

Unprotected People #46

Meningococcal meningitis

The laughter of our hearts: Losing a teen to a vaccine-preventable disease

This is the 46th story in our series, but unfortunately, it is not our first story about meningococcal meningitis in a college student. This story is a moving testimonial by a parent whose unvaccinated son became ill and died—all within one day.

“The Laughter of Our Hearts: Losing a Teen to a Vaccine-Preventable Disease” was written by Mike Kepferle, founder of the nonprofit Meningitis Prevention and Awareness Children’s Trust (MPACT), on the Web at <http://www.nmaus.org/>. It is republished here by permission of ShotClock, the newsletter of the Massachusetts Chapter of the American Academy of Pediatrics Immunization Initiative, where it appeared in the Winter 2002 issue.

Joseph Patrick Kepferle, our oldest son, left us suddenly on March 5, 2000. Patrick’s smile and charisma lit every room he entered. He was a natural actor and comedian—intelligent, witty, daring, and restless. He continually challenged us to question our complacency and seek greater visions of what truly could be. Poetic, selfless, caring, and athletic, he captured the imagination of his friends, pushed the limits of his world, and injected his carefree, often irreverent spirit into all facets of our world.

Like too many other children in this country, our Pat died in less than 24 hours from a vaccine-preventable killer, meningococcal meningitis. The summer before Pat started college, we received information on meningitis in his college paperwork. It probably said something about considering a meningitis vaccination even though there seemed to be little or no concern about the disease. Nonetheless, at his pre-college physical and immunization updates, we asked for the meningitis vaccine. We were told none was available there, but we were not concerned. Meningitis was supposedly a “rare” disease, and the vaccine wasn’t on the CDC or state “required” list.

So, we were lulled into a false sense of security.

When Pat started school, we reminded him to get his vaccination, and assured him we would cover the cost of about \$70. He promised he’d get the immunization. But college life was hectic, and it wasn’t his top priority.

Our nightmare began the first Sunday night in March when an emergency room doctor contacted us. Pat had been brought in by friends and was extremely sick. The doctor wasn’t sure what Pat had and mentioned a rash spreading on his body. We should, he said, come as soon as possible.

We could not fathom what awaited us at the hospital. Pat’s college friends filled the hallway as we rushed in. When I saw the priest in the critical care unit, where a nurse finally had taken us, I knew that things weren’t good. Although the team was still working on him, Pat was gone. The doctors let us touch his head and tell him how much we loved him. Our hearts were broken; we had lost our Pat, the laughter of our hearts

I have searched my soul for what we could have done to save our son. The answer seems simple—ensure that he was vaccinated. But is it? Until weeks after Pat’s death I couldn’t even pronounce meningococcal meningitis, and I didn’t understand the issues related to it, such as the effectiveness or the limitations of the vaccine. I couldn’t comprehend that a disease primarily associated with developing countries in Africa could kill a strong, athletic person like my son here in our country. I believed in the myth of American medical infallibility. I didn’t realize how many high school and college students have been maimed or killed by meningitis until I reached out to other parents.

Trying to find out why and how I lost my son, I

(continued on next page)

found that many medical personnel know little about meningitis and that much of the information provided to the public is technically accurate but potentially misleading, downplaying the seriousness of the disease and underscoring the rarity of complications. Some health professionals warned that getting the vaccine would provide a “false sense of security” since it “only” protected against the A, C, Y, and W135 strains and not the B serogroup.

Raising awareness among parents and medical professionals has been challenging. I contend that a shield against four out of five of the major strains is better than nothing at all. Fortunately, recent studies have helped highlight the dangers in the college environment and the growing incidence of meningitis among all teens.

The week after Pat died, the Maryland legislature overwhelmingly passed ground-breaking legislation requiring incoming Maryland college dorm students

to be vaccinated or sign a waiver declining the vaccine. Since then, several more states have passed similar laws, most recently in California. [Editor's Note: The California law requires that colleges and universities inform students about meningococcal vaccine and document that they have done so.] I have talked to many parents who have lost children to meningitis. We want everyone to know the human impact of this “rare” disease. We all desperately want other parents to know that the tragedy we endured could have been prevented.

Pat's laughter is gone, but his presence is all around us. He and all the other victims compel me to write again and again that vaccination and education are the best protection against this killer.