BEYOND THE SCIENCE: PUTTING A FACE ON MENINGOCOCAL DISEASE

Statistics based on high quality scientific studies are essential to developing best medical practices, but they only tell part of the story.

AN IMPACT REPORT FROM A NATIONAL MENINGITIS ASSOCIATION ROUNDTABLE
Herrick said of meningococcal disease: “No other infection so quickly slays.” This is still true nearly 100 years later.

While the majority of meningococcal disease occurs as isolated cases, outbreaks—such as those that occurred recently on U.S. college campuses—bring additional challenges. College and public health officials face an often-panicked public and demands for action from concerned parents, students, faculty, staff and community members.

The National Meningitis Association brought together individuals who experienced meningococcal disease from all of these viewpoints at a roundtable in Philadelphia in January 2015 (see page 15 for details). All of their stories are presented here.

**PERSONAL STORIES:**
**BEYOND THE STATISTICS TO A DEEPER UNDERSTANDING OF MENINGOCOCCAL DISEASE**

To truly understand the wide-ranging impact of meningococcal disease, it is necessary to talk—and listen to—the people directly affected by it. That starts with survivors. Their stories feature prominently in this report.

But there are so many others who are affected by meningococcal disease. The families of those who get sick often face heart-wrenching decisions about their care. Because the risk of meningococcal disease is higher in adolescence through early adulthood, including college-age students, it is often parents facing these decisions about their own children. Based on the documented mortality rate of meningococcal disease, more than one in 10 mothers and fathers whose adolescents contract the disease will face the death of their child. Their stories are here, too.

Health care professionals fear meningococcal disease. It can be difficult to diagnosis in its early stages, and it usually progresses rapidly. In 1919, Dr. William...
I remember it was 6:00 am, and I heard the scariest sound I’ve ever heard in my life. It was my 6-month-old daughter just waking up screaming and screaming—a scream that babies just don’t scream. And I remember running over to her and picking her up, and before my hands even got to her, I could feel the heat coming from her body. And we had put her to bed completely healthy.

—Tammy Wolf, mother of Addy, survivor at age 6 months

At the NMA roundtable, physicians described a “precipitous drop” for patients within hours of the onset of meningococcal disease symptoms. This is part of what makes the disease so frightening—not only is it difficult to diagnose early, but once that early stage passes, the level of sickness can increase quickly and dramatically (see Timeline on page 7). Patients themselves describe going from feeling mildly ill to fighting for their lives within one day.

I thought I had the flu. I had the symptoms—fever, chills, nausea and severe fatigue. I went and saw my primary care doctor. He agreed with me, and he sent me home and said to sleep it off. But my symptoms worsened through that day, and into the night. I woke up—went to the rest room. Everywhere I looked I’m seeing spots, so—you know, in my mind I said, “This isn’t right. Something’s wrong.” And I called 911. The EMTs arrived and they loaded me up in the ambulance—and I lost consciousness.

—Amy Aiken, survivor at age 29

Within hours of feeling ill, Caitlin was on a respirator. After two days in a coma, she passed away from serogroup B meningococcal disease.

—Eileen Boyle, RN, mother of Caitlin, died at age 19

Heather was out walking with friends the night before and she felt weak, but she didn’t think much of it. Around 3 AM, she woke up nauseated. She tried to get up and fell to the floor. She crawled back to bed and woke up again at 7. She called me and I had her father go straight to her apartment and drive her to my hospital. I’d been a pediatric nurse for nearly 30 years. I took care of a child with meningococcemia years before who died in just two hours. I learned later that Heather was watching from her hospital bed when the doctor told me that’s what she had. Heather saw me just slide down the wall when he told me.

—Carol Tufano, RN, mother of Heather, survivor at age 18

When she came in, her fever was about 100 to 101. She was cheerful and smiling. She looked fine and said she was feeling better than she had the night before. We were cautious because we’d already had meningococcal cases on campus, so we took blood, watched her, and then sent her to the emergency room. She did not have a rash when we sent her, but just a few minutes later when she arrived at the ER, the first spots were appearing on her skin and she went rapidly downhill from there.

