



HALOS RIDE TO CURE DUCHENNE A RACE AGAINST TIME IN HOPES FOR A CURE

Dreama Whitlock is the founder of Halos for Muscular Dystrophy, an organization with the primary focus of creating awareness for muscular dystrophies. On August 9, 2014, Dreama and her family are hosting a poker-run event called "Halos Ride for Life." All proceeds will benefit CureDuchenne and will be invested into the newly launched initiative

CureDuchenne Ventures. Dreama says, "I wanted to support CureDuchenne and the newly launched CureDuchenne Ventures because the goal is to find a cure for all boys and girls living with Duchenne. My grandson, Riley was diagnosed with Duchenne in 2011; he has a point mutation. There are not a lot of clinical options for children with point mutations, however I believe that CureDuchenne is going to change that with this new initiative."

Dreama's grandson Riley is also turning 8 years old on August 9, 2014. He will be ridden up Main Street after the run and will celebrate with a huge Lego cake as everyone sings "Happy Birthday." People from all over the world have been sending him birthday cards to celebrate!

THE BIG DAY!

Riders from all over West Virginia and furthering states are all riding together to fight Duchenne Muscular Dystrophy and raise awareness. Participants will begin at the American Legion Post and stop at Buddy's All-American BBQ in Huntington.

Before leaving for the poker run, riders will draw 5 cards, building the best possible hand to beat each other out for the grand prize of \$175 cash and 4 tickets for a Ski Day at the fabulous Canaan Valley Resort!

Other raffles include tickets for 4 to Disneyland, tickets for 4 to Camden Park, Harley Davidson trunk filled with memorabilia and more, NFL Hall of Fame inductee Marshall Faulk autographed football, and much, much more!

We will be serving pig roast or chicken with sauerkraut, baked beans, corn on the cob, mashed potatoes, mexican corn bread or rolls. Serving will begin at 5:30 p.m.

At 7:30 p.m., we will bring a very special message from Sarah Burgess, *American Idol* contestant on season 6.

Barry and Noah Frazee and The Double Yellow Line Band will begin performing live at 8:30 p.m.

Attend the event!

**HELP RAISE FUNDS
FOR CURE DUCHENNE!**

When:

Saturday, August 9, 2014

Where:

Starts at 139 Milton, WV and ends at Buddy's All-American BBQ in Huntington

Cost:

Pre-Register Price: \$20 per rider

Registration on Ride Day: \$25 per rider

Passengers with Shirt: \$18

Passengers without Shirt: \$10



**WE HOPE
TO SEE YOU
THERE!**

The Phantom

Fictional short story written by: Melody Burgess



In the Spring of the year 2014, the mid-sized, Midwestern American town of Hillburg was stalked by a silent yet brutal killer. The town was a normal one: a place of tree-lined sidewalks, neat suburban houses all in a row, a few public schools, one private school. There were the usual mainstreet businesses (barbers, laundromats, delis, grocery stores), as well as a shoe factory which had weathered decades of outsourcing and several years of recession. Hillburg even had its own community college, which featured a great nursing program, right next to the hospital! But in the midst of the successful

"IT WAS AN ENEMY WHICH THE NEWS NEVER MENTIONED..."

merchants, the dedicated workers, and the capable healthcare workers, there lurked this killer, this mysterious stealer of young lives. The kind of killer that grips parents', siblings', friends', and communities' hearts with the chilly claws of fear and helplessness.

For John and Traci Spencer, the

phantom danger was all too real. It had already cast a horrific and dark shadow over their lives, for it taken their beloved only son, Oliver, from them, at the young age of fourteen. Many friends and relatives had come to the funeral from across the country to lend their sympathy in the couple's time of grief; to share hugs and sympathy cards and well-meaning words. But none of it could bring Oliver back. Oliver, with whom John used to play catch, and to whom Traci used to read bedtime stories. Oliver, who loved Pokemon, Cub Scout camping trips and activities (and had recently gotten into Boy Scouts, as best he could, before his death), and soccer, when he was very young. But on a Saturday afternoon, his heart rate went erratic, and then beat for the last time.

