

Women Who Make a Difference

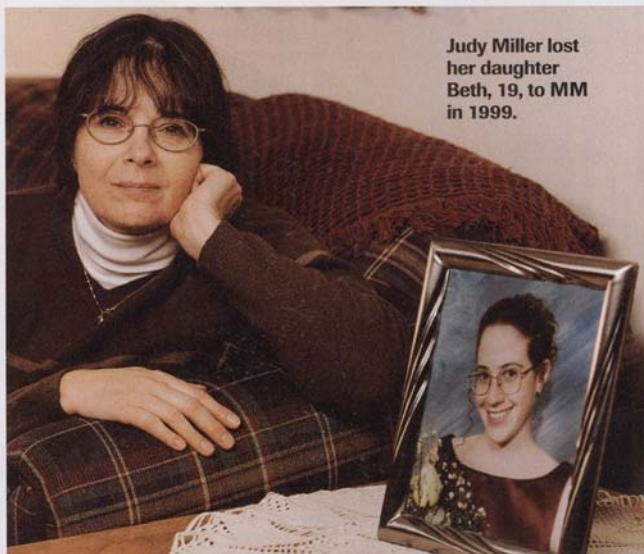
By Lisa Collier Cool

# Danger in the Dorm

Five mothers band together to get the word out so that no one ever loses another child to meningitis.



John Kach, an MM survivor, and his mother, Paige, have been active in educating students about vaccination.



Judy Miller lost her daughter Beth, 19, to MM in 1999.

It was the most agonizing decision a mother could make. In March 2000 Paige Kach leaned over her 19-year-old son, John, who lay in a medically induced coma hooked up to an array of life-support machines, and gave him permission to die. Not knowing if he could hear her, the 51-year-old building department clerk told him, "If you want to fight, we'll fight this together. Either way, Mommy will understand."

Just three weeks earlier John was a star basketball player at Salve Regina University in Newport, Rhode Island. Then one night the college freshman suddenly got sick with a high fever, flulike symptoms and vomiting. By morning his girlfriend had taken him to the emergency room. Soon after, he broke out in a purple rash and was diagnosed with meningococcal meningitis (MM), a potentially fatal bacterial disease that can cause inflammation of the membranes around the brain and spinal cord, an infection of the blood, or both. The disease can lead to gangrene, organ failure, brain damage, hearing loss or death, often within hours.

Despite massive doses of IV antibiotics, the infection raged through John's body so fast, one ER doctor compared it to watching a house burn down. By the time Paige

and her 55-year-old husband, Mike, reached Rhode Island Hospital from their Carmel, New York, home, they were told "he wouldn't make it through the night," says Paige. "I collapsed and said, 'Dear God, no!'" A priest administered last rites as they prayed by their son's side.

Against the odds, John clung to life. "It was devastating to see our beautiful child being eaten away by this disease," says Paige. "He was bleeding from the nose, ears and eyes, and his fingers started dying." Gangrene had set in, forcing doctors to amputate all of his fingers, his right leg below the knee and the toes of his left foot. The 6'4"

Photos: AP/Wide World (top left); John Sibilisk (top right);

Award-winning author Lisa Collier Cool writes frequently about women's health issues. She lives in Pelham, New York.

Melanie Benn survived (with mom and sister, right). Lives lost: Patrick Keperle getting kiss from mom Deb, below left; Evan Bozof with mom Lynn, below right.



“ I can't tell you how much it hurt to know he didn't have to die. ”

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teenager, who normally weighed 210 pounds, dwindled down to barely 100.

As the Kaches stayed by his bedside, they were tormented by guilt. They knew their son might not have fallen ill if he'd gotten a \$70 vaccine against MM, a relatively rare disease that annually strikes 5.1 out of 100,000 freshmen in dorms. Why these students are more at risk is not exactly known, says Lee H. Harrison, M.D., head of the infectious diseases epidemiology research unit at the University of Pittsburgh. But lifestyle factors believed to play a possible role are: crowded living conditions, smoking, passive exposure to tobacco smoke and heavy drinking. MM is spread through close contact with an infected person (*see box, page 16*).

Before John started college, his family received a letter from the university recommending students be immunized. The Kaches' doctor didn't stock the shot, so the couple urged John to be vaccinated at the campus health clinic. Sadly, he never got around to it. "If I had any idea this disease could cause amputations or horrible deaths, I would never have left it up to a nineteen-year-old," says Paige.

