

Thrive!

In The Face of Duchenne Muscular Dystrophy

May Issue
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Scott Sands

ALIVE!

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Scott Sands

ALIVE!

**“Duchenne muscular dystrophy may destroy my body but it will never destroy my spirit!”
~Scott Sands**



Not sure exactly *HOW* I met Scott Sands but I do know he irritated me. I can't recall if it was something I read on his blog or something he posted on facebook. However, the mild irritation left me with wanting to find out more when I learned he was in his 40's, that he is actually older than myself! WHAT?? Older than me and has Duchenne? That's it! I had to connect with him. Keep reading and you'll understand why. He is that contagious!

Thrive~ What has Duchenne taught you?

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Duchenne has taught me to keep life in proper perspective. I have a terminal disease, so the odds are and have always been against me. Stuff happens. Life happens. I just have to accept what is thrown in my face, adapt, cope, fight and win. The fact that I am still here at age 45 - despite nearly dying more times than I can count - says it all. As far as I'm concerned, I've already won! Duchenne has also forced me to appreciate every waking second of every single day, and all that's around me, and to take zero for granted.

Thrive~ If you had one wish given to you what would that be?

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One wish, huh? Well, to be totally honest, I'm not into the whole wish and fairy dust thing. I could tell you that I wish I could walk, but I can't move my legs. I could say that I wish I could drive a Ferrari, but I can't move my arms or legs. I could spew a bunch of wishes about fulfilling every one of my goals and dreams, but what would I have to gain - frustration? Wishes are exactly that - wishy washy. Sure, wishes and dreams are fodder for excellent escapism, and can see a person through rough times. Been there, done that! Now, at my age, I take reality very seriously and I have to focus on what is instead of what I wish was. I do the things that I know I can do, rather than wish for pie-in-the-sky. A cure for Duchenne muscular dystrophy - well, that would be the common answer, and yeah, a cure would be amazing. And when it happens, I'll be wishing that I could do cartwheels!

Thrive~ Does the thought of dying scare you?

ALIVE!

The thought of dying certainly does not frighten me. After all I've been through with Duchenne in my lifetime so far, nothing scares me. Why should I allow myself to get bogged down by the notion of dying when I have way too much living to do? I can't stomach people who live in fear of death and the unknown. Death is inevitable, and the unknown is, well, unknown - accept it and deal with it! I refuse to fear things that are beyond my control. Heck, I refuse to fear anything for that matter! Actually, I'm lying. I'm afraid of one thing, and one thing only: people thinking that I am afraid to die. It totally ruins my "tough guy" persona. Now, that is just too funny!

Thrive~ What are your thoughts about the overall current landscape of Duchenne?

ALIVE!

I have always said that if a kid is going to have

Duchenne muscular dystrophy, the time is now. The disease is way more understood nowadays. Science continues to seek answers.

Technology is on a significant upswing. There are major advances in research and medications and therapies, with a new drug or other experimental treatment trial being conducted seemingly every day. Yes, a cure still might take awhile, but the quality of life is vastly improved, and many of us are living longer.

Thrive~ What do you look forward to most?

ALIVE!

Well, I look forward to waking up in the morning, simply because that is not a guarantee for those of us with Duchenne. I look forward to continued life, continued love, happiness, people, places, experiences and endless possibilities. I look forward to all things positive, not just for myself, but for everyone, especially for those in our growing Duchenne community. And I look forward to beating the odds for years to come! ~SS

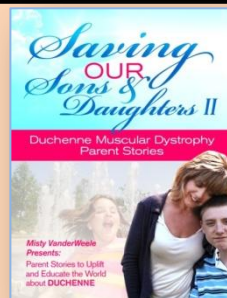
WHO is Scotts Sands?

I am 45 years old with this rotten disease called Duchenne muscular dystrophy, yet despite everything I have been through, I have miraculously managed to keep chugging along. I have a tracheostomy and breathe through a ventilator. I have an ICD (pacemaker/defibrillator) in my chest, and I am a sitting duck just waiting for that device to shock the living daylight out of me! Still, I never let this disease keep me down, nor do I allow it to prevent my accomplishments or shatter my dreams. I'm a stubborn old bugger who refuses to give up or go down without a fight. I wanted to be included in this book to show that having DMD is not the end of life, and that a positive attitude can go a long way towards happiness and longevity. I am a college graduate, published writer and amateur photographer. If you yearn for more details, check out my blog at www.scottssandsalive.com or reach me at scott@scottssandsalive.com.

More from Scotts Sands

ALIVE!

Taking A Bow From The End Stage - by Scott Sands
(Excerpt out of *Saving Our Sons & Daughters II*)



Duchenne muscular dystrophy experts and clinicians have isolated me into a category that I absolutely detest – *End Stage*. I never particularly cared much for that term, especially when it is associated with yours truly! Why? Well, *End Stage* tells me that I'm essentially *old*. *End Stage* implies that I'm a lot closer to the finish than I would like to be, like some aging baseball player winding down his career as a tired, broken, overweight, pinch hitter. *End Stage* indicates that I'm in grave condition and might as well start knocking on death's door because it won't be long. *End Stage* says just that – nearing the *end*. I am close to the end of life, the end of love, and the end of pleasure and pain and possibilities. The end.

If you go with the textbook definition, then yeah, I am in the *End Stage* of Duchenne muscular dystrophy. Yes, my heart is bad. Yes, my lungs are screwed. Naturally, at this point in the disease, I have progressed about as far as I can go just short of, say, maggot food. I am under constant watch by nurses and never left alone. If a tree farts in the woods, can anybody hear it? Yeah, my nurses can - they hear everything! They are trained to notice my every little nuance, every ventilator alarm, every change in color, every sneeze, every *ouch*, every swallow, and everything else. Plus, I have a team of physicians monitoring my condition and ready to intervene if I go awry. And I could easily go awry on a moment's notice, like the time I suddenly went into complete heart block! Indeed, you will find my picture in the dictionary under *tenuous*.

Heck, doctors were giving me the *End Stage* spiel when I was twenty-three! I didn't buy it then, and I certainly don't buy it now! Duchenne is way too unpredictable. Some die at ten. My brother did not get past fifteen. Others reach thirty. I am forty-five and still crushing odds. I am not in this part-time; I am in it for the long haul, baby! www.scottsandsalive.com

**REST IN PEACE
SCOTT !!**

**YOU WILL FOVER BE
REMEMBERED!**