Now Traci lay in bed beside her husband, weeks later, trying to read a novel but unable to focus. It was another Saturday night, much like the one in late winter when they had lost their son. The petite redheaded woman tried to focus, to focus on the present and the future rather than the past, but could not. Her thoughts were caught up in the perfect little face of her baby boy; his green eyes like his father's, and his orange curly hair like her own. All gone forever now. Taken by that killer in the dark, that taker of young boys. Traci knew that this wasn't the sort of monster that the police could or would find, let alone stop. It was an enemy which the news never mentioned, and which no one seemed

to understand. Traci (and her husband John, who was half-asleep but having similar thoughts) pondered the danger of this enemy, and how little other people knew or talked about it, and she came to a course of action.

She got out of bed, went downstairs, and booted up her desktop computer. Then, she got on her Facebook and Twitter accounts. With the energy provided by the will to take some sort of action, however small, to help stop the killer which took her son, Traci Spencer began to share her experience. In a Facebook status and a few tweets (she also linked back to her Facebook through the twitter posts), she described her and her husband's love for their son, some pictures of the boy, and the essential story of how he mysteriously withered away and then died one night. She even included a few pictures of Oliver, as a baby, and growing up through the years, as best as he could grow up. Maybe, just maybe, the desperate mother thought, this message to the world would start to get something done...

Traci felt an arm around her shoulder, then a kiss on her cheek.

"Hey, babe. What are you doin' up still?" said John, tiredness and concern in his voice as he squinted at the bright computer monitor.

"Oh, just, I thought I would share some information with our friends on Facebook, especially the people here in town."

STORY CONTINUED... "THIS IS ONE REAL MONSTER WORTH SLAYING."

"About Oliver?"

Traci nodded, and fought back tears for the millionth time. She would avenge her son; for herself, and for all the other parents and little boys.

"Hmm...not a bad idea," said John, nodding thoughtfully, "I think I may just do the same thing...let's see what our friends in person may say, too. We both know Oliver was far from the first boy to have to be hurt by this. And, on Facebook, hopefully other people will share their own experiences."

The couple had their course of action set, at least until they could learn more information to truly do more. But it was a good start. They hugged and kissed each other and went back to bed.

The next day, when Traci first had a chance to check her Facebook account during a lunch break at work, she was shocked at the number of new comments and messages. She read through a few of them; some were just repetitions of the same loving condolence messages as from the time Oliver died, but others were stories or forwarded messages from friends of similar experiences! Even a few right there in the everyday American town of Hillburg! The mysterious serial killer had targeted many boys, in Hillburg and other towns and states, at around the same age! The children had faced similar threats and sufferings before their deaths, too. Clearly, there was a pattern at work here, thought Traci. She called her husband, and for the brief time they had to talk during their overlapping lunch breaks, she told him about how other people had the same experiences and were going to have a get-together at one of the other couples' houses to discuss this common threat. A couple of the moms, and one of the dads, were nurses, too. Perhaps they would be of special assistance in getting to the bottom of this...

A couple nights later, John and Traci met at the home of another family in Hillburg, who had lost their second child to the same monster as had taken Oliver. The mood was somber, and yet in a way, hopeful, and even a bit cheerful at times, that dark night as the parents (and a few older siblings) gathered in the living room next to a fire, eating a few snacks and drinking drinks as they discussed the matter. They agreed on the strangeness that there was so little, or basically no, media coverage of the killings and the preceding suffering, and they agreed that normal police authorities would be of no use here. One of the moms, by the name of Diana, was a nurse at Hillburg General Hospital. She had gotten her degree right there in town at the community college and had lost her son Jeremy a few years ago. She was a single mother of two other children, but still found time to read and learn new things every day. And, she announced, in a quiet but confident voice, as everyone fell silent, that she had finally tracked the monstrous phantom killer down:

