History of the Many Faces of Moebius Syndrome

www.manyfacesofmoebiussyndrome.com
The mission of the Many Faces of Moebius Syndrome is to create a better tomorrow for ourselves and our children with Moebius Syndrome by educating the general public and spreading global awareness. Our current board member are Kevin Lockwood, Will Harrison, Kacie Brailsford, Gavin Fouche, and Tim Smith.
The MFOMS (many faces of moebius syndrome) was established in 2009 by Tim Smith an adult with Moebius Syndrome. Their mission began during the summer of 2008 when Tim met Katie Pennycate a moebius mom who recently lost her daughter. As Tim knelt by young Hannah's grave he wondered why he had been spared and she hadn’t? Years earlier when he was an infant doctors told his parents that there was no way he would survive. Tim knew he had to do something to make a difference. He had to do something to give his life and Hannah's death more meaning.
Tim and Katie decided they wanted to go on Oprah and tell their story. So they contacted other moebius syndrome families on myspace and asked them if they wanted to write stories about their experiences and join them. A friend of Tim's with moebius syndrome told him he should go on Facebook and try to bring people together because everyone was joining Facebook.
When Tim arrived on Facebook he found a few people he knew from myspace, but for the most part people with Moebius syndrome weren't connected. One lazy Sunday morning he decided to do a keyword search on Facebook to see who else he could find with Moebius syndrome. To his surprise he found about 50 families. None of whom knew each other. Tim, Katie Pennycate, Kari Storm, and others sent friend requests to everyone on the list and told them about what they were planning to do.
Once the friend requests were accepted they put everyone they talked to in touch with others on Facebook. In a short span of time everyone else started doing the same and a chain reaction happened which caused the birth of the global online Moebius syndrome community.
In 2009 the moebius needs Oprah campaign wasn't going very well. A lot of people were interested in doing it, but Oprah wasn't returning their emails. Then the other shoe fell when they found out that Oprah was going off the air.
They had collected 14 personal stories and wanted to find a good home for them because each story was written from the heart. One of the stories was written by a moebius mom whose husband was killed in combat overseas in the Middle East. None of the existing Moebius syndrome organizations wanted the stories unless they could be edited for content and size. That was something Tim refused to do.
A few weeks later Tim used the stories as a building block to create the many faces of moebius syndrome website. www.manyfacesofmoebiussyndrome.com. In time 14 stories turned into what is today 170+ stories. Shortly after the launch of the website a board of directors was formed and Tim was elected to be the President of the MFOMS. It was not a position he sought. He voted for Donnie Downs a moebius dad.
Tim said he had no idea of the impact the MFOMS had had on the community until the summer of 2010 when a Moebius mom from New York state attending the Moebius syndrome conference in Colorado texted him and said everyone was talking about them because he and others were the ones who had connected them together online and now they were able to finally meet in person. She went on to say that a lot of people said they would not even have known about the conference if it hadn't been for their work in connecting everyone.
At the time Tim was recovering from quadruple heart bypass surgery and was not able to go to the conference. The women's text brought a smile to his heart and it was at that moment that he realized he was a part of something very special.
In 2010 - 2011 the MFOMS founded and organized the first moebius syndrome awareness day. [Click here for more information.](#)

In November of 2011 the MFOMS created the Moebius Syndrome Awareness Season which goes from November 1 to January 24 (MSAD) They kicked the season off with the launch of their 1st Annual [Holiday Heroes](#) campaign.
During the second Moebius syndrome season they formed a coalition of over 60 groups from various walks of life to promote MSAD 2012 which showed their commitment to working with other organizations to promoting moebius syndrome awareness. The names of the groups in the coalition can be found at the end of that season's holiday hero video. 

www.youtube.com/watch?v=TLiJOHWHUfg
In 2013 the MFOMS created their MFOMS Ambassador Program. Spearheaded by Gavin Fouche. The program has been instrumental in spreading Moebius syndrome awareness around the globe.
The MFOMS is not a non profit. All money spent comes out of the pockets of various people within the organization or from donations raised through fundraising. For the 2014 - 2015 Moebius Syndrome Awareness season they did take out a week long Facebook ad at the end of the season which promoted all of the moebius syndrome organizations. Everything else has been done by word of mouth and community related awareness projects.
During the summer of 2018 the MFOMS teamed up with Derek White and B2B Solutions to take spreading Moebius syndrome awareness to the next level. They are currently working on a new website at www.manyfacesofmoebiussyndrome.org.
Our global Moebius syndrome community is small compared to other communities like the Autism community. The MFOMS believes that all of the moebius syndrome organizations should do different things but should work side by side at improving the lives of everyone in the global Moebius syndrome community.
The MFOMS sticks to doing what they do best which includes but not limited to:

- Pioneering new ways to educate and spread moebius syndrome awareness using social media and the internet.
- MSAD event planning,
- Moebius Meet ups.
- Community building.
"Who are the MFOMS?" To answer that question all you have to do is look in the mirror because now that you know about us you are one of the MFOMS. We are all in this together.
We hope you’ve enjoyed this presentation. We encourage you visit our website to learn more about Moebius Syndrome and our Global Moebius syndrome community.