

Wednesday, July 9, 2014



79 DAYS OF DUCHENNE A UNIQUE WAY TO RAISE AWARENESS FOR DUCHENNE MUSCULAR DYSTROPHY

Hey, everyone! My name is Sarah Burgess, I'm a singer-songwriter from Pittsburgh, Pennsylvania, and I want to tell you about the 79 Days of Duchenne. My 7-year-old brother, Jacob, was diagnosed with Duchenne, an extremely fatal muscle disease that affects 1 out of 3,500 boys. Currently there is not a cure, and life expectancy is between the ages of 18-25 – we are literally in a race against time.

In 2013, I wrote "Run Away" for my brother Jacob, and for *all* boys with Duchenne. I donated "Run Away" in its entirety to CureDuchenne.org. The song started out as a simple idea and quickly turned into a project involving a lot of hands, and that is what led to *The Run Away Project*. Basically, it is a bunch of creative ideas that allow me and so many others to raise money and awareness for CureDuchenne. *The Run Away Project's* newest venture is the 79 Days of Duchenne – the goal is to bring major awareness to Duchenne and stop its destructiveness. In this regard, the number 79 is significant: there are 79 exons in the dystrophin gene (dystrophin is missing in the body of a child with Duchenne). We are using that number to hopefully gain the vital awareness we need for this disease. Starting today, July 9th, for the next 79 days, every single day *The Run Away Project* will release a different video of a person performing "Run Away" in their own unique way. 79 talented and caring individuals have decided to be a voice for these young men and to help them run far, far away from Duchenne muscular dystrophy...Forever!

Sarah Burgess

get involved

**WE STILL NEED
YOUR HELP!**

ANYONE who would like to participate by performing "Run Away" in their own way is more than welcome, we will be accepting videos until there are no more being sent! You can use absolutely any creative idea you have, no matter how strange or weird it might seem... Whether it's you and a camera or you and an entire production team, ANY video will be greatly appreciated. With so many talented people coming together, all at once, we believe this has huge potential to raise MAJOR awareness for Duchenne. Would you please help with this project? Will you help my brother and everyone else with this devastating disease? Will *you* help Cure Duchenne?

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

79 Days of Duchenne Official YouTube:
www.youtube.com/TRAPProject

"PERHAPS THE
BUTTERFLY IS PROOF
THAT YOU CAN GO
THROUGH DARKNESS,
YET BECOME
SOMETHING
BEAUTIFUL"



SIBLING TALK: "I KNOW THE PLANS I HAVE FOR YOU" – JEREMIAH 29:11

"My baby brother, Kyle, is one of the most inspiring people that anyone could have the pleasure of meeting. I might be a little



Katelyn & her brother, Kyle

biased, but I know he touches the hearts of everyone around him. Growing up with Kyle was such a blessing. He has taught me so much about happiness

and filled my heart with more love than I thought was possible. Kyle and I always find new ways to have fun! Some of our favorite things to do are to just be goofy, laugh, go on walks together, play badminton and card games, watch movies, and just spend quality time together being near each other. Sometimes we Face-Time just to make faces at each other. That's what I love about Kyle. You would never know he had a disability if you couldn't see his chair because he doesn't let it define him. He does whatever he wants to do, however it's possible for him to do it. Kyle always has a smile on his face, he is the one who keeps our spirits up during the down times of Duchenne." – **Katelyn Cox**

"My brother, Braden, and I may fight a lot, but we love each other so much! We are always there for each other, even when it seems like we're not. My life would be totally different without



Alyson & her brother, Braden

him. He means the world to me, and he teaches me so much about the world – and he's only 7! The way that I am able to stay positive in a negative situation is through his smile and laugh, the little jokes he makes up keep everyone smiling! I will support my brother, every step of the way. I plan to change the Duchenne outcome by raising awareness and money through fundraisers for the Duchenne Community." – **Alyson Taborski**

