In Your Face
Duchenne Muscular Dystrophy
...All Pain...All GLORY!

Alaskan Mom's Journey With Son's Deadly Disease
By Misty VanderWeele

For my favorite son, Luke

"Believe that there's light at the end of the tunnel.
Believe that you may be that light for
someone else" ~KOBI YAMADA

FOREWORD

"In Your Face" is a true life journey of tremendous love, hope, continuous heart break, silent pain and the cherished mystery of life. A candid story that is both the worst and the best thing that has ever happened to me. A story of transformation that started when my son Luke was only four years old.

On a sunny Alaskan July day, life as I knew it changed in 9 words. Words that no parent should ever have to hear. Words I'll never forget: "I am sorry, your son has Duchenne Muscular Dystrophy." The pain was deafening in my ears, my entire world was spinning. My mind was screaming NO! Not my little boy! In an instant I went from dreams of sports, bicycles, outdoor hunting and fishing, snowmobiling and most of the outdoor Alaskan lifestyle, to living in the face of the possibility of my son's early death.

If you have ever watched the Jerry Lewis MDA Labor Day Telethon, you have heard of Duchenne Muscular Dystrophy or (DMD). DMD or just Duchenne as I like to call it, is the most common life threatening form Muscular Dystrophy (MD) and is often confused with MS. Duchenne is considered a genetic muscle wasting disorder. Typically Duchenne boys are diagnosed before age 5. They noticeably fatigue easily and find it challenging keeping up with others their age as their muscles swell and joints become restricted. The simplest of tasks like holding a pencil or rolling over in bed become difficult and eventually impossible. Most Duchenne boys need a wheelchair between ages of 10-12. As they get older and Duchenne progresses the heart and breathing muscles become compromised and begin to fail. Sadly most boys with Duchenne have not survived their teens. Duchenne affects about 1 in 3500 boys, nearly 20,000 born each year around the world.

Duchenne is caused by a gene mutation on the X chromosome and that is why the disease almost exclusively affects males. Females have two X chromosomes and so if the Duchenne causing mutation occurs in one, the other compensates for the fault. Women carry the defective gene but almost never manifest the symptoms to a deadly degree. Carriers have a 50 percent chance of passing along the

defective gene to their male offspring and since males don't have another X chromosome to compensate for the fault, they develop the disease. The daughters of carrier women have a 25 percent chance of being carriers themselves.

Those with Duchenne appear normal at birth but are usually rendered to a wheelchair by their early teens as the disease progresses. At the time of Luke's diagnosis over 14 years ago before the internet, I was told that Duchenne boys usually pass away during their teen years. The last few years, however, that outlook has changed somewhat as many Duchenne boys are living several years longer, some even into their early 30s.

My son Luke is now 18 and is considered to be in the last phase of the disease because he is in a wheelchair full time and requires respiratory and cardiac therapy.

I have gone from "Why God why?" to "Thank you Luke for honoring me in choosing me as your mother." I believe that each and every one of us choose our parents before being born here on this planet. It is the only explanation that makes sense to me, because in my book no loving God would make or cause this sort of pain in anyone's life especially that of a little child.

The one thing that stands fast is that although Luke hasn't been cured, he has lived longer than "they" told me he would. There have been times that I thought I would die from the pain of it all and times of complete and utter bliss. The many angels who have crossed our path in the form of teachers, journalists, doctors, nurses, therapists, family, friends, care providers and complete strangers I wouldn't have known otherwise. Life is such a mystery and I don't want to miss any of it!

I am writing In Your Face during Luke's senior year in high school as a gift to him for graduation. I think completing 12 years of education is an accomplishment for any 18-year-old, but especially for a Duchenne boy who has triumphed in the face of death. I am writing it as a way to preserve the essence of our sacred journey of unknown length together. To have something tangible that will go on and help others long after his passage to heaven. With that being said, now I know why parents write memoirs after their children pass. I had no idea about the amount of energy writing would take and the emotion I would expend while still living every day and providing Luke care and sound advice so that he is able to go on and advocate for himself and deal with his medical condition.

When I sat down to write this book, I realized that I remembered the past in sort of a dream-like consciousness. I don't know if we all remember our pasts like this or whether my memory is trying to help me distance myself from the horror of watching my boy's body being ravaged by Duchenne. I thought long and hard about how I was going to be able to tell my story in an uplifting positive way without being consumed by the pain as I relived the good, the bad and the ugly imprint Duchenne has tried to force upon me. I especially want to make sure I convey how I have had to change my internal belief system and the way I perceived everything about who I am and about life in general to not only survive, but thrive. My entire mission is to weave what is a very sad human circumstance into threads of hope to inspire a Duchenne Movement. People not knowing that 20,000 boys a year are being diagnosed with Duchenne who some have considered a death sentence, is not acceptable!

