

“The Hope”



1Q 2014 Newsletter for One Breath, One Hope Inc.

OBOH Visits the TODAY Show!

On February 28th, two members of One Breath, One Hope Inc. braved the sub-zero temperatures of New York City to stand in the crowd outside of the NBC TODAY Show Studios at Rockefeller Plaza! Aside from trying to see Matt Lauer, Meghan Montana and Sara Manwaring were hoping to gain some exposure for National Rare Disease Day, which, until this year, was not an officially recognized day of awareness in the US. They were hoping to get some air time for their signs and also pass on some information to the crowd about OBOH and the rare disease community. In the US, a “rare” disease, is a disease the effects less than 200,000 people. Today, there are more than 6,700 defined rare diseases that effect between 25-35 million Americans. That means about 1 in every 10 people is afflicted with a rare disease, not so rare when you think in those terms. The OBOH team got to the plaza very early and were able to stake out some prime real estate



CEO Meghan Montana and Founding Member Sara Manwaring stand outside the TODAY Show studios in NYC advocating for Rare Disease Day.

right in front of the TODAY Show window. They proudly displayed the brand new banner (thank you *Signs by Tomorrow!*) along with a great Rare Disease Day sign made by Sara and her family including several pictures of kids with PCOD. They handed out pamphlets to the crowd, and even Savannah (a TODAY Show anchor) took one! Many of the shots that panned the crowd showed our signs and our Facebook page received over a thousand hits, it was a great day! The OBOH family had an amazing time telling our story and raising awareness, and as the year goes on, we are looking forward to many more opportunities like this one.

If you would like to be a part of the next big adventure, please let us know by contacting us at info@onebreathonehope.org

or by visiting our Events page on our website www.onebreathonehope.org.

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Rare Disease Day...

This year on Friday Feb. 28th, a bipartisan resolution was passed that was led by U.S. Senators Sherrod Brown (D-OH) and John Barrasso (R-WY) that officially recognizes the last day of February as "National Rare Disease Day" to raise awareness for the 30 million Americans living with rare diseases or disorders.

What an amazing landmark for the rare disease community!

NY State of Mind...

When Sara and I jumped on the short 2 hour train ride into Grand Central Station on Thursday evening, we were not sure how we were going to be able to make it through the next day. It was a heady mix of excitement and nerves as we arrived in the city around 8:00pm and were greeted by absolutely frigid temperatures and wind. It was going to be tough morning if this kept up. We took a cab to the hotel room and relaxed for the night, only going out once to visit Shake Shack which was a fabulous pick for a late dinner. We went to bed right after hearing the weather report for the next morning. 15 degrees with a below zero wind chill. Oh boy. Sara and I both woke up at around 5:00 am, put on every piece of clothing we had, and headed out the door with our signs in hand. We again took a cab instead of walking to try to conserve the heat in our bodies and arrived at Rockefeller Plaza just as it was beginning to get light out. Being avid TODAY Show fans, we were really feeling excited, to be there together, and to be advocating for something we are both so passionate about made it even better. There were more people out at the show that day than we had thought there would be and we had to slide our way in a few places to get our signs more visible. All those nights of pushing through club crowds in our college days was paying off! As the show started it was such a surreal feeling of actually being there watching the people you see everyday on your TV screen. The women were gorgeous and so friendly, and Carson was hysterical when he was talking with the crowd. The only downer...NO Matt Lauer. Sara and I alternated the signs, and screamed like crazy when it was time for us to be on. The texts and the Facebook posts started pouring in, our phones were going crazy, people were really seeing us! How exciting! Our banner and our sign out there on national television for Rare Disease Day...who would have ever believed it! We got to shake hands with most of the anchors Savannah took one of our pamphlets, and Tamron even signed one for us to bring home! As the morning began to wrap up, people started leaving and we really began to feel the cold in our bones, or more accurately started losing feeling in our legs. We decided to pack it in and head back to the hotel to thaw out. All in all, the day couldn't have gone any better, we got some great exposure and with any luck we touched a few people's lives. Letting them know they are not alone, there are people who care, and there is always hope. Thank you to all of you who have, and continue to support us on this journey!



Sara and Meghan taking a selfie by the TODAY Show arch!



Savannah and Carson doing the morning news!



Tamron Hall (above) auto-graphing an OBOH pamphlet for us!



Meghan Montana

CEO - One Breath, One Hope Inc.

In The Spotlight...



Angelina doing her vest.
Camo for this PCD warrior!

Meet Angelina! She is one of our tough PCD warriors and the main reason behind why One Breath, One Hope was formed. Angelina was born 6 years ago and had no signs of disease when she was born but soon battled some health problems that were not so normal. She had many ear infections, was diagnosed with RSV only a short time after birth, and started getting pneumonia before age 2. As the next couple years went on, visits to the doctor and emergency room were increasingly common to help with breathing issues, recurring pneumonia, and flu like symptoms. Angelina, along with her family, went through countless sleepless nights filled with violent coughing spells and vomiting. With very few answers and even less relief from symptoms, they experienced months of hopelessness and confusion as failed treatments and unclear test results continued to give no answers as to what might be causing the issues. Finally, after all other testing had been exhausted, and no clear reason for the continued illness had surfaced, their pulmonologist performed a biopsy of Angelina's lung cilia to test for a rare genetic disease called PCD. It was a long 6 weeks to receive the news, and when a positive result came back, it was a mix of fear of what this now meant, and relief to at long last have a definitive diagnosis, and hopefully some kind of treatment plan. Now, almost a year after the diagnosis, things are beginning to look up. Angelina is being seen by the completely amazing Doctors and Staff at Boston Children's Hospital, which has a specialized PCD center. Together with the team of Doctors and Nurses, we are learning

more and more about her specific case. She has gone through many long drives, blood draws, procedures, and prodding and through it all, she still has kept her fighting personality and brilliant smile. She has made lots of friends at school and is able to do homework on her tablet when she can't be in class. This road may be a long one, but she's a fighter and we are so proud of her!

If you or your child would like to be featured on our "In the Spotlight" section for the next newsletter, please email info@onebreathonehope.org!

Kickoff Success...

On Saturday, November 16th, 2013 we held our first ever event for the One Breath, One Hope organization. We had a great pasta dinner prepared lovingly by your OBOH board members and friends, and were able to raffle off some

amazing prizes! Because of each and every one of you who sent in notes of encouragement, money donations, and raffle items, we were able to almost double our goal for the evening! We cannot thank you all enough and look forward to all that we can do together for the PCD and Rare Disease community!

Holiday Hope...

Through your generosity, OBOH was able to send \$300 each to two very special families struggling with PCD and other rare diseases this holiday season. Thank you for your continued support, you are making a real difference in the lives of so many!





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Our Mission:

One Breath, One Hope Inc. is a Connecticut based non-profit organization serving the PCD (Primary Ciliary Dyskinesia) and rare disease community by providing financial support for treatments, advocating for medical research, and helping families get in touch with the information and support groups they need.

Visit Us Online...

Website: www.onebreathonehope.org

Friend us on Facebook: One Breath, One Hope Inc.

Follow us on Twitter: @IbreatheIhope

Meet the OBOH Executive Board



From left to right: Amy Hermann—Director of Communications, Jennifer Marrero—Fundraising Director, JoAnn Kelly—Treasurer, Barbara Jarvis—Secretary, Meghan Montana—Chief Executive Officer