



The mission of the Moebius Syndrome Foundation is to provide information and support to individuals with Moebius syndrome and their families, promote greater awareness and understanding of Moebius syndrome, and to advocate for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions.

2021-2026 Strategic Plan				
	Goal 1	Goal 2	Goal 3	Goal 4
	To provide information & support to Individuals with Moebius syndrome & Their families	To promote greater awareness & understanding of Moebius syndrome	To advocate for scientific research to advance the diagnosis and treatment of Moebius syndrome and its associated conditions	To maintain sound fiscal & governance practices
	Maintain a membership database & send new member informational packets to individuals with moebius syndrome & parents of children with Moebius syndrome	Provide information to professionals interested in Moebius syndrome & friends and family members of individuals with Moebius syndrome	Maintain a Board Research Committee who solicits, reviews & approves funding for research projects	Conduct a biannual financial audit & biannual financial review
	Connect members with peers and professionals for support through a mentorship program	Connect professionals with necessary resources to work with patients with Moebius syndrome	Maintain a Scientific Advisory Board of physician & researchers who share their experience and expertise on behalf of patients and families affected by Moebius syndrome	Board members will review conflict of interest policy annually and disclose conflicts
	Maintain an informative website for the Moebius syndrome community	Maintain an Online Advocacy tool kit for Moebius Syndrome Awareness Day	Establish a Moebius Syndrome Patient Registry to enable rare diseases patient organizations to better promote and support patient-focused research	Board will conduct annual performance review of Executive Director
	Maintain a vibrant online support community for the Moebius syndrome community	Provide stipends for Moebius Syndrome Awareness Day Events throughout the United States	Host a biennial Conference and Research Symposium	
	Host a biennial Conference and Research Symposium		Earmark financial resources to support critical research on Moebius syndrome	
	Produce a bi-annual newsletter			
	Provide scholarship funding to college students with Moebius syndrome annually			