—Peter Johnsen, MD, Director of Medical Services, Princeton University
To protect our nation’s children, NMA supports the broadest possible access to all vaccines, including meningococcal vaccines. Relatively high meningococcal quadrivalent vaccine (MCV4) coverage rates show that parents want to protect their children from this disease and that the health care system is able to deliver meningococcal vaccines to adolescents. One dose of MCV4 is recommended at 11-12 years of age with a booster dose at 16 years of age.

MCV4 coverage rates have increased every year from 2006 to 2013. Nearly 80 percent of teens between the ages of 13 and 17 have received at least one MCV4 dose. The proportion that received the second dose as recommended is low, though, at just 30 percent. NMA supports all efforts to close the coverage gaps for MCV4, but also emphasizes that this alone is not enough to fully protect our children.

MCV4 protects against four of the five major disease-causing strains of meningococcal bacteria (A, C, W and Y). Two newly approved vaccines protect against the fifth major cause of meningococcal disease, serogroup B. In fact, serogroup B is the most common cause of disease in adolescents. The question facing policymakers, and that soon will be facing health care professionals and parents, is who should be vaccinated?

Meningococcal disease cases have been decreasing in the U.S. since 1996. But low overall incidence is of no comfort to adolescents who get meningococcal disease and their families, the health care professionals who care for them, and the college health and public health officials who manage outbreaks and their aftermath.

No one knows why meningococcal disease incidence, usually cyclical, has been decreasing over a longer period than usual. The current downturn started before widespread vaccination began and no one can predict when, if, or on how steep a curve it will increase in the future. But we do know that a large unvaccinated population presents a substantial public health challenge when meningococcal disease attacks. This is exactly what happened during serogroup B outbreaks in 2013-14 at Princeton University and the University of California, Santa Barbara.

On the one hand, you know, you go through all these risk-benefit analyses or cost-benefit analyses [to make vaccine recommendations]. But the fact of the matter is, there is no assignment for cost of suffering or assignment for cost of death. And for everybody in this room [survivors and family members at the roundtable], you know, the cost was tremendous.

—Paul A. Offit, MD, pediatric infectious disease specialist and vaccine expert, Children’s Hospital of Philadelphia

Education alone doesn’t appear to have a meaningful impact on vaccination rates. There’s no way to validate that the education is happening, or that it’s happening properly, or even in a way that truly could be defined as education. If the goal is to to immunize large numbers of adolescents, the best way to do that relatively expeditiously is to have a routine recommendation for vaccination [from the CDC] and follow it with a state school requirement.

—Amy Middleman, MD, adolescent medicine specialist, commenting on adolescent immunization generally
University of Oklahoma
In 1919, Dr. William Herrick, Chief of Medical Services at Camp Jackson, South Carolina, described 315 cases of meningococcal disease on the base. Outbreaks were common in crowded army camps, so medical staff were well versed in meningococcal disease. “The very hour the recruit in a well regulated camp is incapacitated…he is rushed to the base hospital where specially trained staff awaits him,” wrote Dr. Herrick. But even with rapid diagnosis and treatment, Dr. Herrick goes on to say, “No other infection so quickly slays.”

Despite major advances in critical care medicine over the past 100 years, there has been no meaningful change in meningococcal disease fatality rates. For serogroup B, the most common cause of disease in U.S. adolescents today, the fatality rate over the last 14 years has been 12 percent in 11- to 19-year-olds and 17 percent in 20-year-olds.

Up to 15 percent or more of adolescents with meningococcal disease will die.

The meningococcal toxins were traveling to all parts of Evan’s body. We stayed at his side as he struggled to fight the infection for weeks. But one complication followed another—extremely low blood pressure, damage to his lungs and liver, gangrene followed by amputation of all his limbs, seizures and finally, irreversible brain damage. Evan died after 26 days.

—Sue Greene, aunt of Evan, died at age 20

I knew something was strange because he was coming home for Christmas Eve and I hadn’t heard from him. That wasn’t like him. Instead, I got the call that he was in the hospital and that he was falling in and out of consciousness. That was 5 PM. Thomas died in my arms just eight hours later, at 1:02 AM on Christmas Day.