Since memory comes back to us in flashes of conversations, tidbits of recollection and the emotional impact that past events have upon us, instead of one continuous thread, I started each Chapter with a titled introduction then titled memory segments that follow Luke's progression of Duchenne. Eventually ending with an entire chapter dedicated to anyone who is touched by Duchenne wanting to join the Duchenne Movement or at least wear the t-shirt. You can find out more about me and pick up a free guide for "THRIVING" In The Face of Duchenne at http://MistyVanderweele.com.

Some of the names have been changed as some of the issues and challenges often involved a group of individuals and not always in the most positive of ways. I am extremely happy that I was able to use a lot of real names, as many of the people in this story have been very supportive. Many heartfelt tears have

been shed during the creation of this book and I wouldn't change that for the world. After all life is meant to be felt and *lived!*

From the beginning I, like every other mother out there, didn't want to miss one smile, one tear, one struggle, or one triumph of my child's life. What other choice does a mother have when the reality of her child's probable death is so IN YOUR FACE?

Preface by Debra Miller

The very first book of the Bible depicts a story about Abraham's nephew, Lot, who was kidnapped by the enemy. When Abram (Abraham) heard that his nephew had been taken captive, he called out his army of trained men and went in pursuit. During the night Abram attacked the enemy. He recovered all the goods and brought back his nephew, Lot and ALL his possessions. (Genesis chapter 14:14-14:16)

"In Your Face" is a story about a remarkable young man, Luke, the love of his mother and the call to action that is the result of her love and her faith. It's a safe assumption that Abraham was in constant prayer with God, but he didn't stop there. He also took action and stepped out in faith to save his nephew. Misty VanderWeele is building a different kind of "army," an army of parents, patients and advocates that aren't content to let others decide the future for those they love, that are afflicted with Duchenne muscular dystrophy. The small town in Alaska where Luke and Misty live is about as isolated as you can get from the hubs of science and support groups. Perhaps Misty's self reliance is enhanced by this distance since she had to find her own way in dealing with Duchenne. Whatever the cause, Misty sets an example for all families that have had their dreams for their child's future shattered. She did not shelter her son from living a full life, in fact, Luke has had the benefit of the great outdoors and is getting ready for college next year.

None of us really know what we are capable of until the need arises. If we get lulled into thinking that the "experts" will take care of our children then we are short changing our children and ourselves by not experiencing the deep satisfaction that comes with knowing you are working toward the solution. Those who have taken action, whether it be local fund raising or advocacy, have started a chain reaction of events and contacts that will move us much closer to a cure for Duchenne.

When our son was diagnosed with Duchenne seven years ago, we knew that this disease was much bigger than we were and that our son was truly in God's hands. We noticed a tendency among some other DMD parents we met to put their faith in people they believed had the answers, whether it be organizations, science or medicine. But as Abraham showed, God gives us opportunities to act and help others. "In Your Face" is a perfect title for this book. Misty has taken the gloves off and has posed a challenge to everyone to be part of the cure for Duchenne. She is a perfect example of a mom who has recognized the power of the individual and she offers solutions and encouragement to families everywhere. Very few people ever hear the word Duchenne until someone close to them is diagnosed. Until the public knows about this disease, it will remain underfunded for research and care. Misty knows this and is stepping outside the box to get the word out about Duchenne.

We don't know what the future holds for our boys that have Duchenne, but we do know that everyone affected with this disease has a responsibility to contribute what they can to change the outcome. Everyone has something to add. Misty didn't train to be an author but when she saw the need she rose to the occasion.

