

## Sound Advice

*This is an edited transcript of a telephone interview recorded in May 2009.*

Frankie Milley is the mother of an only child, Ryan Milley, who died from a vaccine-preventable form of meningitis when he was a teenager. Frankie Milley is the founder and executive national director of a non profit organization called Meningitis Angels. The organization educates on meningitis, vaccine preventable diseases and the vaccines to prevent them while offering support to those affected by them.

**Q:** Tell us what happened to your son, Ryan.

**Milley:** On Father's Day, Ryan became ill with a fever and an earache. Through the evening, I would give him Tylenol and ibuprofen, but his fever never really came down, and later on, I would find out that that was a really definite sign of bacterial meningitis – unrelenting fever. But through the night, off and on, we kind of watched over him, much to his dismay because, at 18, most boys don't want their mothers, like, hovering over them. In early morning Ryan got up, and he was still just not feeling well, still running a temp, so I called his doc, our doctor, our family doctor. I called our family doctor and said, you know, "Ryan is running a temp. He's complaining with his ears and, you know, I think I just need to go ahead and bring him in," so we made an appointment for 10:00.

Ryan came into my bedroom about 8:00 that morning, shortly after I hung up from the doctor and, in the dim light, I could see something that appeared to be spots and some sort of a rash on his body, so I turned on the light, and I could literally see his blood vessels rupturing under his skin. He had places on his body that looked like hickeys, that looked like bruises, that looked like strawberry patches, but they were purple. He had a little pinprick looking rash on various places, and at that moment, because I'm trained in EMS, I realized Ryan had bacterial meningitis.

So I called my doctor back because we live in a real rural area. I just wanted to – I just took Ryan to the emergency room myself, so I called my doctor back and told him, I think Ryan has meningitis, and he said get him here as soon as possible. So I got Ryan dressed, and he – as sick as he was, he argued with me about what he wanted to wear, which I thought was really strange, but we got him dressed. I got him into the car, and on the way to the hospital, Ryan's heart rate – I kept taking his pulse, and he was kind of fading in and out on me. He was talking out of his head a little bit. He would just kind of just be really still all of a sudden, and I had my hand on his pulse, and his pulse rate was over 185 at that point.

And I drove 17 miles in 5 minutes, and we got to the hospital, and Ryan was 6' 2.5" and wore a size 14.5 shoe, and as I got Ryan out of the car, he told me. He said, "Mom, my legs are numb." And I said, "I know, honey. Just come on. We've got to go fast," and his shoe fell off. His sandal fell off in the parking lot. And I said, "Just leave it, Ryan." And he said, "No; I want my shoe on." I knelt down on the ground and put his shoe back on his foot, and got him to the elevator. And there were people going to get on the elevator, and I said, don't get on here. He has meningitis. We got on the elevator, and Ryan said, "Mom, I can't feel my legs," and he

collapsed. And I carried my 6' 2.5" baby boy into that emergency room screaming, "Somebody help me. He has meningitis."

We got Ryan on a gurney, and Ryan looked at me and he said, "Mom, am I going to be okay?" I never answered because I really knew that Ryan probably wasn't going to be okay at that point. We got him on the gurney. They put him in a treatment room, and I was right there with him the whole time. We were never asked to leave. My husband got there shortly after we got into the treatment room and went on the other side of Ryan's gurney. And Ryan told his dad he was cold, and Bob kind of was rubbing his feet as they were getting warming blankets for Ryan. And I just kind of stood in the corner. Looking back, I think I must have been in shock. It was like I was there, but I wasn't. I was just watching it all through a window. It was just a really strange thing.

And they did four spinal taps on Ryan before they could really get anything substantial, and the spinal fluid was just like a bloody fluid. It wasn't milky. Ryan had meningococemia, so he had not yet developed full-blown meningitis. He just had sepsis.

He began to vomit blood, and the nurse told him. She said, "Ryan, honey, we're going to put a stomach tube in. You're vomiting." And he looked at her, and he said, "I'm sorry." And she started crying. She said, "My God. What a good boy you have. He's apologizing to me. I can't believe this."

