

BRINGING ATTENTION TO SDS

SuperNathan

by Michelle Grenell

Back in August when it was time to celebrate Nathan's birthday, we didn't want to have a party because we had surgery that week. The exposure to germs was too high to risk it. When the fire department reached out to have us out, we graciously accepted! We were all given the grand treatment, but Nathan was most excited to ride in the front of the fire truck. His new BFF, Fireman Brad, proudly put on his Be the Match bracelet and swabbed for the news cameras. Since then, over 50 people have reached out to us personally or through the website to swab in honor of all of the Shwachman-Diamond fighters who may need a transplant someday.



<http://fox17online.com/2017/08/23/muskegon-twp-firefighters-help-boy-with-rare-disease-celebrate-birthday/>

Healing Henley

by Jess Johnson



After Henley was diagnosed, we were connected with Be the Match. I remember them calling and asking if we would be open to sharing Henley's story with the media. For a moment I thought - no I don't want to. My husband is a very private person and I spent nearly 13 years as a police officer, which left me NOT liking media attention. However, after that moment of considering saying *no*, I realized that by sharing Henley's story we could maybe help someone else. So, from that point forward we decided as a family that we would say *yes* anytime we were asked to share Henley story. Specifically, we feel very motivated to grow the bone marrow registry and help everyone who needs a match find theirs. Most recently, an article was published across the state of North Dakota about Henley, and as a result, we were able to connect with a 58-year-old male who was diagnosed genetically as SDS at MAYO clinic in Rochester, Minnesota in 2013. He saw Henley's story and wrote us a letter. He did not know about the foundation or about the Shwachman-Diamond Registry.

<http://www.valleynewslive.com/content/news/One-in-a-million-North-Dakota-girl-in-desperate-need-of-a-bone-marrow-transplant-456774953.html>

Garden of Dreams

by Stephanie Gregoretti

Thanks to the Garden of Dreams Foundation, Anthony Gregoretti had his dreams come true! Anthony who goes through so much himself wanted to cheer up one of his great friends who was going through some serious medical complications. Anthony would pray that his friend could get out of the hospital, play hockey with him again, and watch a Ranger game together. These boys are diehard Ranger fans since their days of preschool together. When the Garden of Dreams and the New York Rangers heard about the boys, they wanted to do everything they could to help, and boy did they! Both of our families were invited to the season home opener at Madison Square Garden back in October; our families received the royal treatment, getting to meet every single player, watching practice from the penalty box, watching the game in a catered suite with a visit from Adam Graves, to ending the night on the actual ice! It was a night we will never forget. Then, in November, both of our families were invited back for Hockey Fights Cancer Night where the boys were asked to do the ceremonial puck drop! It was another incredible night! They had their own dressing room and another shot to stand on the ice. They walked the red carpet to drop the puck while a video collage of their friendship was played on the big screens! We could never thank enough all who were involved in creating memories to look back on when times get tough.



<https://www.youtube.com/watch?v=LkT5ASJ1EFk&sns=fb>