Misty and Luke's journey is an extraordinary story of love, determination and bravery. If Misty had analyzed her experience and skill set to determine if, or what she should do to help boys with Duchenne, it's very possible she'd still be pondering that list. She realized that there just wasn't enough time to do

that, and she took the first step. When you read this book, I hope you will be as inspired as I am by Misty's determination.
To Misty with gratitude from another parent of a boy with Duchenne,
Debra Miller
President and Founder
CureDuchenne

Acknowledgments

First thank you to Luke Delia for being my son. You are my light at the end of the tunnel. Thank you Jenna VanderWeele for being the best daughter a mother could ask for. Remember your love and sensitivity is *your* gift. Thank you to my husband Glen VanderWeele, you make my life sing, I swell with love and awe witnessing your love for my son. Thank you to Patrick Delia for standing by your son's side when many dad's don't, also thank you for your often times stubborn, quiet, unbending streak which has pushed me to the max to be a better me and the mother I am today. Thank you to my little sister Autumn Tweedy. My life is sweeter when you're in it. Know that your love and encouragement in writing this book has helped to keep me going. Thank you to my little brother Boone Tanner. I had no idea I was your hero until you told me. Not sure when that happened, but I'll take it. Thank you to my mother Raylene Getts, I honor you for our sacred mother-daughter path we are taking together, it is no accident that you are my mom. Thank you to my "daddy Mike" for being my childhood fantasy, my night in shinning armor, the feather story and not climbing on that whale. Thank you to my step dad Doug Tanner, you are the dad that showed up, giving me just what I needed to survive and thrive. Thank you Mary Krall my grandmother for showing me that living in dysfunction is a choice you don't have to live, our memories together permeate my daily life. Thank you to my wonderful mother-in-law Suus VanderWeele, your shoulder has been a huge blessing, your guidance is treasured beyond measure. Thank you and Namesta to Raymond a Patricia Veenkant for showing me possibilities, your belief in me and the mystery of life is one of the greatest gifts I have ever received. To my dearest friend Kelly Caraway and her wonderful husband Tim, thank you for the unconditional, genuine love, friendship and honesty you give me and my family. Also Kelly thank you for being my sounding board more times than I can remember. Thank you to all of you who gave me permission to use your real names. You are the reason that this story can be told, the wind beneath my wings to carry on. Thank you to everyone who has ever worked with Luke or been on his support team from pre-school , high school and onward. Thank you to all of the Duchenne boys and a few girls who are the trailblazers for new treatments and research trails. Thank you to Pat Furlong at Parent Project Muscular Dystrophy, you are the first mom who spoke directly to my heart. Thank you to Parent Project Muscular Dystrophy for using the photo of Luke as your 2009 Christmas Card. It's the same picture that I have always wanted to use for this very book. Thank you to my dear "soul" friend Jay Johnson at Healing Life Touch Photography for taking the picture that graces the front cover, the minute I saw it I knew it had to be a book cover. Thank you to Debra Miller founder of CureDuchenne for all your encouragement and believing in me and the Duchenne Movement. Thank you Linda Bjore for pointing out the title "In Your Face" during our getting to know each other session. Knowing the title propelled and inspired me to get to work writing! All the pieces just fell into place. Finally, a great big ball of thank you to Mindy Cameron, without your expert editing skills and your intimate knowledge of Duchenne and pushing me to dig deeper this book transformed into a the message of inspiration, action and motivation, the catalyst that propels the Duchenne Movement.

In Love and Transforming Hope Into Action,

Misty

Introduction: Hold On

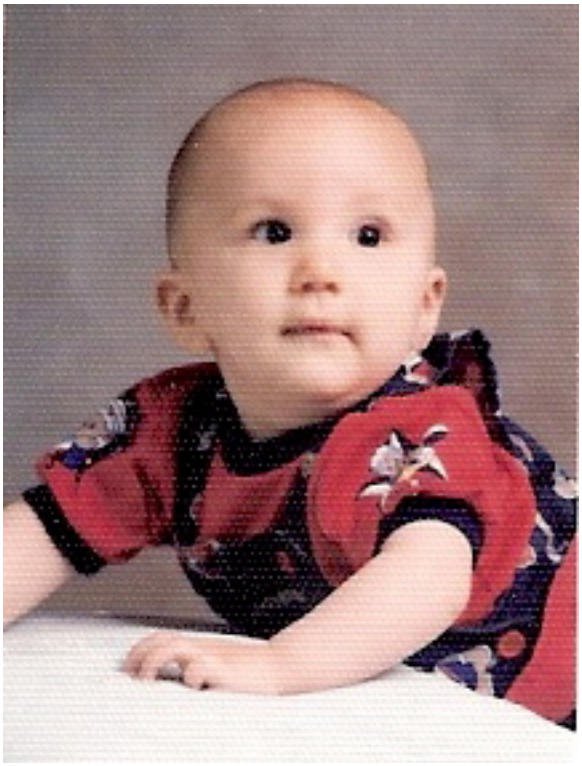
What would you do if you were told your child would die from a life threatening incurable disease, but before death came your child would require a wheelchair to walk and depend on someone else to provide all their physical needs, that living into adulthood most likely wasn't going to happen? That there isn't anything you can do about it. But, "here take this card and contact the Jerry Lewis Muscular Dystrophy Association."