—Robbin Thibodeaux, mother of Thomas, died at age 19

Andrea was away at college. She called our parents because she had a high fever. She went to the ER but was sent home with a diagnosis of a viral infection. The next day she was found unconscious and was rushed back to the hospital, but it was too late.

—Lucia Jaime, sister of Andrea, died at age 19

There was no time or possibility for a missed diagnosis for Stephanie. She went to bed earlier than normal one night because she felt very tired. The next morning when she didn’t turn off her alarm, her sorority sisters found her unresponsive in her bed. Stephanie was rushed to the hospital where she died after several hours of trying to revive her. She was just 19.

—Stephen and Beverly Ross, parents of Stephanie, died at age 19
If a patient comes in with high fever, stiff neck and the typical rash, most physicians will make a meningococcal disease diagnosis very quickly. But that typical presentation only happened in a very small proportion of our cases.

—Peter Johnsen, MD, Director of Medical Services, Princeton University

Diagnosing meningococcal disease can be challenging even for experienced health care professionals.

The early symptoms of meningococcal disease are often non-specific and similar to flu symptoms. What can look like a mild illness at first can leave an adolescent close to death before the day is out (see Timeline opposite).

I woke up feeling a little bit sick, but went about my normal routine. As the day progressed, things started to get a little bit worse. Within six hours I was having extreme chills and my temperature was 104. I went to my primary care doctor. He said it was most likely pneumonia. He sent me for chest x-rays and then home. That night I got very confused and by the next morning I was unconscious. I was airlifted to Yale-New Haven Hospital and given just a 20 percent chance to live.

The first few weeks out of the hospital were the most difficult part of my recovery. I had to relearn how to walk. About a month later I started to realize I had a hearing problem. I also have trouble with my cognitive functioning and I have vision loss. Today I’m grateful to be alive, but how do you come to terms with something that completely changes your life when you’re just 17?

—Francesca Testa, survivor at age 17

Several years ago when I was moonlighting in a pediatric emergency room, I was told about an infant who returned with a new rash, after being seen and diagnosed with a virus hours earlier. The emergency medicine physician treating this infant on his return, who had more than 25 years of emergency department experience, realized the baby was sick but did not recognize the rash as typical of meningococcemia. Despite appropriate antibiotics, the infant died within 90 minutes after being admitted to the pediatric intensive care unit.

—Paul Lee, MD, pediatric attending physician, Winthrop-University Hospital

Most young physicians have never seen meningococcal disease. That’s good because this is an awful disease. But it also means they don’t have the personal experience that makes early diagnosis easier. We need to be vigilant in our training of young doctors so they are aware of the signs. They need to know that many cases won’t look like the textbook examples of meningitis or meningococcemia when they walk in the door.

—Carol J. Baker, MD, pediatric infectious disease specialist and vaccine expert, Texas Children’s Hospital
Early diagnosis of rare but important diseases (like meningococcal disease) outside (the) hospital is extremely difficult.
—Thompson and colleagues

Evan called to tell me he had a terrible migraine. Just a few hours later he was in intensive care because of meningococcal disease.
—Lynn Bozof, mother of Evan (died at age 20)

Her early symptoms weren’t bad—a fever of 101 and body aches. I asked if her neck was stiff. She said no. Her pediatrician thought it was the flu. I had seen her much sicker before. But by the next morning she had the meningococcal rash on her ankles. At the doctor’s office I watched the rash go right up her back—it turned purple right in front of me. Kim was rushed to the ER and diagnosed immediately, but by the time they got her to the ICU her organs were already failing.
—Patti Wukovits, RN, mother of Kimberly (died at age 17)

In the ER they thought I had the flu. I told my folks, “Something’s wrong. This isn’t the flu.” The doctors sent me to Vanderbilt Hospital in Nashville, but they said I was well enough that my parents could drive me the three hours there. The last thing I remember, I passed out on my dad. I kind of leaned my head back on him. I woke up two weeks later in the hospital with a tube down my throat.
—Blake Schuchardt, RN, survivor at age 18

Meningococcal disease causes long-term, serious complications for many.

