

Unprotected People: #101 Meningococcal

In Memory of Ryan Milley

The Immunization Action Coalition (IAC) publishes Unprotected People Reports about people who have suffered or died from vaccine-preventable diseases. This is the 101st in our series.

Meningococcal disease is a serious, potentially fatal bacterial infection that strikes nearly 3,000 Americans annually. In particular, adolescents and young adults are at increased risk of getting meningococcal disease. The disease strikes quickly and has severe complications, including hearing loss, brain damage, limb amputations, and, in too many cases, death.

In this report about meningococcal disease, Frankie Milley, founder of Meningitis Angels, shares the devastating account of the death of her only child, Ryan Wayne Milley, with the Immunization Action Coalition.

My name is Frankie Milley. This is my story of the needless death of my only child, Ryan, to a vaccine-preventable form of bacterial meningitis. Ryan had all of his required vaccines. He did not have the one that could have saved his life because it was not recommended. In fact, it was not even talked about.

Today, it is, thanks to the tireless work of those parents like me who refuse to let other kids die needlessly from meningitis or any other vaccine preventable disease. No child in America should die with a vaccine-preventable disease.

Ryan had just graduated high school, reached his pro-golf status and realized the love of his life. It was Sunday afternoon, Father's Day, June 21, 1998. Bob and I had a beautiful morning together, attended church and met Ryan at a local restaurant for lunch. We laughed and talked and Ryan gave his dad a shirt he really liked himself. He made sure his dad knew he would want to borrow it. We all parted, and Ryan went back to work at the golf course.

We visited with friends and returned home at about 6 p.m. Much to our surprise Ryan was home. I walked down the hall to his room and found him lying in the bed. He said his ears hurt. I felt his head and it was warm. His temperature was 102°F. After many years in the medical field and the last few in EMS, I asked him all the questions you would ask to check for meningitis. He had no headache, no stiff neck, no nausea, no diarrhea, no sore throat, no joint pain, he just had an earache. I gave him ibuprofen and his fever seemed to come down.

He slept, and I checked on him throughout the night. Again, repeating the questions I had asked before. His fever was up and down with medication. During the night he got up and got a drink of water from the refrigerator. His dad asked him if he was okay. He looked at his dad strangely and said, "Yes, Dad, I am fine." As I checked on him throughout the night and still his fever was up and down but never normal. I would later find that unrelenting fever can be a true sign of bacterial meningitis. You should know Ryan always had an amazingly high tolerance for pain. His appendix had ruptured on his 18th birthday, just eight months before, and he never complained once.

The next morning at 8 a.m., I called Ryan's doctor and made an appointment for later in the morning. As I hung up the phone Ryan came into my room. In the dim light, I could see what appeared to be brown spots on his upper legs and around his waist. I thought he might have diarrhea and told him he should go and take a bath. He said, "Mom, I just got out of the shower."

I turned on the light and saw petechiae (hemorrhaging under the skin). I could see the blood vessels rupturing right before my eyes. I called

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the doctor back, and told him I was sure Ryan had meningitis and he said to get him there immediately.

I helped Ryan get dressed and we left for the hospital. As I drove Ryan was in and out. He was talking out of his head. I kept telling him to hang on baby, talk to me. We are almost there. I drove 17 miles in less than eight minutes.

We arrived at the hospital which was also my doctor's office. As we got out of the car Ryan's shoe fell off. I told him to leave it. He said, "No, I want it on, Mom."

I bent down and put my son's 14 1/2-inch shoe back on his foot. As we approached the building Ryan said his legs were numb.

I said, "I know honey, just keep going." As we got into the elevator, he collapsed.

He said, "I can't feel my legs."

I carried my 6-foot 2 1/2-inch beautiful boy into the doctor, screaming for help.

Ryan was placed on a gurney. He asked me, "Mom, am I going to be okay."

I did not answer.

I knew my beautiful boy was in trouble. His vital signs were off the chart. In the emergency treatment room, he began to vomit blood. The nurse said, "Ryan, you are vomiting, honey, we are going to put in a stomach tube."

He said, "I am sorry."

She began to weep and said, "My God, he is apologizing. What a beautiful boy you have."