Would you keel over and die yourself from the pure agony of it, would you go down to the bar and drink your sorrows away. Would you pray like you have never prayed before? Would you convince yourself that “they” are doing everything they can to find a cure? Or, Would it be your “wake up call” to face all and even more than you think you can be?

Further how would you write about something that has ripped your heart out too many times to count at the same time given you a voice of inspiration?

Fasten your seat belt and hold on cause your about to find out.

Chapter One



Little Luke (6 months) 1992

Picture taken before we had any idea the word
Duchenne even existed, This very year Luke
won a beautiful baby contest. I remember thinking
how incredible it was to have a beautiful healthy son.

Where's Luke?

Luke was born a healthy bouncing baby boy on December 22 1991. What better gift to receive than a baby for Christmas? Luke's father Pat shed large hot tears that landed on my arm when he first laid eyes on his son. The hospital gave us a giant Christmas stocking to take him home in and I still have the pictures of Luke in the stocking under the Christmas tree.
Now every time I think of Luke's birth I think of the bible verse "Through him you shall know me." For I have come closer than most to the true knowing of the spirit through watching my son face his mortality much sooner than any of us feel comfortable with.

My relationship with Luke's dad was rocky before we married and worsened over time. In a one month time span we were married, miscarried our first child and my dad died. All of these are huge stresses for any relationship, not to mention for kids of only 19. We officially divorced when Luke was two and we have always shared joint physical custody. Luke spends pretty much equal amounts of time at each home. He often says he is the luckiest kid around because he has two parents who love him, two bedrooms, two incredible stepparents, two sisters, two brothers and a family so large that we have to rent the local borough gym for birthday parties.

The first time I had any inkling that there might be something wrong with Luke was when a childcare provider who had special needs children of her own told us that she noticed Luke was not as strong as he should be and that he seemed overly cautious about doing anything physical like the swings or walking up and down stairs. My immediate reaction was anger. "There was nothing wrong with *my* child." I took him to a program called "Child Find" to get him evaluated so that I could prove her wrong. But Luke wouldn't participate in any of the physical tests at all. As I looked around at the other children breezing through the tests, I knew that Luke couldn't perform most of what I as seeing. It was so "In My Face." I can still remember my throat tightening and those first threatening feelings of nausea in the pit of my stomach that would soon become the norm. Somewhere in the back of my mind I knew but I wasn't ready to face it. I quickly pressed the feeling down.

Nagging Feeling

I knew I had to find a doctor and I wanted the very best pediatrician Alaska had to offer. At the time, Alaska's total state population was just over 603,000 and the closest and largest hospital in the state was over an hour and a half away. It was also 1996, just before the internet became the rage that it is today. I had to find a doctor using the old-fashioned Yellow Pages phone book.

The pediatrician I wanted was on vacation but I went ahead and made the appointment anyway. I needed to find out what was going on with my son. More and more "little things" kept taking me back to the same spot. Little things like Luke standing at the top of a long steep staircase crying for my help. This behavior might be normal for a one year old, but definitely not for a 4 year old.

Luke was examined for a long time and pretty soon, every kid doctor on staff at the hospital that day was in the room. I have come to learn over the years that this is never a good sign. They all agreed that Luke was a little small for his age and that he was slower than the average 4 year old. They all said they

were pretty sure that he would catch up in a year or two. But just to be on the safe side I was to bring Luke back in year. I, being a young mom with my first child, accepted with relief what I was being told.

Hide-and-Go-Seek

Kids were running all around playing hide-and-go-seek. They were having a blast! When I realized I hadn't seen Luke for some time, I started looking for him. I almost started to panic when I spotted him sitting on a mound of grass. I remember stopping in my tracks and feeling sort of sick inside. He was happy and had a smile on his face but he wasn't participating with the other children. This bothered me big time. I knew something had to be wrong, but I just didn't know what.