According to studies, 11 to 19 percent of meningococcal disease survivors live with major long-term challenges such as hearing loss, amputations, brain damage or organ failure. For adolescents, these are changes that will affect how they live for probably five, six or more decades. Some complications are not evident to casual onlookers. Meningococcal disease survivors talk about these scars, too.

I lost my legs below the knees, all ten of my fingers, and I had complete kidney failure. My legs are basically 90% skin grafted. I have scars all over my body. I was in the hospital for almost eight months, and I was in the ICU for over five months. I went through two years of dialysis. I received a kidney transplant from my mother on October 25, 2013, exactly two years to the day that I contracted bacterial meningitis.

I still have a lot of challenges and complications. Prosthetics—the fitting—and my legs are so small and fragile, and skin grafted, that I constantly develop sores, wounds, blisters and infections, which can affect my walking, and sometimes it even sets me back into a wheelchair. We are also having complications with the kidney. It’s week by week. I have to get weekly blood work done. And I take about 30 pills a day.

—Amy Aiken, survivor at age 29

After almost dying several times, they amputated both my feet and three of my fingers. I had eleven surgeries over the next four months. When I went into the hospital I was 14 years old, 6-foot-4-and-a-half and 185 pounds. When I left, I weighed 112 pounds. I have skin grafts over all of my residual limbs—so I suffered a lot of breakdown, and prosthetics were very hard for me to get started with.

It’s a devastating disease, and the effects on my family and friends were far—well, emotionally—were worse for them than they were for me. When you go through it yourself, you deal with it every day, and you can deal with that. But people who are on the periphery and see your improvement on an incremental basis, it’s hard for them. They remember what you were when you got sick, when you were 14, or 18, and how you were. And then they see you after, and they just can’t understand it.

—Carl Buher, survivor at age 14
Most experts are well-informed about treating the acute illness, but once meningococcal patients leave the hospital they are beyond our view. We’re focused on their survival. That’s no small task against meningococcal disease, but we don’t necessarily recognize that they will be dealing with the impact of the illness for the rest of their lives.

—William Schaffner, MD, preventive medicine, infectious disease and vaccine expert, Vanderbilt University

I spent two months in the hospital. I needed to have amputations. They amputated most of my right foot and half my left foot. I elected to amputate my right leg below the knee about a year later, because the foot they had built me using my back muscle was just very difficult and painful to use.

It was a long recovery. After I came out of my coma, I couldn’t sleep. I had anxiety and fear and depression. I used to fall asleep and couldn’t sleep for more than 10 minutes before I would wake up violently just, you know, afraid I probably wasn’t going to wake up.

—Mike LaForgia, survivor at age 39

After my coma, it was another month before I was strong enough to leave the hospital and many months more before I could walk independently. My kidneys shut down, so I was on dialysis. It was only about a year before my kidney transplant, but I still take anti-rejection medications that need regular monitoring. Today I work as a dialysis nurse.

—Blake Schuchardt, RN, survivor at age 18

When I left the hospital two weeks after waking up from a five-day coma, I couldn’t control my facial muscles. I got depression that went along with my inability to express emotion with my face. When I started college in the fall I realized I was having a problem with my memory and concentration. It took me a while to understand that it was a result of the disease and that I wasn’t just suddenly stupid and it took me a while to come to terms with the fact that this was a big deal. I still struggle with impressing on people the severity of the disease because they can’t see anything wrong with me.

—Casey Mahlon, survivor at age 17

When something horrible, like meningococcal disease, puts you in a hospital, in an intensive care unit for so long, you don’t come out the same.

—Carol J. Baker, MS, pediatric infectious disease specialist and vaccine expert, Texas Children’s Hospital
The family members really suffer. My sisters suffered more than I did. I ended up as a quad amputee with a kidney transplant but they suffered significantly more than I did, especially my twin—she probably has PTSD. She was six months pregnant, had a young son and a husband and she moved her whole family from the Bay Area [San Francisco] to San Diego to take care of me. And then a year later, she donated the kidney that allowed me to get off of daily dialysis.

