other related symptoms) – to the souls within, we begin to see and honor one another in their humanity, just like everyone else.

We are a global family - united in recognizing both the progress we have made as well as the hopes we embrace for our future. We honor the diverse journeys we all have taken to find our worthiness while living with Moebius syndrome. And we celebrate on January 24th - the birthday of Professor Paul Julius Moebius (who first described this syndrome in medical literature) because we share an identity through his name – Moebius syndrome.

Moebius Syndrome is an extremely rare congenital neurological disorder which is characterized by facial paralysis and the inability to move the eyes from side to side. Most people with Moebius Syndrome are born with complete facial paralysis and can't close their eyes or show facial expressions. Limb and chest wall abnormalities often occur with the syndrome. Respiratory problems, speech and swallowing disorders, visual impairments, sensory integration dysfunction, sleep disorders and weak upper body strength may also be present.

The Many Faces of Moebius Syndrome organization is the world's largest all volunteer Moebius Syndrome nonprofit. In 2009, we brought the global Moebius syndrome community together one family at a time. In 2011, we founded Moebius Syndrome Awareness Day. Many Faces of Moebius Syndrome continues to support our global community by: Creating awareness about Moebius Syndrome. Providing financial support for medical needs. Providing holiday gifts and meals to Moebius families in need, Camp Moebius and much more.

Many Faces of Moebius Syndrome could not achieve its goals without the help of the global community. Through your dedication and perseverance to raise awareness worldwide by sharing your stories and lifting each other up, you have become the greatest volunteers of all! Thank you!

To learn more about Moebius Syndrome and the Many Faces of Moebius Syndrome organization, please visit our website at www.mfoms.org.

To learn how you can get involved with MSAD 2023 visit our website at www.msad.world.