Six weeks into his illness, the teenager stabilized enough to let doctors bring him out of the coma. "I freaked out when I found out what I'd lost," says John, who was hospitalized for three months, then spent six more months at Burke Rehabilitation Center in White Plains, New York, where he learned to walk with a prosthetic leg. "Sometimes I'd ask, 'Why me?'" says John. "Then I'd see other people at the rehab hospital who were worse than I was." Using the palms of his hands and the stumps of his fingers, John figured out how to feed and dress himself, write legibly, type on his computer keyboard, and even throw a basketball with close to his old accuracy.

**a**fter he recovered, John wanted to warn other kids about meningitis. Accompanied by his parents, he gave several talks at high schools in which he told his story and offered a demonstration of what he had to overcome. "I'd wrap up one of the students' hands in an Ace bandage, then throw him a bag of candy and tell him to open it and pass the candies around. When the kids saw how hard it was to do without fingers, it opened their eyes to what this disease is all about," he says. "The biggest thing was to tell them about the vaccine, because I wanted to save a life." He and his parents also gave over 100 interviews to newspapers, radio and TV shows, and appeared in a TV documentary about John's illness.

In March 2001 Paige got a call from a publicist for the Meningitis Foundation of America, a nonprofit education and support group for people affected by meningitis. The publicist, who had read about the Kaches, invited her to join four other women—all of whom had college-aged chil-



Founders of the advocacy group Moms on Meningitis (MOMs), left to right: Lynn Bozof, Candie Benn, Paige Kach, Deb Kepferle and Judy Miller.

dren who either died of MM or were left seriously disabled—to form an advocacy group called Moms on Meningitis (MOMs). Their mission was to publicize the benefits of vaccinating college students through a national campaign targeted at parents.

A month later the five women held an emotional meeting in Atlanta. "We needed a big tissue box when we shared our stories, because everyone cried and cried," says Deb Kepferle, a 52-year-old stay-at-home mom from Lexington Park, Maryland. In a heartbreaking coincidence, Deb's son had caught meningitis within days of Paige's. Two of the moms, Lynn Bozof and Judy Miller, had children die of the disease in the spring of other years. (Rates are highest in late winter and early spring.) The fifth mom, Candie Benn, had a daughter who survived but suffered amputations.

Like the Kaches, Deb and her husband tried to get their 18-year-old son, Patrick, vaccinated before he left for Towson University near Baltimore, only to find their doctor didn't have the shot. Then, less than 24 hours after the Kepferles drove Patrick back to his dorm after a visit home, they got an urgent call: Their son was in the emergency room. By the time Deb and her husband arrived two hours later, Patrick was on life support. "Fifteen minutes later he was gone," she says. "It was that quick and deadly. We were in such shock that our minds could hardly even accept what we were being told. We went into the room with a priest and sat there for a long time, praying. Over 1,000 people came to the wake and funeral." It wasn't until an autopsy was performed that a diagnosis was made: meningococcal meningitis.

## What's Your State Law?

So far 25 states have adopted laws that either require colleges to educate students and parents about MM vaccination or mandate vaccination unless parents sign a waiver. Here's a state-by-state breakdown, compiled by the National Meningitis Association ([www.nmaus.org](http://www.nmaus.org)).

States that require colleges to educate: Arkansas, Illinois, Michigan, Minnesota, Mississippi,

Nebraska, New Jersey, South Carolina, Texas, Washington.

States that mandate vaccination unless a waiver is signed: California, Connecticut, Delaware, Florida, Georgia, Indiana, Maryland, Missouri, New York, North Carolina, Oklahoma, Pennsylvania, Tennessee, Virginia, Wisconsin.

States considering vaccination legislation: Alabama, Massachusetts, Ohio, New Jersey.

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Deb and her husband, Michael, a 49-year-old retired naval officer, immediately had their other three children immunized. Their tragedy pushed Maryland legislators to pass a law making it mandatory for college students to be vaccinated. Michael traveled to other states considering similar laws and testified about what happened to his son. He also wrote a brochure about the importance of vaccination. "We want people to know it can happen to their child," Deb says. The family keeps Patrick's memory alive through a college scholarship they've funded in his name. His fraternity also holds a fund-raiser and candlelight vigil yearly on his behalf.

Soon after the first MOMs meeting, Lynn Bozof, Michael Kepferle and Candie Benn started a nonprofit educational foundation called the National Meningitis Association. It is financed by private donations, fund-raisers and grants from Aventis Pasteur, the maker of the MM vaccine. Through the foundation over a million copies of Michael Kepferle's vaccination brochure have been distributed. Lynn serves as its executive director.

