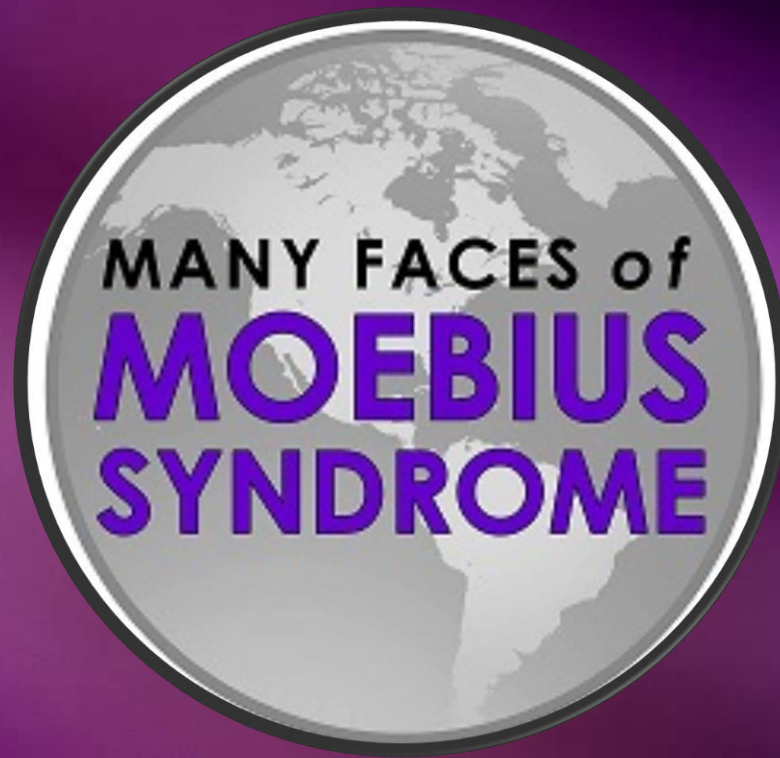


# History of the Many Faces of Moebius Syndrome



[www.manyfacesofmoebiussyndrome.com](http://www.manyfacesofmoebiussyndrome.com)

[www.manyfacesofmoebiussyndrome.org](http://www.manyfacesofmoebiussyndrome.org)



# Our Mission:

- 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 members are Kevin Lockwood, Will Harrison, Kacie Brailsford, Gavin Fouche, and Tim Smith.



## About Us:

- The MFOMS (Many Faces Of Moebius Syndrome) was established in 2009 by Tim Smith an adult with Moebius Syndrome. The 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 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.

# 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 to see who 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 occurred which caused the birth of the global online Moebius syndrome community.

When it's important  
you find a way!  
Help us make a  
difference!

MoebiusNeedsOprah  
[www.myspace.com/timmedly](http://www.myspace.com/timmedly)

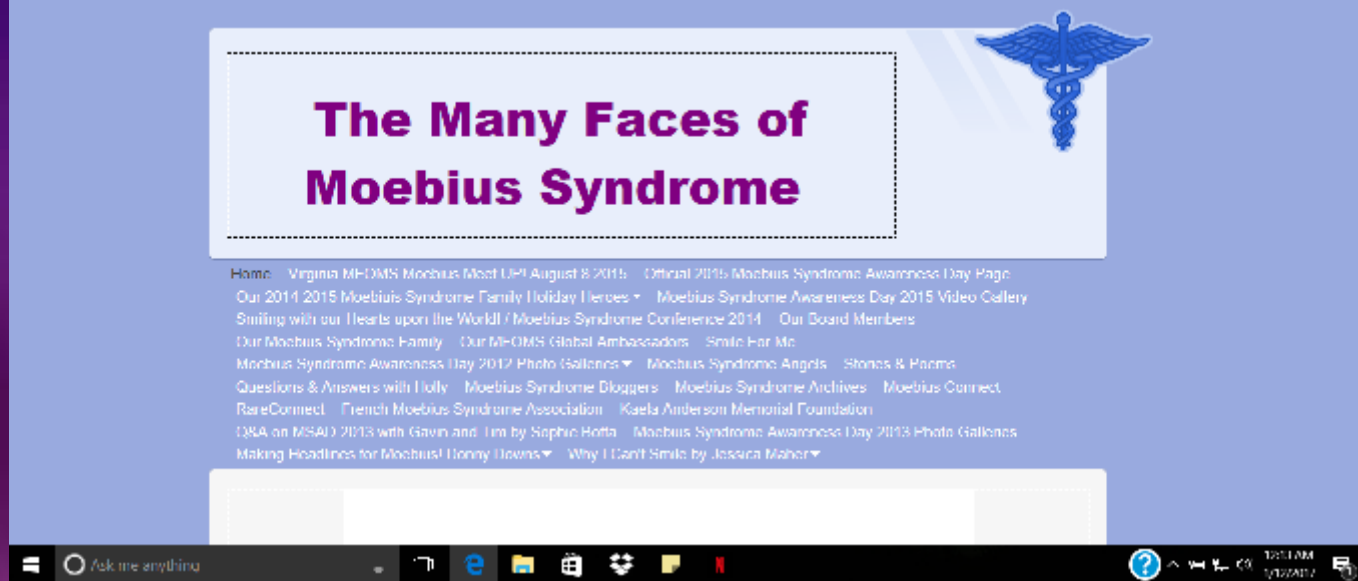
- In 2009 the Moebius Needs Oprah campaign wasn't going very well. A lot of people were interested in doing it, but Oprah wasn't returning their emails. Then the other shoe fell when they found out Oprah was going off the air.