—Kyla Winters, survivor at age 37

Even the word ‘meningitis’ did not register in my mind. It did not sink in with me that my brother was on the brink of death until I saw my mother. When my father and I arrived at the hospital, my mother was already there, sitting in the room with my brother. It was the moment I saw her from the hallway that I would remember for the rest of my life.

What I remember most is my mother’s eyes. Her eyes seemed to pierce into mine as soon as they made contact. The mere expression exuded the true nature of pain as though torment was sitting in the room next to her. Her gaze taught me more than any doctor, WebMD, or Wikipedia could. In an instant, I understood the true nature of his disease, not in the biological or medical sense, but in the emotional sense. I understood the true pain invoked by the mere thought of losing someone you loved.

—Younger brother of a survivor of a college outbreak at age 19

JEAN AIKEN DISCUSSES HER DAUGHTER AMY’S QUESTIONS

Amy asked me four questions in the course of her illness. They got progressively harder for me to answer.
The first thing she asked me when I walked into the ICU was—
“Did I do the right thing?” By that she meant calling 911. I said, “Oh, absolutely!” It saved her life.

The next question was “Will I get better?” She asked this right after the doctor told me that she probably had an hour to live. But I have faith in an afterlife, and I don’t see death as a bad thing. So I was able to say “Amy, I guarantee you, you will get better.” Either she would live or be in heaven. When I made that guarantee, I literally felt her whole body relax. But I’ve always felt a little guilty. Did I lie to my daughter? It was our last conversation for two months. She was in a coma after that.

While she was in the coma we had to sign the paperwork for her feet to be amputated. The next question—the hot potato question—was how do we answer when she asks, “What happened to my legs?” I thought the doctors would handle that one, but they made it clear they did not want to be the ones to tell her. Amy never actually asked that question. Later she told me she just sensed, more than anything, that her feet weren’t there. She said she couldn’t look down for two weeks. Finally one day, she looked me in the eye, and I looked her back in the eye, and I just—kinda nodded, “Yes, I know, dear. I know they’re not there.”

And the last question—and this is the one I dreaded the most was, “What made you think I would want to live this way?” I was so thankful that I had an answer when the question came. While she was in a coma, a friend directed me to some videos of survivors. It was amazing to see others who had dealt with amputations and were living. They were happy and I knew there was life after this.

Since Kim died, I’m not the same wife to my husband. I’m not the same mother to my son. I’m not the same daughter to my parents.
—Patti Wukovits, RN, mother of Kimberly, died at age 17

A young girl asked me if I could go back and stop what happened to me, would I? My initial reaction is, “Of course,” because you know, to see what my wife went through—two of my three kids still struggle with what they went through. To see my 80-year-old father at the time, the only memory I have around the coma was my father standing over my bed, crying.
—Mike LaForgia, survivor at age 39

You know, you can empty your bladder, and you won’t have to go for a while. But tears just keep refilling.
—Eileen Boyle, RN, mother of Caitlin, died at age 19

I didn’t say goodbye to Evan in the hospital. Everyone else went in to say goodbye to him but me. I wanted to remember him as he had been. I should have gone in. And that will stay with me always.
—Sue Greene, aunt of Evan, died at age 20

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“Did I do the right thing?” By that she meant calling 911. I said, “Oh, absolutely!” It saved her life.

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Parents cannot be expected to know their children are not protected against serogroup B

The majority of U.S. parents get their children vaccinated with MCV4. Participants at the NMA roundtable noted that they believed this meant their children were no longer at risk of meningococcal disease. But MCV4 vaccines provide no protection against serogroup B disease. In addition, like all vaccines, MCV4 greatly reduces risk, in this case of getting serogroup A, C, W or Y meningococcal disease, but it does not eliminate it completely.