"It's called Duchenne Muscular Dystrophy. It's a genetic disease, normally only ever expressed in boys...boys like my Jeremy. Or, your Oliver, John and Traci. She nodded sympathetically to the other parents, "It steals away the strength and, ultimately, the entire use of the victim's muscles...and, like we all saw, after a while the poor boy can't even walk. Often by his teens, he'll have trouble breathing, and his heart will have trouble beating, until ultimately this real and deadly killer takes him. The disease may be rare, but it's all too real for us, as a community and as parents. We've all been touched by the lives of our sons, as have so many of our friends and neighbors. It's time for all of us to fight back for them; for every victim: the dead, the living, and those already fighting for their lives. It won't be an easy fight, but knowing your enemy is the first step. I've read of, and even talked to, scientists who are working on genetic treatments that can not only detect Duchenne, but someday cure it altogether. I know we've all been scared, and may still be scared now, but we can't give up. This is one real monster, and one worth slaying."

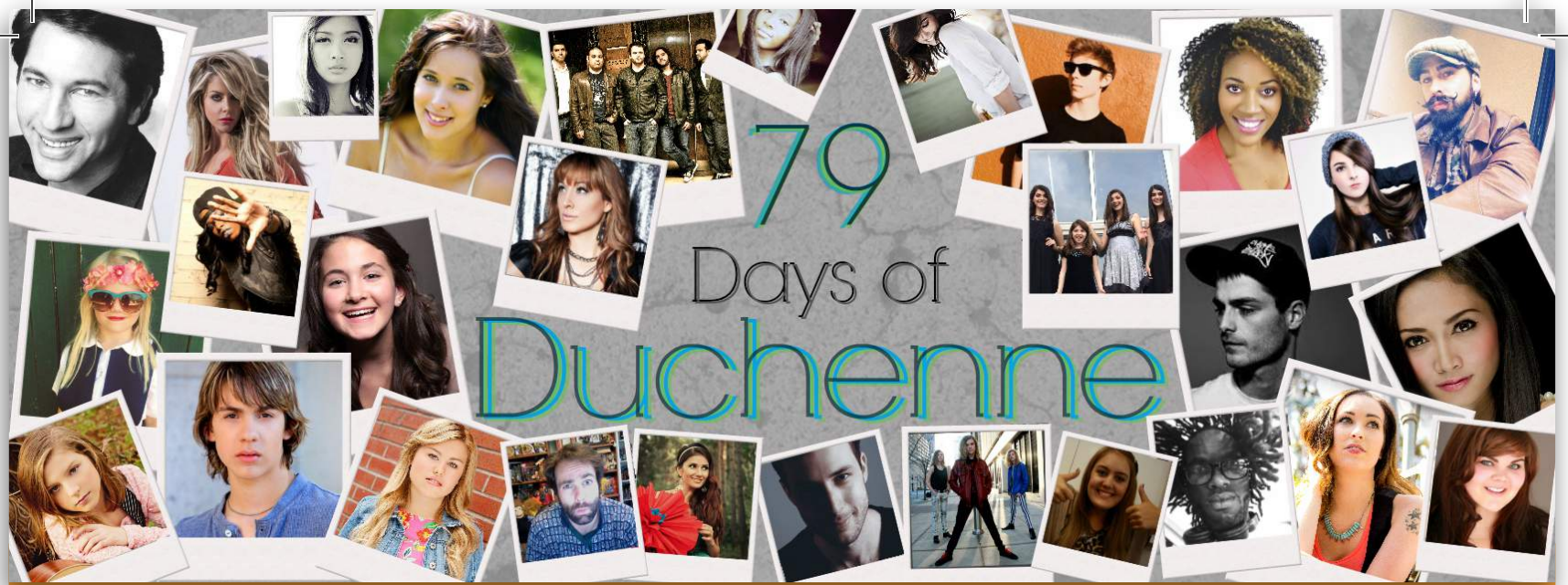
Diana's eyes teared up, and she took a breath as she finished. At first, everyone paused, staring at her, some with tears of their own in their eyes. Then, they clapped: first one father, then another, then a couple mothers, and soon the whole room was in applause at Diana's heroic words. Someday, they knew, with their efforts, this real life horror story would become a story of hope and change. Someday, Duchenne Muscular Dystrophy would be no more.

