

July 14, 2014

The Run Away Project Newsletter



THANK YOU FOR THE SUPPORT!

It's been almost a week since the start of the *79 Days of Duchenne*, a unique awareness project that will release a different video of a person performing "Run Away" in their own unique way. It's really great to see such an overwhelming response in less than a week! Hans Schikan, CEO of Prosensa, said it's one of the "most **inspiring and creative**" campaigns he has seen.

The beauty of this project is that it only works if everyone works together. We all have one goal, and that is to get treatments as quickly as possible to those with Duchenne, and then actually *Cure Duchenne*. Everyone is essential in making this happen, so we think it's about time to start working together! You can do things we cannot, we can do things you cannot, and together we can do GREAT things.

Together, we can Cure Duchenne! Together, we will Run Away!

MISSED A VIDEO?

You can watch all
released videos at:
www.smarturl.it/79Days

Email your questions or videos to:
Sarah@TheRunAwayProject.org

"MOST
INSPIRING
AND
CREATIVE"



MY BIRTHDAY WISH

By: Sarah Burgess

Today, July 14th, is my twenty-seventh birthday. When I think about my life up until now, I can't help but think how quickly time has gone by. I know birthdays are supposed to be fun and a time to celebrate, but way in the back of my mind there is a sadness that my brother Jacob might not ever see his twenty-seventh birthday. I wish time would slow down, just enough to allow all of the amazing progress towards a cure to be complete. My brother, friends and every other with Duchenne deserve to live a life that isn't cut so short. Today, I am asking all of my friends to help my birthday wish come



true. Please donate \$27 (or *any* amount you're able to give) to CureDuchenne. CureDuchenne is leading the way with research and they take the risks needed to find a cure. On top of that, CureDuchenne's overhead is the lowest compared with any other Duchenne-focused organization.

I feel comfortable knowing that any funds raised are going directly to research. I wish for nothing more than a cure. I trust God and whatever His will may be, but I know He didn't give me my stubborn determination for nothing! Please help us Cure Duchenne! Please help fund research and donate \$27 or *any* amount to CureDuchenne today.



HOW TO DONATE!

Donate (tax deductible) directly to CureDuchenne.org:

www.smarturl.it/RunAwayDonate





ROCKIN' TRIPLETS

Fusion Series custom-built cajon, donated by: *ARJ Percussion*. This item will be auctioned off on *The Run Away Project* website (www.TheRunAwayProject.org) along with MANY other amazing donated items!

Online auctions will begin in August!



"It was very cool to have the opportunity to meet Jacob, and to get to know the inspiration behind this project. He's a very cool kid!" - More Like Me



INTERVIEW WITH THE BAND

For more information, please visit:
www.smarturl.it/79Days

MORE LIKE ME

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

More Like Me: Because we feel it's our duty as a band to use our gift of music to help others.

Had you ever heard about Duchenne before the project?

MLM: No we had not.

Do you think it's important for music to have a positive message?

MLM: Yes, it's always a good thing to have a positive meaning to you songs. You can't always have everyone be positive, but we try to do our best.

You guys have decided to release your cover of "Run Away" on iTunes and donate 100% to CureDuchenne – What's more important to you, making a difference with music or making money?

MLM: We feel having an opportunity to make a difference with our music is more

important than making money because we have a voice as a band that can help people just by doing what we love to do.

What would you do if one of your brothers were diagnosed with a disease that had not yet a cure?

MLM: We'd do everything we could to find a cure as fast as possible.

Do you have any hopeful words you can give to those with Duchenne to inspire them?

MLM: We want them to know they are not alone, and there are a lot of other people like us doing whatever they can to help find a cure, and the cure could come tomorrow, so don't ever give up hope.

Can you tell us a little bit about your video, without giving too many details away?

MLM: Well, we asked a lot of special guest artists to join us on the song, to help get the message out to a larger audience. It was

a lot of hard work, and a lot of people and companies we work with came together to support us on this project.

What is special about *More Like Me*? What are your plans for the future?