- 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. ([www.moebius syndromeawarenessday.org/bradley.html](http://www.moebius syndromeawarenessday.org/bradley.html)) None of the existing Moebius syndrome organizations wanted the stories unless they could be edited for content and size. That was something they weren't willing to allow.





- A few weeks later Tim used the stories as a building block to create the Many Faces Of Moebius Syndrome website. In time 14 stories turned into what is today 170 + stories. Shortly after the website was created a board of directors was chosen 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.
- In April of 2010 they put out their first newsletter.  
[www.manyfacesofmoebiussyndrome.com/mfoms\\_newsletters](http://www.manyfacesofmoebiussyndrome.com/mfoms_newsletters)



- Tim said he had no idea the impact the MFOMS had on the global community until the summer of 2010 when a Moebius mom from New York state attending the Moebius syndrome conference in Colorado texted him letting him know everyone was talking about the MFOMS because of the work they had done in bringing them together. They were excited because they finally got to meet everyone they had been talking to online for over a year in person.



- At the time Tim was recovering from quadruple heart bypass surgery and was not able to go to the conference.  
([www.manyfacesofmoebiusproject.com/tim\\_smith\\_affairs\\_of\\_the\\_heart](http://www.manyfacesofmoebiusproject.com/tim_smith_affairs_of_the_heart)) The women's text brought a smile to his heart and it was at that moment he realized he was a part of something very special.





- In 2010 - 2011 the MFOMS founded and organized the first Moebius syndrome awareness day which was held on January 24 2011. An Australian tv show named the Kerry Anne show did a story on Jack Lawrance and featured the MFOMS website. MSNBC picked up the story and MSAD went global. The MFOMS website got over 12,000 hits that day.  
[www.manyfacesofmoebiussyndrome.com/moebius\\_syndrome\\_awareness\\_day\\_highlights\\_2011](http://www.manyfacesofmoebiussyndrome.com/moebius_syndrome_awareness_day_highlights_2011)





- November 1 2011 marked the beginning of the 1'st Annual Moebius Syndrome Awareness season which goes until January 24 MSAD. They kicked the season off with the launch of "Moebius Syndrome Holiday Heroes" which has become a seasonal event. That year the MFOMS formed a coalition of over 60 groups from various walks of life to promote MSAD. Proving they were committed to working with other organizations in promoting Moebius syndrome awareness. The names of the groups in the coalition can be found at the end of the season's Holiday Hero video. [www.youtube.com/watch?v=TLiJOHWHUfg](http://www.youtube.com/watch?v=TLiJOHWHUfg)
- They were also awarded letters of support by the National Order of Rare Disorders, and the Global Genes Project for their efforts.  
[www.manyfacesofmoebius syndrome.com/yahoo\\_site\\_admin/assets/docs/Untitled\\_4.8161032.pdf](http://www.manyfacesofmoebius syndrome.com/yahoo_site_admin/assets/docs/Untitled_4.8161032.pdf),  
[www.manyfacesofmoebius syndrome.com/yahoo\\_site\\_admin/assets/docs/jointglobal.8163259.pdf](http://www.manyfacesofmoebius syndrome.com/yahoo_site_admin/assets/docs/jointglobal.8163259.pdf)



- In 2012 the MFOMS teamed up with Fresh Printz a Virginia based Athletic Apparel Company and over the next three years thousands of Moebius Syndrome Awareness shirts were shipped around the world.



# Many Faces of Moebius Syndrome

## Ambassadors



[www.manyfacesofmoebiussyndrome.com](http://www.manyfacesofmoebiussyndrome.com)

Gavin Fouche  
Vice President  
[gavinmfoms@yahoo.com](mailto:gavinmfoms@yahoo.com)  
[www.manyfacesofmoebiussyndrome.com](http://www.manyfacesofmoebiussyndrome.com)

[www.twitter.com/manyfacesofms](http://www.twitter.com/manyfacesofms)  
[www.facebook.com/pages/Many-Faces-of-Moebius-Syndrome/189215821115287](https://www.facebook.com/pages/Many-Faces-of-Moebius-Syndrome/189215821115287)

- In 2013 the MFOMS created their MFOMS Ambassador Program. Gavin Fouche came up with the idea and his vision once created has helped spread Moebius syndrome awareness around the globe.