Ryan's dad arrived. A Foley was placed in Ryan and there was blood filling the bag. The stomach bag was filling with blood. Ryan said, "I am cold." His dad was rubbing his feet. Doctors and medical staff surrounded our son as we stood in horror. Me knowing what was to come and Bob afraid of the unknown. I began to pray God would do what was best for Ryan. This had to be the hardest thing I ever did or would do for I knew he would soon leave this life. Blood began to come from Ryan's eyes, his ears, his mouth. Four spinal taps were performed. My God, how much could my sweet boy endure. Ryan

was dying.

Bob was trapped between the wall and the gurney where Ryan lay. I went toward Bob to get him out of the room so he would not see advanced life support (ALS) begin. Ryan's heart stopped. Bob was reaching for Ryan and telling him over and over again, "Daddy loves you, baby boy. Daddy loves you, baby boy." Before the ALS began, Ryan's heart started on its own and Ryan rolled his head in his dad's direction and said, "I know." The medical staff was in shock at what they had seen. They later gave us the electrocardiograph to prove it. Ryan's heart stopped again. ALS began and the team worked on Ryan for 45 minutes.

Bob and I waited outside the door. Someone brought a chair for me, and I laid my head against the cold door as Bob stood, hands on my shoulders, praying. I had to know when my baby was gone.

We heard the doctor ask God to help him save Ryan. A nurse came from the intensive care unit (ICU) and said, "I will be Ryan's ICU nurse." I said, "Ryan is not going to ICU." She began to weep and knelt at my feet and began to pray as did everyone in the emergency room.

On Monday, June 22, at 10:15 PM, at age 18, Ryan was declared dead. Our beautiful perfect boy, the light of our life, the reason for my existence had gone from perfect health to what almost seemed to be a science fiction condition in less than eighteen hours. He was dead.

His body then had to endure an autopsy. My beautiful boy would be cut, dissected, probed and then taped back together. The medicinal examiner said, had Ryan lived he would have lost all four extremities, been blind, deaf, had extensive brain damage, total kidney failure and his adrenal glands were ruptured. Otherwise he was perfect, no cavities, no illness, without deformities. A perfect child except what this vaccine-preventable devil had done to our boy.

I praised God for taking him home but he should not have gotten sick to begin with.

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The next days were filled with people, tears, laughter, confusion, shock, fear and most of all just hard grief. How could this be?

Ryan's funeral was over four hours long. It was a celebration of his short life, love and the Lord. The funeral director said he had quit counting at 500 people in attendance and there were at least that many more not counted.

After Ryan's friends and our family began to leave the reality of what had happened sat in. I began to look for reasons why this horrible disease had taken my boy. I found there was a vaccine that could have prevented it. Our military had gotten it for almost thirty years but not our kids. How could this be?

I went with four other parents to the research and development center of the company who made the vaccine and educated myself. We then, along with other parents, started education and advocacy to make sure college freshmen were immunized. Later I would serve as a stake holder on the Centers for Disease Control and Prevention's Advisory Committee on Immunization Practices committee on recommendations for 11-year-olds through college freshmen to receive the meningitis vaccine.

I began a nonprofit organization called Meningitis Angels, working with other families and survivors of this disease. Angels now has over five hundred members across the United States and some 50 abroad. I began to realize we were not immunizing enough kids for the required vaccines and not only were kids dying from meningococcal meningitis but also pneumococcal disease/meningitis, pertussis,

hepatitis B and influenza. I decided my fight had to expand and make sure kids were not only vaccinated against bacterial meningitis but were vaccinated against all of the diseases which could cause debilitation and death. So began my mission.

As of today, I have helped to write, advocate for and pass over 18 laws across the US. My heart screams kids are still dying today in spite of all of the work. As more and more parents opt out of vaccines, this number will increase. The loss of life will be immeasurable.

Ryan's name should have been on college graduation and wedding invitations, on birth announcements but it isn't. It is on a piece of granite in a cemetery. With his death Bob and I will never be called Dad and Mom again, ever be the parents at his wedding, ever hold a grandchild or have his comfort in our old age when one has to leave the other.

One simply has to walk around an old cemetery to understand the value of vaccines. I have to simply look within the pain and memories of my heart to know. I believe if children had a voice and could choose between vaccine preventable diseases and a vaccine, they would choose vaccine. But they don't have a voice. We have to stand up and be that voice for children, proven science and reason, and one of life over death and debilitation. Disease kills, vaccines save lives.

Frankie Milley, Ryan's mom

For more information visit [Meningitis Angels](http://MeningitisAngels.org).