

History of Moebius Syndrome Awareness Day

The concept of a worldwide Moebius Syndrome Awareness Day in which people are encouraged to wear purple and spread awareness about the syndrome originated from the MFOMS (Many Faces of Moebius Syndrome), an organization run by Tim Smith from Virginia, USA, Gavin Fouche from Cape Town, South Africa. Smith and Fouche have Moebius syndrome. Most of their organization and preparation for the event is done through social media platforms such as Skype, Twitter and Facebook. Smith and Fouche have never physically met, but both share the same passion for spreading education and awareness about Moebius syndrome which will enable those affected by it to lead better lives, they believe.

The initial idea was pitched to Smith by Donnie Downs, a father of a son who is affected by Moebius syndrome. They started a cause page to see if the global Moebius syndrome community wanted their own awareness day. Over two hundred people joined the cause in it's first week. "We knew we had a hit on our hands," says Smith." But we also knew that we faced an uphill challenge in making it happen since we did not have any money to promote an awareness day." In the late winter of 2010 they created a video of the climb they were about to undertake. "It was very rewarding to see people sharing it." says Smith. By the start of MSAD 2011 six

thousand people had joined the cause and said yes they wanted a Moebius Syndrome Awareness Day.

In December of 2010 after it was confirmed we were going ahead with MSAD 2011 Kelsey Ferrill from Calgary, Alberta started a Facebook event page called "I pledge to wear purple on January 24th Moebius Syndrome Awareness Day". 700 people took the pledge to wear purple. Kelsey chose purple because it was the color of the MSF. Awareness purple is very popular and over [Fifty Awareness groups](#) use it as their color. Kelsey did a tremendous job in getting people to wear purple. [Click here](#) to view the comments they left on her event page that first year. In the coming years Kelsey and others like, [Fresh Printz Industries](#), [Kevin Lockwood](#), and [Gavin Fouche](#) carried the torch forward and found new ways for people to show their purple support.

During the first MSAD an Australian television network ran a story on a boy named Jack Lawrance who had Moebius syndrome which was then picked up by news media outlets in the United States and around the world causing an unbelievably large number of hits on the original MFOMS website in its first 24 hours. "It was quite surreal to see words that I had written appear in an American newspaper on the other side of the world." Says Fouche.

Many who are affected by Moebius syndrome - both young children and adults - now use the day as a means to educate their teachers, classmates, friends and colleagues about Moebius syndrome. Where once there were only feelings of alienation and unacceptance there is now a sense of self-pride for both children and parents of children who are affected by the syndrome.

"We want to take Moebius syndrome out of the Dark Ages," Says Fouche "We want to show the world that, despite our differences, those of us who have Moebius syndrome are just as normal as the next guy."

Each year, from November to January, the MFOMS runs their Moebius Syndrome Holiday Heroes campaign which highlights those who are affected by Moebius syndrome.

Both the MSF (Moebius Syndrome Foundation) and the MRT (Moebius Research Trust), fellow organizations specializing in the scientific research into the condition and the assistance to those who have it, are in full support of Moebius Syndrome Awareness Day.

"Moebius Syndrome Awareness Day has become more successful than I ever dreamed possible. It took off like wildfire and spread right around the globe. Each year it gets bigger and bigger and more people get involved," Says Smith.

"It's all about spreading awareness. Anyone can participate. People can do something simple like pass out flyers or wear purple to show their support."

Moebius Syndrome Awareness Day is held every 24th of January as it is the birth date of Professor Paul Julius Moebius, who first diagnosed the disorder in 1888