The doctor said to me, “We believe that he has meningococcal meningitis.” I looked at him and said “What school did you go to? You’re crazy. There’s no way he has this.” I was that mom with the plastic vaccine card with every date on it. Tommy got all of his vaccines.

—Robbin Thibodeaux, mother of Thomas, died at age 19

She called me that day and said, “Mom, my headache hurts so bad. My neck hurts. My body hurts like a truck ran over me.” And I said, “Well Cait, you—honey—you can’t get meningitis, you’ve had your vaccine.” I—I was so sure of it. I didn’t know. They don’t tell you that the vaccine doesn’t protect against serogroup B.

—Eileen Boyle, RN, mother of Caitlin, died at age 19

I knew he needed a meningococcal vaccine before going to college and so we made sure he had it. I had no idea as a layperson that there was a strain [serogroup B] that wasn’t included in the vaccine. I didn’t think he was at risk because we did the right thing—we got him vaccinated.

—Debbie, mother of a survivor of a college outbreak at age 19

When Kim got sick, I didn’t think she could have meningitis because she was vaccinated. Even when she started to get the meningococcal rash, my oncology nurse training made me think first that she must have some kind of blood cancer, not meningitis. But Kim had meningococcal serogroup B, which was not covered by the vaccine.

—Patti Wukovits, RN, mother of Kimberly, died at age 17

Our daughter had been vaccinated for meningitis, per the college’s requirement. We had no idea that there was a strain of the disease for which there was no vaccination available at the time.

—Stephen and Beverly Ross, parents of Stephanie, died at age 19
The impact on college campuses ranges farther and wider than medical studies can explain

Most cases of meningococcal disease in adolescents are not part of an outbreak and do not happen on campuses. But when a case does happen on a campus, it causes a great deal of anxiety because it may signal an impending outbreak.

Four cases in just one month at the University of California, Santa Barbara (UCSB) sent fear through the campus and the surrounding community. On the opposite coast, a Princeton University outbreak lasted a full year and included nine cases.

Dr. Mary Ferris (UCSB) and Dr. Peter Johnsen (Princeton), talked about the challenges of outbreak control and dealing with the anxiety on their campuses.

Word travels fast on a college campus. By the morning after the first case we had a line of students waiting for us to open. They wanted a vaccine.

Telling people they were not at risk didn’t stop the panic. The local school district wouldn’t let our graduate student Teaching Assistants into their classrooms. We had phone calls from local residents who were afraid to ride on the city buses with UCSB students.

Increased anxiety led to hundreds of urgent care and ER visits from people afraid they might have early symptoms.

—Mary Ferris, MD, MA, MSEd, Student Health Director at the University of California, Santa Barbara

Our outbreak was sustained over a longer time than usual. The CDC could only provide us with one example of another university that had experienced a sustained outbreak. That outbreak went on for nearly three years.

Other university outbreaks were associated with attack rates on the order of 15 to 25 cases per 100,000. Princeton experienced a rate greater than 130 per 100,000. This was comparable to the attack rate in the meningitis belt in Africa.

—Peter Johnsen, MD, Director of Medical Services at Princeton University

The last case associated with the Princeton outbreak was in a student from nearby Drexel University. The student had attended a party with Princeton undergraduates. Unfortunately, this student died.

The questions and concerns came from all over the campus. From our faculty and our staff, and in this case, police officers as well, who weren’t sure if they were at risk because they were near the student who was sick. We heard from students, parents, media and the community. So trying to manage the emotions, manage the grief, manage the chaos, manage the sadness, while also managing students, managing parents, managing faculty and staff, managing the media—was—was continually challenging. One of the scariest things was the waiting. We expected another case because of what happened at Princeton.

We called a meeting of the sorority that evening to let them know one of their best friends had just died, but also that there’s this cause of concern for meningitis. So as you can imagine, there’s panic and grief in this room full of women who lost their best friend and now are scared to death about their own lives as well.

And then I had to go to a fraternity house—a room of 80 men, and let them know that their friend and sister had passed, as well as—that whole threat of meningitis. I was in a room of 80 men being reduced to tears and emotion.