- At the 2014 Moebius Syndrome Conference in Bethesda, Maryland the MFOMS did a session called “Smiling with our hearts around the World”. They had over 50 people in attendance. Kelsey Ferrill, Jessica Maher, Rebecca Maher, and Tim Smith were the speakers. Some of the parents also spoke.

[www.manyfacesofmoebiussyndrome.com/smiling\\_with\\_our\\_hearts\\_upon\\_the\\_world\\_moebius\\_syndrome\\_conference\\_2014](http://www.manyfacesofmoebiussyndrome.com/smiling_with_our_hearts_upon_the_world_moebius_syndrome_conference_2014)

- On the last day of the conference Vicki McCarrell presented Tim Smith an award for his work on MSAD through the years.





Beginning in January 2015 Kevin Lockwood a Moebius Dad from California created Facebook ads for the MFOMS which promoted Moebius syndrome awareness for all of the organizations. During the first year the ads reached 37,713 people on Facebook. 10,108 of those people had no previous association with the Moebius community.



- MSAD 2016 was a little crazy. In late October 2015 the MFOMS decided to create a Moebius Syndrome Awareness Day website. [www.moebius syndromeawarenessday.org](http://www.moebius syndromeawarenessday.org) They had to finish it in a month before Holiday Heroes started. They also needed the website up and running to allow enough time for the Google search engines to pick up on it for MSAD 2016. They made it happen.



- For MSAD 2017 Kevin Lockwood designed the official MSAD logo. Dionne Read from the Moebius Research Trust, Vicki McCarrell from the Moebius Syndrome Foundation, and Tim Smith from the Many Faces of Moebius Syndrome, all approved the design.
- The theme for MSAD 2017 was a quote from Vicki McCarrell, "We are all in this together".





- MSAD 2018 was about giving back to the community. Through Custom Ink the MFOMS sold approximately 60 heart shaped Moebius syndrome awareness shirts. With the money earned they brought and donated approximately 20 shirts to individuals in the community.





- 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.manyfacesofmoebius.org](http://www.manyfacesofmoebius.org).



MSAD

MOEBIUS SYNDROME AWARENESS DAY  
JANUARY 24TH 2019

- Coming Soon
- [www.MSAD2019.org](http://www.MSAD2019.org)

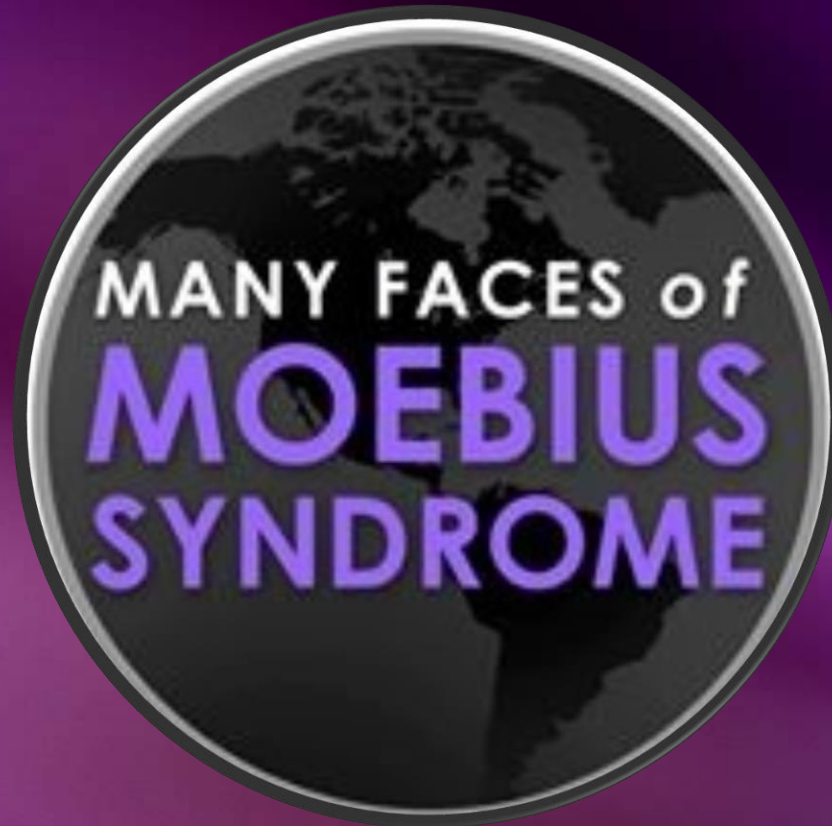


- The MFOMS sticks to doing what they do best which includes but not limited to:
- Pioneering new ways to educate and spread moebius syndrome awareness using social media and the internet.
- MSAD planning,
- Moebius Meet ups.
- Community building.



- "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 to visit our website to learn more about Moebius Syndrome and our Global Moebius syndrome community.
- -Team MFOMS