"The word 'weak' comes to mind when I think about Duchenne. It makes you weak, not just physically, but at times, mentally and emotionally. It's an exhausting disease. But when I think about my brother, Andrew, a 32-year-old fighting the Duchenne battle, the last thing I think of is weak. He is on the front lines, beating the odds and living longer than most boys with Duchenne. From my perspective, he is the epitome of heroism. He has taught me how to find joy in the moment. He has taught me to appreciate all of the little things that we hardly ever bother to think about, such as being able to lift a fork to our mouths to feed ourselves. He has taught me how to be strong in the hardest of times. My brother's future may be limited, but he lives his life to the fullest. He may only have a few more years, but I like to think it's going to be 100 more years. He has more life and energy than most, and loves to crack a joke, even if it's at his own expense. When it comes down to the struggles, it is laughter that cures him, and his smile is infectious. We fight the fight because we have to, but we make the best of it day in and day out. We are thankful for the hard times, as they only make us stronger. The fight against Duchenne will be a never-ending battle – until it is cured. These boys are in a race against time, and I pray each and every day that they will win the race. Until that day, I will fight to save this generation of Duchenne boys. I believe God has a plan in it all, and I want to be a part of that plan." – **Liza Mulloy**

"I BELIEVE GOD HAS A PLAN IN IT ALL, AND I WANT TO BE A PART OF THAT PLAN."

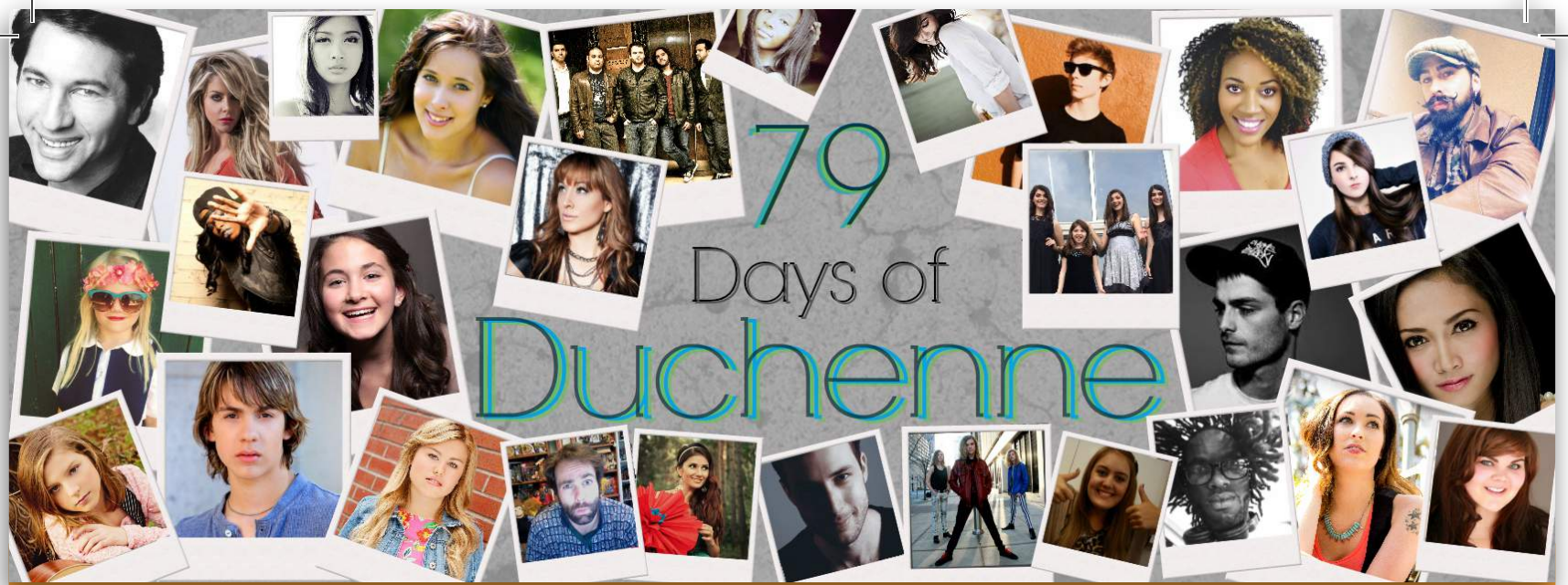


Liza & her brother, Andrew

"My brother, Jacob's life would be so different without this disease. He wouldn't have to be scared of falling, he could keep up with our younger brother, Nicholas and he could pig out on junk food once in awhile - stuff that everyone deserves to do. All I want is for Duchenne to be cured." – **Joshua Burgess**



Joshua & his brother, Jacob



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

During March I contacted hundreds of people to see if they were interested in helping spread the word about Duchenne. Some moments became frustrating – for every hundred emails I would send, I would get only a few replies in return. To make matters a little more stressful, I never heard back from more than half of the people who originally said yes.