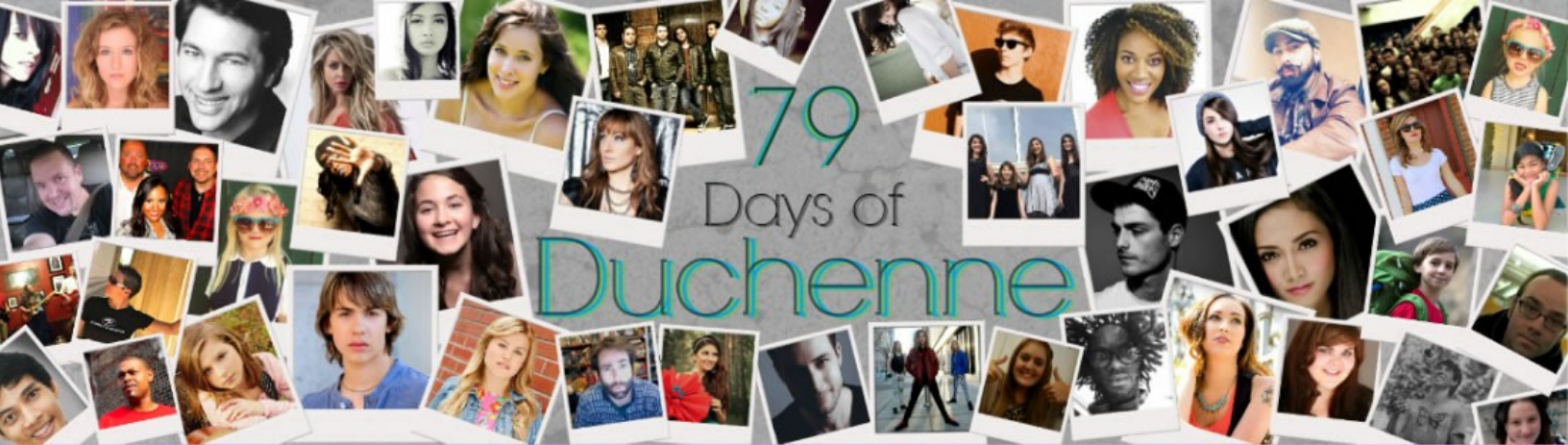
MLM: Well, we're *identical triplets*, and we're currently planning Triplet World Domination.

I heard you met Jacob Burgess – What was that like? What did you guys do?

MLM: It was very cool to have the opportunity to meet Jacob, and to get to know the inspiration behind this project. He's a very cool kid and we had a lot of fun hanging out and playing video games.

Will you continue to spread awareness about Duchenne?

MLM: Yes, we really like the song "Run Away" and plan to continue to play it at all of our shows and help spread the word about Duchenne.



79 Days of Duchenne

79 videos raising awareness to find a cure for Duchenne Muscular Dystrophy

Earlier this year, I contacted *More Like Me* to take part in the *79 Days of Duchenne*, an awareness project where artists cover my song "Run Away" (donated in its entirety to CureDuchenne.org) and give a PSA about Duchenne Muscular Dystrophy. To my surprise, the triplets went above and beyond, having the song professionally recorded at the House of Blues Studios (Nashville), and had an equally awesome video to go along with it! Even better, *More Like Me* will release their cover version of "Run Away" on iTunes and other digital retailers. This option is available for *all* artists, but only if they agree to donate 100% – from the very first sale – directly to CureDuchenne. *More Like Me* had many special guests featured on the track, such as Mark Slaughter (*Slaughter*), Eric Brittingham (*Cinderella*) and Robert Mason (*Warrant*), to name just a few. It feels good to know that others are so willing to help, not giving to get, but inspiring others to give, too. When we give, and take action, it begins the process of change and moves us to remember that we are one very important piece in the bigger picture. Together, we can Cure Duchenne! – *Sarah Burgess*

For more information, please visit: www.smarturl.it/79Days

To download *More Like Me's* cover of "Run Away": www.smarturl.it/MoreLikeMe

UPCOMING VIDEOS:



7/16

Tyler Armstrong



7/17

Matt Jaffe



7/18

Ryan O'Neil Edwards

I'M NOT ANGRY

HOW ONE MOTHER FIGHTS THROUGH THE DEATH OF HER ONLY CHILD.



Michael, Laura and Joshua Hamby

On April 8, 1987, I gave birth to my miracle son, Joshua Caleb Hamby. Life was *beautiful*. We decided it was time to have another child, but in the summer of 1990 we found out that health complications would make this nearly impossible. I was *devastated*.

Shortly after, it was brought to my attention that Josh was not able to keep up with other children at his preschool. He was constantly falling and having trouble

climbing stairs. I took Josh to the doctor for an ear infection and mentioned the concerns from preschool. As she examined Josh, her face looked more and more foreboding. She explained Josh needed to be seen by a pediatric neurologist to determine the problem. It never occurred to me it was Duchenne muscular dystrophy. The appointment was made, and after a muscle biopsy the doctor determined it was Duchenne, the worst of all muscular dystrophies. He explained

there was no cure and they would do what they could, but there wasn't much that could be done. Josh was soon put on a drug study, fitted with orthopedic night splints and started doing physical therapy in the evenings. Our dream turned into a nightmare. Not only would there be no more children, the one we had was going to slowly deteriorate, then die at a young age. All the muscles you normally use, including the heart and lungs, are affected over time. As the years progressed, Josh lost one ability after another. Eventually we needed to feed him, bathe him and more.