"SOMEDAY, DUCHENNE MUSCULAR DYSTROPHY WOULD BE NO MORE."

The End



This fictional short story was written by Melody Burgess, inspired by her feelings towards Duchenne. Her son Jacob Burgess is seven years old and lives with Duchenne.



79 Days of Duchenne

79 VIDEOS RAISING AWARENESS TO FIND A CURE FOR DUCHENNE MUSCULAR DYSTROPHY

With any life-threatening illness, awareness is the number one priority. Awareness is what educates. Education is what teaches. The scientists are those who are taught. The cure is what the educated scientists will find.

Duchenne was a foreign word to me until my son, Wil, was diagnosed on 9/11/2007. Upon his diagnosis, I began to research in order to educate myself and my family. Once I had a grip on the disease, I began to advocate and use my voice to spread awareness.

I became involved with CureDuchenne in 2010 when my family relocated from South Florida to Southern California. I simply called Debra Miller (founder of CureDuchenne), shared my story, listened to her story, and immediately bonded based on our mutual love for our sons and the determination to go to the end of the earth to find a cure. She also knew that awareness is key and that we need to work as hard and as fast as possible to help the scientists find the cure!

79 Days of Duchenne is a fantastic way of spreading awareness and increasing education! The lyrics of the song "Run Away" embrace every aspect of what is needed to provide these boys with the hope and determination crucial to beating this child-robbing disease.

Each of the videos has elicited a different emotion for me. Hearing Sarah's lyrics and seeing the actions of the performers, all who have different perspectives, have brought on feelings of: purity, courage, rhythm and blues, kindness, inspiration, gentleness, bravery, sweetness, and dedication. Each morning, I look forward to viewing the video of the day and opening the gate of my emotions.

- Tiffany Cook



Wil Cook

**DON'T WORRY IF YOU MISSED A VIDEO!
WATCH ALL VIDEOS AT:**

WWW.SMARTURL.IT/79DAYS 



TODAY *CHS Honors Band*



7/26 *Nichole Marceaux*



7/27 *Brittany Patz*



7/28 *OZS Choir*

INTERVIEW WITH MATT JAFFE

For social media & information about *Matt Jaffe* please visit:

www.smarturl.it/79Days



Why did you decide to participate in the *79 Days of Duchenne* project?

Matt Jaffe: I believe that music and art are very powerful instruments for change. I am intent on using my music to directly help others as often as I can, and *79 Days of Duchenne* is a very worthy cause that I am thrilled to be involved with.

Have you ever heard about Duchenne before the project?

MJ: I had not heard of Duchenne before getting involved.

"I THINK OUR STRENGTH CAN BE BOLSTERED BY EXTERNAL REINFORCEMENT, BUT IT MUST PLANT ITS SEED WITHIN THE INDIVIDUAL"

What's more important, making a difference with music or making money? Why?

MJ: If making a difference meant that we were able to positively influence anyone's life, either emotionally or, in the case of this project, physically, that would be much more important. Hopefully, money will only ever be a

byproduct of any musical success. The music should always be paramount, so if money became more important, then we would have lost the reason to even make music.

Duchenne is a disease found mostly in males – what would you do if one of your bandmates or brothers were diagnosed with a disease that had not yet a cure?

MJ: I hope that I would find a way to help them through art. Art has the dual benefit of having a tremendous emotional benefit and being able to raise money. Emotion and finance are both critical to progress in this area.

What hopeful words can you give to inspire those with Duchenne?

MJ: I would encourage them to have faith in the art surrounding our cause, the people (like Sarah!) who have dedicated so much energy to them, and most importantly themselves. I think our strength can be bolstered by external reinforcement, but it must plant its seed within the individual.

Can you tell us more about your band, *Matt Jaffe and the Distractions*?

MJ: We are about to start recording our first album, which will hopefully see release relatively soon. After that we hope to tour to support the record. Our band is unique because of our

dedication to real instruments and an entirely live performance. Many bands, even some ones I love, have fallen victim to the over-utilization of electronics and pre-recorded tracks onstage. We do not have a deliberate retro bent, but our predisposition to making all of the music onstage allows us a different kind of energy. I believe we are also different in that we focus heavily on the songs before we even think about sound. Some groups seem preoccupied with production and sonic quality, which, while very important, sometimes diverts needed attention from actual song craft.