That's just life though, isn't it? There always seems to be some kind of hiccup, something trying to bring you down, trying to make you give up... That's when you say a little prayer, refocus your mind and try just a *little* harder. Every time this happened, like clockwork, I would receive an email or message that reminded me why this project was so important, and why I needed to keep moving forward.

Having Addison Station participate in this project is an honor. Not only are they insanely talented, but the amount of compassion they have is overwhelming. I cannot thank them enough for investing their time and energy into helping us spread awareness of Duchenne. These are the people we need on our side – they will help us change the Duchenne outcome. In total, we have received well over 79 videos, and we've decided to keep the 79 Days of Duchenne going much longer than just 79 days ;) Together, we *can* Cure Duchenne! – **Sarah Burgess**



7/9

Addison Station kicks off the 79 Days of Duchenne! Watch their amazing video at: www.smarturl.it/79Days

UPCOMING VIDEOS THIS WEEK!



7/10 Koli Cutler



7/11 LJ Lethal Junkie



7/12 Elan Noelle



7/13 Alyssa Kelly



7/14 More Like Me



7/15 Animal

INTERVIEW WITH THE BAND

For social media & information about Addison Station, please visit:

www.smarturl.it/79Days

Why did Addison Station decide to participate in the 79 Days of Duchenne project?

Addison Station: We were really impressed by Sarah's vision and we thought she was putting together something really beautiful and unique. As artists, we are always looking for opportunities to be part of projects that we believe will stand out and make a cultural impact.

Have you ever heard about Duchenne before the project?

AS: Admittedly, no. We actually watched several videos on YouTube once we agreed to be part of the project so that we could have a better understanding of the disease and what the families of those afflicted with DMD go through.

"I WOULD GO TO THE ENDS OF THE EARTH TO HELP SAVE MY BROTHER ANY OUNCE OF PAIN - HE'S MY BEST FRIEND"

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

AS: Addison Station believes in the importance of positive role models. I think all artists (musicians, actors,

ADDISON STATION

Jeff Kenniston, Trent Gerbers, RC Roberts, Vince Caiafa, Kenny Razz



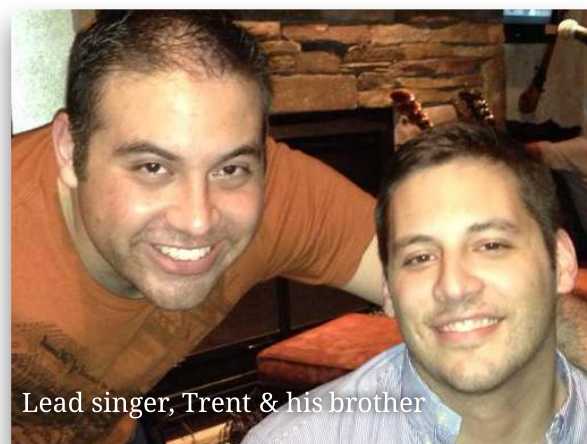
painters, etc.) try to capture the world around them with a unique perspective, which doesn't always result in a positive message. That being said, we understand that because of our unique position as artists, we have the ability to influence those around us and we believe it is important to stand up for our convictions.

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

AS: The first show ever performed by lead singer Trent Gerbers and rhythm guitar player Jeff Kenniston was a benefit show for HIV/AIDS research when they were 16 years old. The roots of Addison Station run deep with charitable work and we try not to stray too far away from our ability to help those in need. As we get older and start settling down, money certainly becomes an issue that needs to be discussed but we never try to make that the primary focus. Helping other people is worth more than any paycheck.

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

AS: I would go to the ends of the earth to help save my brother any ounce of pain. He's my best friend and if he were sick then I guess I'd find out how much money I could put on my credit card, how many favors I could call in, how many miles I could walk going door-to-door raising awareness, and most importantly, how many prayers I could send up to God to give me and my family the strength to get through it no matter what the outcome may be.



Lead singer, Trent & his brother

INTERVIEW CONTINUED...

When your video is released, a lot of young men with Duchenne will look up to you – What advice do you have for them? What hopeful words can you give to inspire them?

AS: Be kind to each other. You NEVER know what someone else is going through until you get into their lives. The differences between people should be the strength of our society, not our weakness. Trust in the people that love you and try to find the good in everyone. Finally, don't be afraid to fail. Sometimes we try our best and we still don't succeed. Those moments hurt, but they make us stronger, better people. Continue to go into every situation with hope and optimism and you will find that other people will gravitate towards your inner light.