—David A. Ruth, PhD, dean of students at Drexel University
ALL ASPECTS OF MENINGOCOCCAL DISEASE IMPACT SHOULD BE CONSIDERED IN MAKING VACCINATION POLICY

The stories of those affected by meningococcal disease need to be part of the national discussion about who warrants the protection afforded by effective and safe meningococcal vaccines. The worry about whether a patient will survive the acute stages of meningococcal disease is well known to medical professionals and policymakers. Less recognized and discussed is the long-term impact on the disease survivors and the life-altering changes for the families of those who have died or whose lives have been affected, along with the impact of cases and outbreaks on campus and community members.

For vaccine-preventable diseases, prevention via immunization is generally a much better solution than treating cases. Nowhere is this more true than it is for meningococcal disease. Medical treatment is often too little, too late to prevent serious sequelae. These chronic sequelae lead to “hidden” long-term health costs, both medical and psychological, that should be considered in the economic impact of this disease.

As national policy is discussed and implemented, the National Meningitis Association urges all those involved to remember the personal stories. Statistics are important, but the human suffering and long-term impact of meningococcal disease must not be forgotten.

Lynn Bozof
President
Program Co-Moderator
National Meningitis Association

Paul J. Lee, MD
Program Co-Moderator
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Winthrop-University Hospital
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This report was based on a roundtable convened by the National Meningitis Association on January 16, 2015 in Philadelphia. This one-day program brought together a cross-section of meningococcal advocates, including survivors and family members, along with college health officials, infectious disease specialists and others with unique perspectives and knowledge about meningococcal disease. The goal of the meeting and this report is to give voice to the concerns and viewpoints of those directly affected by the disease. NMA thanks the following for sharing their stories and expertise.

Amy Aiken, meningococcal disease survivor
Jean Aiken, mother of Amy, meningococcal disease survivor
Carol J. Baker, MD, Baylor College of Medicine and Texas Children’s Hospital
Eileen Boyle, RN, mother of Caitlin, who died at age 19
Lynn Bozof, National Meningitis Association, mother of Evan, who died at age 20
Anna Buher, wife of Carl, meningococcal disease survivor
Carl Buher, meningococcal disease survivor
Mary Ferris, MD, MA, MSEd, University of California, Santa Barbara
Sue Greene, aunt of Evan, who died at age 20
Lucia Jaime, sister of Andrea, who died at age 19
Peter E. Johnsen, MD, Princeton University
Mike LaForgia, meningococcal disease survivor
Paul Lee, MD, SUNY Stony Brook School of Medicine and Winthrop-University Hospital
Casey Mahlon, meningococcal disease survivor
Amy Middleman, MD, University of Oklahoma College of Medicine
Paul A. Offit, MD, Children’s Hospital of Philadelphia and University of Pennsylvania
Trish Parnell, Parents of Kids with Infectious Diseases (PKIDs)
Amy Pisani, MS, Every Child by Two
Stephen and Beverly Ross, parents of Stephanie, who died at age 19
David Ruth, PhD, Drexel University
William Schaffner, MD, Vanderbilt University School of Medicine and Vanderbilt University Hospital
Blake Schuchardt, RN, meningococcal disease survivor
Francesca Testa, meningococcal disease survivor
Robbin Thibodeaux, mother of Thomas, who died at age 19
Carol Tufano, RN, mother of Heather, meningococcal disease survivor
Kyla Winters, meningococcal disease survivor
Tammy Wolf, mother of Addy, meningococcal disease survivor
Patti Wukovits, RN, mother of Kimberly, who died at age 17
Debbie*, mother of meningococcal disease survivor

* This family has chosen to remain anonymous

REFERENCES


As doctors, we focus on the physical scarring of meningococcal disease, instead of the intangible consequences among the families who lose children, or even among those who survive. This is an incredibly stressful event, a life-changing event and yet, because someone survived and still has most of their legs, we think “that’s great.” What about the emotional and psychological impact that this has on survivors and those around them, not to mention a potential lifetime of complications?

—Paul Lee, MD, pediatric attending physician, Winthrop-University Hospital