Lynn and her husband, Alan, both 53-year-old engineers from Marietta, Georgia, lost their son Evan, a junior at Georgia Southwestern State University, in April 1998 after a nightmarish 26-day battle in which he suffered lung, kidney and liver failure, gangrene and irreversible brain damage. After his death Lynn called the Centers for Disease Control and Prevention to learn more about the disease. "That's when I found out that there's a vaccine," she says. "I can't tell you how much it hurt to know that he didn't have to die."

In 1999 Lynn testified before the CDC—which had just done a study showing a rise in MM among freshman col-

lege students—and was joined by 26-year-old meningitis survivor Melanie Benn, whose mother, Candie, belongs to MOMs. Melanie described her harrowing medical ordeal, which began on Christmas Eve in 1995, when she developed meningitis. Despite prompt medical care the 18-year-old freshman lost both arms below the elbow and her legs from the knee down. She was so determined to complete her education that a week after completing rehab, she went back to college and ultimately received both an undergraduate and master's degree in social work. Along with helping her mom raise awareness of MM, she has become an excellent swimmer and won a silver medal in the 2000 U.S. Paralympics.

Soon after Lynn and Melanie testified, the CDC issued a recommendation that college health services educate students and their parents about vaccination. Although the CDC didn't make the shots mandatory, it did have a huge impact: Most colleges started offering the vaccine on campus and added meningitis information to the packets they sent to incoming freshman. Lynn also began holding annual vaccination days at local high schools in which she shows a video about MM, and at a later date a nurse is available to give shots. "This year we got over 300 kids vaccinated, which was wonderful," she says.

Another of the MOMs, Judy Miller of Coal City, Illinois, started an immunization program in her county after her 19-year-old daughter, Beth, died in March 1999. "After we said our last good-byes and were literally walking out the door, a doctor told us about the vaccine," says Judy, a 50-year-old Tupperware manager. "It was heartbreaking." She established the Beth Ann Miller Health Foundation, which is financed through fund-raisers. In addition to raising awareness, the foundation donates money to the county health department to pay for meningitis shots for any student in the county whose parents can't afford the fee.

Along with their individual activities, the MOMs get together for group projects. Each August they film public service announcements to send to families of kids getting ready for college. They also share their stories through a "satellite tour," in which they record in a studio interviews to be broadcast on TV shows across the nation. They've seen heartening progress: Twenty-five states now mandate vaccination or require colleges to distribute information.

Paige was thrilled that her home state, New York, passed a law in July 2003 that she and her son John helped lobby for. It requires students who attend colleges, boarding schools and sleep-away camps to be vaccinated. "The law will definitely save lives, because this is a preventable disease," says Paige. "I wish everyone knew that, so no one will ever lose another child." **FC**

## How to Protect Your Family

**What is meningococcal meningitis (MM)?** "It's the leading cause of bacterial meningitis in teenagers and young adults," reports James Turner, M.D., executive director, department of student health at the University of Virginia in Charlottesville. MM can infect the brain's lining (the meninges). If it spreads to the bloodstream, it is known as meningococemia. 35–40% of cases present with meningitis only, 35–40% present with meningococemia only, and 10–20% present with both.

**How is MM transmitted?** "The disease is spread either by close contact with infected people such as kissing or sharing food, drinks or cigarettes; or by bacteria that get in the air when someone with the disease coughs or sneezes," says Dr. Turner. "About 10 to 20 percent of

Americans carry meningococcal meningitis bacteria in their nose or throat and can infect other people, but don't get sick themselves."

**How many people get MM?** "It strikes 1,600 to 2,500 Americans a year, with about 600 of these cases among teens and young adults," says Dr. Turner. The disease causes death in up to 13 percent of cases, and 20 percent of survivors are left with lifelong impairments, such as amputated limbs, hearing loss or brain damage.

**What are the symptoms?** Early warning signs include fever, sensitivity to light, nausea, vomiting, headache, stiff neck and altered mental status, says Lee H. Harrison, M.D., head of the infectious diseases epidemiology research unit at the University of Pittsburgh. "In the early stages it can be confused

with flu. However, within a few hours—at most a day or two—a red or purple rash can also appear."

Getting immediate medical help is crucial, cautions Dr. Harrison. "The infection progresses extremely rapidly, and shock, organ failure or death can occur within hours of the onset of symptoms." MM is treated with antibiotics.

**How safe and effective is the vaccine?** "The shot is 90 percent effective against four of the five main types of MM bacteria," says Dr. Harrison. "It has been used for over 30 years, is safe and lasts for three to five years."

The CDC recommends colleges make students aware of the risk of disease and availability of the vaccine. For children going to sleep-away camp, consult your pediatrician to see if vaccination is recommended.