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

AS: After learning more about the disease and reading more about Sarah's story we decided to listen to her various versions of the song and wait for inspiration. We each took a week to prepare notes about the things we wanted to do musically and then we got together to rehearse. The first time playing through the song, I knew we had something special. As a group we were able to do some things that we had never done before and I felt we

were able to come up with something original, while still maintaining the feel of Sarah's original arrangement. I was very happy about how the video turned out.

What is special about Addison Station? What are your plans for the future?

AS: Addison Station is special because we are friends first. Music can be a tricky business and it can be difficult to navigate through the music business while maintaining a close bond to your bandmates. We don't have a manager or booking agent so we do all of that work ourselves, which means we have to rely on each other to do our part musically and from a business standpoint. It can certainly be difficult, but we always make the time to be there for each other and we try to spend time together in a fun way outside of the band. The future of Addison Station is an open-ended topic. We are continually writing new music and trying to fundraise so that we can record our songs. Right now we are just enjoying the ride while trying to make some headway into the music business.

Any other unique quirks or hidden talents?

AS: Our rhythm guitar player is actually an incredibly talented saxophone player. He received his music degree from Central Connecticut State University and he played saxophone throughout the program. Our lead

singer published a book in 2009 called, The Last Hero Left. Our bass player

"TRUST IN THE PEOPLE
THAT LOVE YOU, AND
TRY TO FIND THE GOOD
IN EVERYONE"

recently completed The Tough Mudder, which is a grueling obstacle course for charity. Our drummer is the most stylish human being on the planet. He wears suits everywhere and to everything. And our lead guitar player is the biggest sports fanatic ever. He lives and breathes the New York Mets and Giants.

Will you continue to spread awareness about Duchenne?

AS: Yes, of course we will. We will continue to spread the word in any way that we can. We love playing shows and making videos to raise awareness, and with leaders like Sarah, I'm sure there will be plenty of opportunities for us to do our part.

Fill in the blank with your own word or phrase!

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

AS: Together, we will See Tomorrow!



My name is Chase and I have a good relationship with my brother Brayden, he is my best friend! We play Legos and video games together. I will always be there to help him and hold his hand so he doesn't fall. I love him more than anything in the world. I stay positive by talking to him and playing with him. I can help him and other boys by raising money to help find a cure, and telling everyone I know about Duchenne.

THE OBSTACLE IN OUR PATH

THANK YOU!!



Thank you so much to everyone who put any amount of time or effort into bringing the 79 Days of Duchenne to life. This project needed many hands, and many hands were graciously lent. I appreciate each and every one of you from the bottom of my heart. Thank you for caring about my brother and every other person affected by Duchenne – thank you for making their lives important. Thank you for being a voice and helping us spread the word about Duchenne.

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

SPECIAL THANKS



BRIAN & KAREN WOLF



DEBRA MILLER



KAREN HARLEY



DREW HOYER



ANTHONY DEVERGILLO



SUSIE ARROYO

MARK BEMBNOWSKI

A super-big thank-you to my husband, Mark. I don't think anyone really realizes how much you do behind the scenes and how many hours upon hours of work you do. You never complain when I give you a mile-long list of programming work... You just get it done, and you create something amazing. Thank you for working so hard and never once expecting anything in return – this project wouldn't have happened if it wasn't for you. Thank you for loving and fighting for my brother. Thank you for being the absolute best, most awesome geeky husband in the world!

– Love, Sarah

In ancient times, a king had a boulder placed on a roadway. Then he hid himself and watched to see if anyone would remove the huge rock. Some of the king's wealthiest merchants and courtiers came by and simply walked around it. Many loudly blamed the king for not keeping the roads clear, but none did anything about getting the stone out of the way. Then a peasant came along carrying a load of vegetables. Upon approaching the boulder, the peasant laid down his burden and tried to move the stone to the side of the road. After much pushing and straining, he finally succeeded. After the peasant picked up his load of vegetables, he noticed a purse lying in the road where the boulder had been. The purse contained many gold coins and a note from the king indicating that the gold was for the person who removed the boulder from the roadway. The peasant learned what many of us never understand. Every obstacle presents an opportunity to improve our condition.

READY TO HELP?

Please email me even if you're unsure on how to help – there are many areas and ideas that need an extra hand or two!

Have a talent? Are you creative? Email me!

Email: Sarah@TheRunAwayProject.org