They put a Foley catheter in, and there was pure blood coming from Ryan's kidneys, bladder. We began to see bloody fluid coming from his ears, his eyes, his nose, his mouth, and he was turning purple, and they were giving him massive amounts of antibiotic. In fact, the nurse looked at me and she said, "God, this is a lot of antibiotic." And I said, "I know." But, you know, they were fighting for Ryan's life. Ryan was dying, and they were doing everything they could to save him.

About two hours after we got to the ER, Ryan's heart stopped beating, and Bob was trapped between the gurney and the respirator and the wall, and I was trying to get to him to get him out because I didn't want him to see the advanced life support, and CPR that they would be starting on Ryan, and as I was going toward Bob to get him out, he was telling Ryan, "Daddy loves you, baby boy. Daddy loves you, baby boy," reaching for Ryan. Over and over, he kept telling Ryan, "Daddy loves you, baby boy."

And on its own, Ryan's heart started beating. Everybody in there just kind of stepped back and took a deep breath, and Ryan rolled his head in the direction of his dad, and he said, "I know." That was the last thing Ryan would say. His heart stopped again, and they gave us the cardiograms to prove that because they were just couldn't believe it.

So I got Bob out, and they started – they started to try to revive Ryan. They called a Code Blue to the ER. We got outside the door, and I shut the door behind us, and one of the nurses asked if we wanted to go to the next room and wait. And I said no. I wanted to hear. I want to hear when he dies. I want to hear when he leaves.

So they brought a chair, and I sat down and put my head against the door, and Bob stood behind me with his hands on my shoulders. And he began to pray out loud. And the hospital chaplain came, and everybody came from treatment rooms, and the ER staff, and they all just stood there. They all just stood there in prayer and shock. And a nurse came from ICU, and she said, "My name is Debbie," and she said, "I'm going to be Ryan's ICU nurse." And I said, "Ryan is not going to go to ICU. Ryan is going to go home today." And she knelt down at my feet, and she started to pray, and I heard the ER doctor that was working on Ryan say, "Dear God, please help me save this child. Please don't let him die." And then a few minutes later I heard, time of death 10:53 a.m.

They came out of Ryan's room, and he said – the doctor said to me, "I'm so sorry. I tried to do everything I could." And I said "Thank you," and he started crying. He said, "My God, nobody has ever thanked me when their child died."

So they let us go in there to see Ryan, but they wouldn't let us touch him. They wouldn't let me kiss my baby. They wouldn't let us hold him. We just had to look at him laying on that steel table. And they thought he was still contagious, which I found out later that was just crazy too, another myth about meningitis.

So then the security person came to us, and a justice of the peace, and she said Ryan has to have an autopsy, and I said, why. And she said because he died in less than two hours. He was a perfectly healthy 18-year-old male, and he died, and they had to do an autopsy to prove, you know, that there was nothing else involved. I mean, what killed him? What took his life? Because he didn't really have, you know, he never had the classic signs of meningitis. He could still put his chin on his chest ten minutes before he died, so ... but we would find out later with meningococemia, , they don't always have the stiff neck and the headache because it's not in the meninges at that point. It's in the bloodstream. The bacteria enter the bloodstream, and when that happens, there is less than 48 hours, they believe, from the time of exposure to death or debilitation, possibly. So there's no time for them to even develop the classic signs, and that's why it's so important that people understand that sometimes when kids get meningococcal, that they're not always going to develop that stiff neck or that headache. They may have other signs and symptoms that appear long before that that are life threatening. Ryan went from being totally healthy to having blood coming from every orifice of his body in less than 14 hours.

**Q:** Could Ryan's death have been prevented?

**Milley:** Yes. I found out within 48 hours after Ryan died there was a vaccine that could have prevented Ryan's death, and no one had ever told me about it. I'd been in the medical field for over 20 years, and I didn't know that. I knew about meningitis. I knew that it could kill you. I didn't know that it could debilitate you like I do now. I didn't know there was a vaccine to prevent it, but yet our military had been getting it for over 30 years, but it was never offered to our children.