Medical Journal

My mom brought over her trusty medical journal with the bad news. The journal described exactly the symptoms my son was having: waddling gait when walking, hard time getting up from the floor, large calf muscles, protruding abdomen. My breath caught in my throat. The sickening feeling in my stomach which was becoming all too familiar, that I had pushed down so many times before, rolled in my gut. I struggled with what I was reading as my mind still wanted to hang onto the idea that everything was fine. After all, my mom was one of 5 sisters who all had healthy boys including my brother. But I knew I had to find out the answers to my burning questions. What was wrong with my little boy? Why wasn't he a monkey? Why didn't he run? Why was he scared to go up and down stairs? Why did he cry and whine all the time?

Mom on a Mission

Enough was enough. I was out for blood by this point. I wasn't going to stop pushing ahead until I found out exactly what was going on with Luke. This time I was going to find the pediatrician I wanted in the first place. I wanted a full blood panel done. I wanted answers.
Dr. Bloodwork (named changed for confidentiality reasons) examined Luke and his face was serious. He not only agreed that we needed to do Luke's blood work, he wanted an additional blood test done to measure the CK or the creatine kinase levels in his blood. If you have extremely elevated CK levels you might have muscular dystrophy.

By the time Luke and I got home a couple of hours later, there was message from Dr. Bloodwork telling us that Luke's dad and I were to come in the next day, which was a Saturday. He also said to make sure that someone else could drive us. No way around it, this was bad news. The message left me barely breathing. I was whirling inside and scared out of my mind! That Friday night was the first of many sleepless nights.

Clown Mobile

I stared at the laughing clown with large curly orange hair swinging from the ceiling, waiting, waiting, waiting. I thought "Damn when was the doctor coming in!" I felt like I was going to vomit. I knew it was

bad news, but I was still holding on to the very small hope that everything was fine. When the blow of what the doctor said sunk in, the room started to spin and voices sounded like they were coming from a tunnel. I am not even sure how I walked out of the hospital. I was floating, suffocating, spinning off balance. I remember I felt like I had no legs. I remember Luke's father and my cousin who drove us. I remember feeling relieved that it wasn't my week to have Luke. I couldn't face him yet. How could I? What was I going to do? How was I going to survive?

Family Meeting

I have a very large and local family so I thought it was imperative that I call a family meeting. I wanted to let everyone know about the diagnosis and I only wanted to have to tell the story once. I remember my cousin driving us to the meeting about 30 minutes away. The trees blurred by as we drove. I felt like there was a hurricane of turmoil raging in side of me, threatening to break me in two!

The first person I saw when I walked in was my mother. The other faces were not in focus. As my mother held me up in her arms, the sound that came out of me was a primal call from one mother to the next. The only thing I could say was, “Its bad mamma!” over and over.

My grandma came to stay with me that night and it was a great comfort to have her there with me. I awoke in the middle of the night to her quietly crying out to god. I laid there and listened to her but I was numb. Everything felt like one big nightmare.

Fetal Position

There are no words to describe exactly what the first week of knowing my son had Duchenne Muscular Dystrophy was like. The shock. The grief of lost dreams I once had for my son. I lay in a fetal position for hours on end, weeping, pleading, begging to whom or what I couldn't tell you. I rehashed my situation a million times, always coming to the same outcome. I had to get my life in order. Time to grow up! Time to get past the divorce and time to end relationships that didn't serve me or Luke's highest good. It was high time I pull up the boot straps and love the shit out of my boy! Whatever time I had left with him. I knew it was going to take "ALL" of me. That which does not kill you only makes you stronger, right? Well, I was going to find out.

Light Bulb Question

Sitting at my grandfather’s glass kitchen table, feeling numb from head to toe, I was spent from all the crying and grieving, not really knowing which way to go. My Aunt Kendra asked me why I thought this was happening and I said “So I can help other people,” as if I had always known the answer. Somehow I knew I had to turn these lemons I had been dealt into something positive, not only for me but for my little boy. The bills had to get paid and life still had to go on. It was up to me now. My life depended on it and Luke depended on it!

Where did this come from

The week after we knew that Luke had Duchenne, my mom, Luke and I all went in to have our genetic blood testing done. Luke needed a formal diagnosis and my mom and I needed to find out if we were carriers. I already knew in my heart that my mother wasn't a carrier and I was. I don't know how I knew, I just knew.

The blood work confirmed is what right: I was a carrier and my mother was not. After the initial wave of guilt washed over me, I felt relieved. I finally knew *why* my boy was different. I was sad because I felt that having more children was out of the question for me and crushed that my boy had a guaranteed struggle ahead of him. Some part of my brain immediately realized that my beloved son would most likely die from Duchenne Muscular Dystrophy.