

Board of Directors Series

Destiny Bachman, Member of the Board of Directors, Moebius Syndrome Foundation

1. Tell us your name and position (executive committee, staff, board member).

Destiny , Member of the Board, Moebius Syndrome Foundation

2. Why is it important for you to serve on the Board of Directors?

My son Hamilton, age 9, has Moebius syndrome. As he's gotten older, I have found a desire to help be more of an advocate for people with craniofacial differences and disabilities in general, and spread awareness about Moebius syndrome. The foundation does both of these things and I felt I would be able to help with this mission. I also want to be able to reach out to other parents and be a support and help for them. Lastly, it is really important for me to help my son learn to be an advocate and I feel this is a way to show him he can be involved and part of this amazing organization and community.

3. What does the Moebius Syndrome Foundation mean to you, personally?

When Hamilton was diagnosed, I reached out to the foundation and Vicki spoke to me and was so positive and helpful. She helped me see that this baby was going to be fine, and he is! The foundation has also allowed us to connect with other families who understand Moebius, and gives my son the ability to meet and be friends with other kids his age who have Moebius syndrome. The community the MSF has built has been important to us and we are so grateful to know such wonderful people.

4. What might the Moebius Syndrome Foundation community be interested to learn about you?

I have three children Hamilton (9), Clay (7), and Ada (3). I enjoy being outdoors biking, camping, and hiking. I also really enjoy home improvement projects and cooking. I currently am a stay-at-home mom but when I go back to work I would like to work in Disability Advocacy. I have a MA in Political Science.

5. What do you want the Moebius syndrome community to know about the Board of Directors and what we do?

The Board is passionate about finding ways to help support the Moebius Community. The community is diverse, consisting of people with Moebius, parents and caregivers, and medical professionals. We are trying to bridge gaps and help people connect with one another to support social and emotional needs and medical needs. We have various subcommittees and are

actively re-starting the regional coordinator program this coming year to help with more social opportunities for the community. We are engaged in research as well.

6. Anything else you would like to add? Any long term goals for the Foundation? Can community members reach out to you if they have any questions or comments about the Foundation/ideas they may have?

I would love to see more awareness of Moebius syndrome and find more ways for people with Moebius syndrome to connect with one another in person. I would also like to continue to grow in helping different populations included in this community.

Please reach out! My email address is destiny@moebiusyndrome.org. The foundation is here to help serve the Moebius community. We love ideas from members and rely on your help to fulfill our mission. We are also learning and growing in how we do things.