You know, when Ryan died, I became really angry, and I said, first, you know, I grieved. Then I got angry. Then I got busy, and I got angry because I felt like, as a parent, and Ryan, Ryan was failed by the pharmaceutical company that had developed the vaccine and never really done

enough education on the disease and the vaccine to prevent it. I was mad at – angry with the medical profession that didn't seem to think that that disease was enough to really educate better on or worry about possibly the fact that we needed to be immunizing kids for it. I was really angry. Ryan did not have to die. He should not have died.

**Q:** What vaccine protects against meningitis?

**Milley:** There's two. One is called MedImmune, and one is called Menactra. There are new vaccines on the horizon that will be out sometime this year or in the next year, and that will cover the same strains of the bacteria.

**Q:** Why did you form the group Meningitis Angels?

**Milley:** Well, when Ryan died, there was no place to go. There were no organizations really for me to talk to. There was nobody out there that really understood what I'd gone through. A lot of the medical professionals couldn't answer the questions that I had about the disease and Ryan's death. Bob and I, this was our only child, and all of a sudden our child, our perfectly healthy child had died, and no one could really explain to us why or anything, and we had no place to go. We just felt alone and fearful.

And so, I wanted to create an organization that people could go to for education and awareness, but I also wanted to make sure that this didn't happen to other kids, and so we formed Meningitis Angels. And it became not only a support group, but a charitable organization, and we serve kids that are victims of bacterial meningitis. You know, we've actually provided hearing systems when there was no insurance to pay for such, and special nursing care, and we've helped with ... programs and computers for kids that are blind or have limb amputations, and we have hospital visitors, and we offer seven international support chats a week, and we have message boards. I just wanted to make sure that there was a place for people to go, number one. But most of all, Meningitis Angels was started to educate the public, the healthcare profession, the government, the policy-makers, everybody on the disease and the need for a vaccine to prevent it.

**Q:** Do you think parents and teenagers understand how dangerous this infection can be?

**Milley:** Absolutely not. I honestly don't believe that many of the healthcare providers understand how dangerous this disease is and how prevalent it is. I just don't. We see more – we see kids all the time. We see infants and children and teens and young adults being misdiagnosed all the time because the symptoms are so similar of that of a possible virus or a bacteria, the flu, so it's easily mistaken.

And right now, the only way you can diagnose it is with a spinal tap, unless you have signs of sepsis, or you have a doctor possibly, you know, in our area, our ER doctor, our head of our ER is a military doctor, a retired military doctor. So he saw a lot of it, so when he has someone come in that presents those symptoms that they're in the age group, he just goes ahead and treats with antibiotics, kind of a better safe than sorry. But because there's not enough education and awareness on it, I think that we have to be more proactive with recommending and requiring the immunizations to prevent it, and then we don't have to worry so much.

**Q:** What frustrates you about the public discourse on immunization?

**Milley:** I think the thing that frustrates me the most about the public discourse on immunizations has to be my fear factor, my fear that those people who are anti-vaccine people, and get on and have media at their fingertips are allowed to just say anything. My fear is that as parents listen to them, especially young parents who don't know any better or aren't educated on the diseases that we have that are prevented by vaccines. My fear is that parents won't understand that their children still have to be immunized. And they're going to listen to these people, and their kids are going to start to die or become debilitated from vaccine preventable diseases, and possibly we're going to see epidemics like we've never seen before.

**Q:** What advice do you give parents who are worried about vaccines?

**Milley:** Well, first of all, if a parent comes to me and says, you know, I'm really hesitant about vaccines. You know, I'm really nervous about them. I just don't know if I want to immunize my child. First of all, I tell them about Ryan, and then I tell them about other meningitis angels within our group who are debilitated or who have died. And I tell them that the science is not there to support what the anti-vaccine people are telling them. That vaccines are the most effective preventative that we have for disease.