It would have been so easy to get angry at God if it wasn't for one very important fact. God loved us so much that He (whose capability for love far exceeds ours) sent Jesus, His only Son, to experience every temptation we do, live a sinless life, and take our punishment to pay the penalty for our sins. Our sins held Jesus on that cross. His love for us is *why He was betrayed, spit on, mocked and whipped with pieces of metal that tore the skin and muscles, had a crown of thorns placed on His head, nailed to a cross and died.* If I or you had been the only one to

accept His gift of salvation, He would have done it just for us. By being capable of so much more love, God was also capable of so much more emotional pain. He could have sent legions of angels to rescue Jesus at any point, but out of His mercy, love, and grace He experienced the pain of watching His Son die. The Bible says "In the fullness of time." God chose the time that would be the most painful. *He knows our pain.*

Josh had declined to the point where he could barely move. He was in extreme pain any time his pain relievers wore off. He had chosen not to have a feeding tube or other such measures to extend his life. When he got to where he could no longer swallow we knew the end was near. The days before he died we got to have a bit of an early Christmas, giving him some CDs he had wanted. We told him how glad we were that he was our son and he told us how glad he was that we were his parents. Friends and family came and spent time with him and us. He was at peace because he knew where he was going. December 10, 2010 we had expected him to die for hours when his

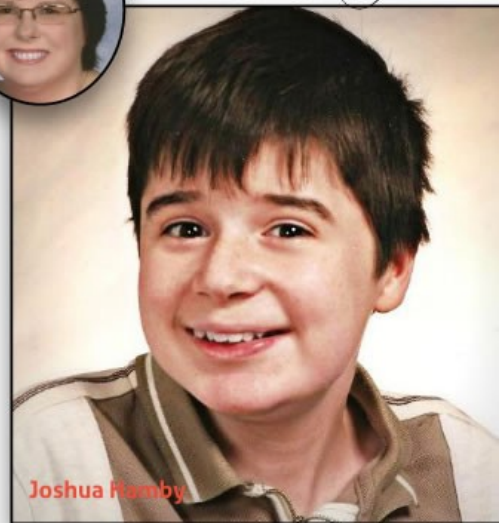
favorite song started playing – "How He Loves" by the David Crowder Band. His eyes had been rolled back in his head from the morphine, and as the song played I watched as he looked straight past the ceiling, breathed in and never breathed out. Josh loved Jesus, and I know he entered Heaven at that very moment. God wiped every tear from his eyes. In Heaven there will be no more sorrow or pain, and our bodies are no longer filled with disease. There are no wheelchairs in Heaven.

Do I miss him? More than I can express! Does it hurt that I can no longer read to him late into the night, and hear him laugh or give him a hug? Absolutely! I will hurt until the day I die, yet I have peace, comfort, joy and hope. I know that life and pain are temporary, I will have an eternity to spend with Josh. My prayer for each person is that they will accept Jesus as their Savior, so they can have the peace, comfort, hope and joy only Jesus can bring. I couldn't survive a day without it. If God and Jesus had done nothing else beyond salvation, it would be more than we deserve. Yet, many times over the

years, God provided so much more: a loving, supportive husband and father, a handicap-accessible house, a service dog for companionship for Josh and to comfort us since Josh passed, a caregiver for Josh that has become my "daughter" with her daughter being my "granddaughter," many other surrogate children, and so much more. He doesn't promise us an easy life, but loves to show His love to those who accept Him as Savior. If you haven't, please get to know God. He loves you more than you can imagine!



Laura Hamby



Joshua Hamby

CARDIAC CARE

BY: SUSIE ARROYO



Duchenne Muscular Dystrophy affects the muscles, but did you know it also affects the heart?

Yes, the heart is a muscle that works very hard pumping oxygen-rich blood throughout our body. Unfortunately, Duchenne Muscular Dystrophy weakens the heart, which eventually leads to heart failure. I am a girl with Duchenne Muscular Dystrophy, I was eleven years old when the doctors noticed I already had signs of cardiac dysfunction. By the time I was showing symptoms, it was already advanced more than they would have liked. I used all sorts of cardiac drugs and did very well on them for many years until those drugs could do no more, and I was implanted with a Left Ventricular Assist Device (LVAD). There are many risks involved in the placement of an LVAD and follow-up care, and it is usually left for people who have not had benefit from other cardiac therapies. But, if you get treated before symptoms start there is more chance for success.

Here are my tips and suggestions to mention to your doctor about your son's or daughter's cardiac care:

- The heart should be checked every 1-2 years, starting from the time of diagnosis, to watch for changes in heart function.
- In Duchenne, the heart is already damaged before heart symptoms appear. People with Duchenne may need to start heart medications even if they do not have symptoms of heart problems.
- Limit caffeine or other products that may cause strain on the heart.

Medications are often started before any heart problems are seen, or they may be started when heart problems are seen on an echocardiogram or cardiac MRI, even if you have no

symptoms of heart problems. Some examples of medications that may help the heart are the following:

- **ACE-inhibitors** and **angiotensin receptor blockers** make blood vessels open wider, which makes it easier for the heart to pump blood throughout the body.
- **Beta-blockers** help the heart to relax, so it beats more slowly and efficiently.
- **Diuretics** help the body remove extra water, so there is less blood volume for the heart to pump.
- Respiratory abnormalities contribute to cardiovascular dysfunction in DMD and BMD. Evaluation and treatment of respiratory abnormalities is recommended. So, boys and girls (with DMD), as much as you don't like using the bi-pap and cough assist, it is a *MUST* if you want to maintain a healthy heart. You *have* to keep those lungs strong.

-Susie Arroyo