



# Misty VanderWeele

Where Hope Of A Cure For Duchenne Turns Into Action



**Misty VanderWeele, Author, Speaker, Duchenne Advocate, Wife, Mother and Alaska Girl** is taking a stand against the most common paralyzing childhood muscular dystrophy –DUCHENNE, (DMD)

When her son Luke was diagnosed with Duchenne at the age of four it was a wakeup call to her passion of helping others. She intuitively knew that through the life altering, life taking disease, Duchenne, she would find a way to not only give her son the best life she could, but be able to assist and support others on the same journey.

Misty wrote *In Your Face Duchenne Muscular All Pain All Glory!* The head author and creator of the book Saving *Our Sons One Story at a Time* a collaboration book of 40 Duchenne stories in 2010. *Saving Our Sons & Daughters II* is scheduled to come out mid-winter 2012. - Also a collaboration book of Duchenne stories.

**Misty VanderWeele**

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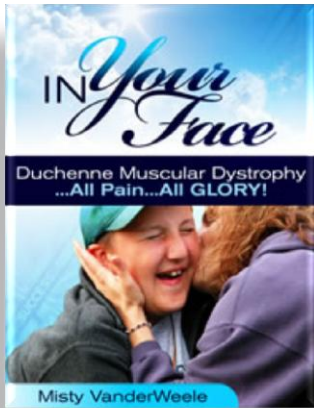
**www.MistyVanderWeele.com**

**Misty's experience and tireless work for Duchenne inspires others to take action in the fight.** She knows as long as DMD is unheard of, research will continue to be under funded keeping a cure and/or treatments out of reach.

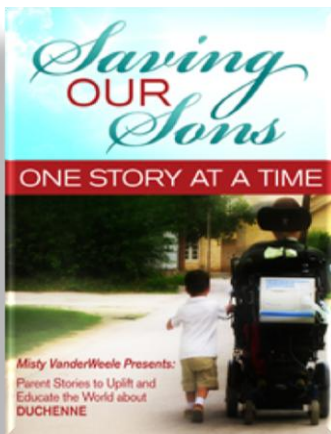
Sharing her story, innovative advocacy strategies, **Misty uplifts, strengthens and empowers the Duchenne community worldwide!**



# BOOKS & MAGAZINE



**Duchenne Muscular Dystrophy** wasn't going to stop this mom from living the best life possible..Misty shares openly the roller- coaster of Duchenne in this heart touching, surprisingly laugh proving book, ***In Your Face Duchenne Muscular Dystrophy All Pain All Glory!***



***Saving Our Sons One Story at a Time,*** First Duchenne-Parent collaboration book of its kind. Where parents come together to share their personal stories as a way to shout out their SOS call to the WORLD, that ***A CURE MUST BE FOUND!***

## RAVE REVIEWS

“Extraordinary story of love, determination, and bravery”  
~Debra Miller, CureDuchenne

“Beacon of light for others who face the same challenges” ~Patti B

“In Your Face is a true **inspiration. I thank Misty from the bottom of my heart for sharing her and her amazing son’s story.** She has helped me move on from my dark place of guilt and depression to give my son the best life I can give him xx thank you Misty x ~Mel Watson

“I know I keep saying this, but I think you need to hear it again. **The work you so is awesome! Forever encouraging and inspiring. As a new Duchenne mum, I feel so encouraged and supported by everything that you do!** You really give us all a sense of strength and community. **THANK YOU!** ~Donna Anderton

“I am beside myself with how good it feels to see my writing in a actual book, *Saving Our Sons One Story at a Time,* **I encourage anyone with a heart to pick up a copy and help us end Duchenne. Caution you will need a box of tissue. Thank you Misty VanderWeele for pushing forward and encouraging me.**  
~Rita Felling

# BOOKS & MAGAZINE



## WHAT IS DUCHENNE

**Duchenne Muscular Dystrophy** is caused by the absence of Dystrophin. A protein that helps keep muscle intact.

### Signs of Duchenne

- Toe Walking
- Frequent Falls
- Enlarged Calf Muscles
- Difficulty in:
- Climbing Stairs
- Running
- Hopping
- Jumping
- Wheelchair by 12

Progression of Duchenne eventually affects ALL voluntary muscles, the heart and breathing muscles. Survival past the teen years is a gift and is extremely rare beyond the late twenties.



**Duchenne affects daughters too!** *Saving Our Sons & Daughters II* includes real life stories from Parents, Siblings and those afflicted with Duchenne. They tell their stories knowing education is “key” to finding a cure!



**Thrive!** In the face of Duchenne Muscular Dystrophy is the leading Duchenne online magazine that supports, inspires and motivates other Duchenne parents to turn their hope of a cure for Duchenne into action! By Sharing advice, advocacy strategies real life Duchenne stories from around the world monthly.

# Thriving!...not just surviving.



**Misty VanderWeele**, is not only a 3 time Duchenne book author, she has over sixteen plus years advocacy experience starting in 1996 when her son was diagnosed with Duchenne muscular dystrophy.

Misty uses her creativity to brain storm and produce advocacy products, books and programs geared to advocate for Duchenne and assist Duchenne parents navigate the roller-coaster of having a child with a life altering disease. Misty's products include the *365 Days of Duchenne Desk Top 2012 Calendar* and *Personalized Duchenne Advocacy Packs*.

Misty is a born and raised Alaskan, where she still resides with her husband, **Glen and her daughter, Jenna on the family vegetable farm.** her son, **Luke now 20 years old is learning how to be an adult with a disability** comes home for dinner from time to time. He often calls on "mom" for support and a shoulder.

Misty is dedicated to the fight against Duchenne. **She inspires and motivates others to do the same.**

*"If we want things to change we need to be apart of the solution."*

*~Misty VanderWeele*

## **16+ years Duchenne Advocacy**

**-1996 Featured in Alaska Parenting Magazine**

**-1996-1998 Speaking for the Alaska Chapter of the Muscular Dystrophy Ass.** (Son was MDA poster child during that time.)

**-1998-2006 various speaking, newspaper and TV interviews. Make-a-Wish trip**

**-2006 Partners in Policy Making Inter graduate.**

**-2006 Run for Your Sons Walt Disney Half Marathon** for Parent Project MD

**-2007 Rocky Run** for Parent Project MD

**-2009-Currently, Duchenne Author & full time advocate**

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