I tell them what one simply has to walk around an old cemetery to see the value of vaccines because if you walk around old cemeteries, you – like really old cemeteries, over 50 years old or more -- you see many, many children, infants, children, young adults buried there. And my guess would be that probably 90 percent of them probably died from some vaccine-preventable disease. Things that we didn't have vaccines for 50-plus years ago, but now, because we do, they don't have to die, and a vaccine is much better than the outcome, the possible outcome of disease that they prevent.

And I truly believe, I believe that if children had a voice and a choice, and they could choose between getting a shot or getting a disease that could cause them to be seriously debilitated or even die, they would choose a vaccine. But they don't have that choice. Parents make that choice for them. And, sadly, to refuse could be a bad choice. So I believe that people like myself and the healthcare providers, policymakers, CDC, ACIP, I believe we have to be that voice. We have to be that voice for children to protect them from deadly disease. We have to step up and be willing to stand the course against the anti-vaccine moment, and let parents know how important it is to vaccinate their children.

And I also believe that you can put as many experts on a stage with people that are in places, in positions to be in front of the camera all the time. You can put experts up there with a mother who claims her child got autism from a vaccine. You can put those experts up there all you want to. But nobody is going to listen to that. They're not going to listen to experts. They're not going to listen to government. But you know what, if you put another mom on that stage with that mother, another mom like myself who is very strong in their belief and does have the scientific data and the proof to back up what we're saying. I can prove what took Ryan's life. I have hundreds of mothers who can prove what left their children with seizures and limb amputations

and organ failure and blindness and deafness. We just both deserve the opportunity to get up there and tell our side and what we believe and what we know.

And I believe that if we can do that, if we can get parents like myself in the media face-to-face, mom-to-mom with some of these people, the public is going to listen to what we have to say. When they see our children and they hear our stories, or they see our young survivors, young adult survivors with multiple limb amputations or who are blind or deaf, they're not going to care what the anti-vaccine movement says. They're going to immunize their kids.

**Q:** Is that why you are so willing to tell your story, even though it's obviously very painful for you to relive it like that?

**Milley:** It is. It is. You know, if I can tell Ryan's story, and it saves one life, as painful as it is, it's worth it.

**Q:** Can you tell us about your new campaign, Stomping Out Meningitis?

**Milley:** Our new national teen campaign is called Stomping Out Meningitis, and we're really excited about it. Our meningitis angels and some steppers from Nashville, Tennessee, from the Metro Health Department there, have all come together. We filmed a PSA, and have created brochures, and we have a new Web site, [www.stompingoutmeningitis.com](http://www.stompingoutmeningitis.com). The Web site is really geared to reach out to preteens and teens, and to educate them not only on meningitis, but also vaccine-preventable disease and preventions, including immunizations. It has personal stories on there, and they're all teenagers. They're all teenagers who have either survived meningitis or have lost someone really close to them from meningitis. There's a student library for educational purposes and references, and that page links back to CDC.

And there's going to be teen support chats and message boards where kids can go on there and ask questions and talk to other teens about meningitis and the prevention for it, and other vaccine preventable diseases as well, we're going to include eventually. So we're really excited. This is going to be a national campaign, so we're hoping to reach out through schools, health departments, immunization coalitions to partner with them to bring our message forward.

**Q:** What do you think is important for parents to know?

**Milley:** I think the most important advice that I could give to parents out there on vaccine-preventable diseases and vaccines is that, number one, the diseases are still there. They're still attacking our children. There are still children dying from diseases like pertussis, pneumococcal meningitis, meningococcal meningitis, Hepatitis D. There are children, still children dying from measles. There are children who are left debilitated by all of these diseases still out there. There are fewer than there used to be, thanks to vaccines, but as we continue to move forward with this anti-vaccine thought, and people being able to choose the schedule and choose not to vaccinate, we're going to see epidemics of these diseases come back, and the cost is going to be huge in life and health.

It's just going to be like nothing we've ever seen because there's so many more of us. We're so – we're on the move. We're everywhere. We're all together all the time. And we're going to see epidemics return to this country like we've never seen before if people don't go back to immunizing their kids, following the schedules, and doing it the right way. We're going to lose, and the cost is going to be loss of life, especially in the infants and children and teens.