Can you finish this statement?

"Together we can Cure Duchenne!
Together we will _____!"

MJ: Together we will overcome adversity with art!"





I KNOW EVERY MILE WILL BE WORTH MY WHILE

A MOTHER GOING THE DISTANCE

November 2010, my life was turned upside down when my then-seven-year-old son, Josh, was diagnosed with leukemia. A cancer diagnosis is scary for anyone, but it shattered my heart to hear that my sweet boy was sick and there was absolutely nothing that I personally could do to help him. I had to sit helplessly by his side as he started on a three-and-a-half-year chemotherapy protocol.

A leukemia diagnosis in 2010 was very different from a diagnosis in 1940. If Josh had been diagnosed then, we would have had a short time to take him home and love him until the leukemia stole his life. Today, Josh's disease, high-risk pre-B cell acute lymphoblastic leukemia, has a 90% survival rate.

During Josh's treatment, his nurse invited me to run a half marathon to raise money for leukemia and lymphoma research. It was then that I finally felt empowered. I was able to do something that would help my son, and others who have been diagnosed with the same disease. Ninety percent is not good enough. Only 100% will satisfy me.

Shortly after Josh's diagnosis, I met

Stacy Zamora. Her son, Alex, was undergoing testing to find the cause of his muscle weakness. When Alex was diagnosed with Duchenne, I became even more determined. I now also run for Alex, and for all boys who have Duchenne. Treatment for Duchenne is

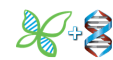
"I REFUSE TO ALLOW FEAR TO DAMPEN OUR LIVES"

currently at the same place that leukemia treatment was in the 1940s. I know that with today's knowledge and technology, a treatment, and finally, a cure, will be found!

Josh's and Alex's diagnoses have given my family a new appreciation for life. We understand just how fleeting life can be. We have had to say good-bye to too many children, but I refuse to allow fear to dampen our lives. We live with joy

and hope in our hearts, because life is too short.

I am also determined. I will run for our children, both cancer and Duchenne patients, until both diseases have been cured. With a smile on my face and the power of determination through my body, I pound the pavement in search of a cure. I have to. Josh and Alex are counting on me.



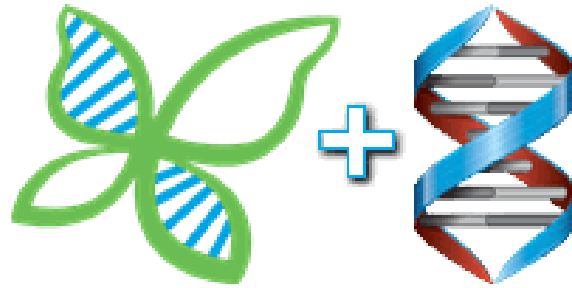
Laura Burt Pita



Laura and Josh

100% OF EVERY DOLLAR

DONATED THROUGH THE RUN AWAY PROJECT GOES DIRECTLY TO CURE DUCHENNE TO FUND RESEARCH!



CureDuchenne is a nonprofit organization on a mission to find a cure for Duchenne and save every person diagnosed on the planet. **Join us.**

SPONSOR A PROJECT OR START YOUR OWN FUND-RAISING CAMPAIGN

CONTACT US FOR HELP OR IDEAS!

HELP FUND RESEARCH THAT MATTERS, BY AN ORGANIZATION THAT YOU CAN TRUST, AND THROUGH RESULTS YOU CAN SEE.

7

Number of research projects that advanced into human clinical trials with CureDuchenne's support.

2014

Year expected to see first drugs approved. Two drug development programs supported by CureDuchenne will be the first to seek approval for treatment of Duchenne.

100 MILLION

People reached through awareness campaigns.

\$100 MILLION

Amount of money leveraged from government agencies and pharmaceutical companies to fund research towards a cure.

Email: Support@TheRunAwayProject.org