



## Press Release – Moebius Syndrome Awareness Day 2022

The Many Faces Of Moebius Syndrome ([www.mfoms.org](http://www.mfoms.org)), the Moebius Syndrome Foundation ([www.moebiusssyndrome.org](http://www.moebiusssyndrome.org)), the Children's Craniofacial Association ([www.ccakids.com](http://www.ccakids.com)), and Face Equality International ([www.faceequalityinternational.org](http://www.faceequalityinternational.org)), are UNITED in announcing the 11th annual Moebius Syndrome Awareness Day which will be celebrated worldwide on Monday the 24th of January, 2022.

*This event will occur in real-time -shared online- as people around the world hold a wide variety of special events in multiple locations to recognize the UNITY of understanding and hope that has brought us all together.*

While the *medical aspects* of Moebius syndrome are quite rare, the *human aspects* of living with a facial difference are ones that can UNITE us all. 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. ***Join us in honoring the journeys many among us have taken – from the numbing isolation of being “the only one” to now being part of an ever-expanding world-wide community that takes pride in its’ identity!***

**We are UNITED in recognizing both the progress we have made as well as the hopes we embrace for our future.** Many of us went years – decades – a lifetime - before even knowing that others shared the same facial paralysis and painful, isolating experiences of stares and rejection. We are grateful for the work of scholars like Frances Cooke MacGregor, who is recognized as the first to write about the unacknowledged, yet major stresses of people who suffer facial disfigurement through birth, accident, disease, or war. Because MacGregor spoke out, ‘awareness’ of experiences such as ours could begin. We are grateful that MacGregor’s work led to a growing self-help network which recognized facial differences as well as media coverage (in the early 1980’s!) that spoke respectfully of life with Moebius syndrome and other differences.

While this special day is held annually on the birthdate of Professor Paul Julius Moebius (who first described this syndrome in medical literature), *we foremost recognize his efforts that led to a name* (Moebius syndrome) – one that brought us all out of isolated anonymity into a network of understanding and support.

From the **Many Faces of Moebius Syndrome** –

*“Since our inception, the Many Faces of Moebius Syndrome (MFOMS) has moved forward with passionate diligence to unite our global community and the other organizations who serve it through our websites, social media pages, and in person events. Only in unity can we satisfy all the needs of our community and build a better tomorrow for those of us living with Moebius Syndrome and our families. We are proud to serve alongside these three great organizations in promoting Moebius Syndrome Awareness. Together the possibilities are endless...”*

From the **Moebius Syndrome Foundation** –

*“For nearly thirty years, the Moebius Syndrome Foundation has been unifying the Moebius syndrome community. Whether we’re bringing people together online or in-person, we always strive to bring our small community together. We support the MFOMS and all our partner Moebius organization groups around the world as they bring unity, spread awareness and support, and celebrate those effected by Moebius syndrome...”*

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

*"Unity is necessary because to meet the biggest challenges in life, we must realize that you or I are not enough to handle it all alone... and that stinks. But it is also beautiful. Unity means that we come together, as a critical mass, to be enough. We have to connect. We have to work alongside each other. We must see each other's unique abilities and brilliance, no matter how different they are to our own..."*

Phyllida Swift, CEO of **Face Equality International** said –

*"We have always been thrilled and honored to collaborate with MFOMS. Seeing the incredible, dedicated community that has been built to support and empower each other has been a privilege to behold. Awareness days are a vital part of advocating for respect, awareness and understanding. But all advocates know that this has to go beyond one single day or week in the year. At Face Equality International, we believe in bringing the facial difference community together to champion respect and eradicate discrimination..."*

Please join our UNITED and now-global community and take part in one of our many real-time and online activities. **Take time to learn more of Moebius syndrome, facial differences, face equality – efforts being made to UNITE us in welcoming those once marginalized by facial differences. We are far more than a medical description** – we are public servants, doctors, nurses, educators, ministers, dedicated employees of all kinds, parents, children, and others allied in support for those with Moebius syndrome and other visible differences. And wear purple (the color of nobility – it reflects wisdom, power, spirituality). Purple also UNITES the two colors it sits alongside – red's power, and blue's stability.