

Unprotected People #76

Pertussis

Newborn's Death Emphasizes Need to Consider Pertussis in Differential Diagnosis of Coughing Adults

Lynne Baker suspects she contracted pertussis from a coughing customer in a bookstore about two weeks before giving birth to her son Nelyn on April 7, 2004. "She coughed all through labor," her husband reports. "Overnight, it got worse and worse."

Still, when Lynne and Nelyn left the hospital for their home in suburban Atlanta, Lynne's cough had not been attended to. Twelve days after Nelyn's birth, on her second visit to her family physician, Lynne received antibiotics. Four days later, Nelyn began coughing and was hospitalized the following day. The next morning, April 25, he died. It wasn't until May 5, when the Bakers returned from burying some of Nelyn's ashes in Michigan, that they learned the cause of death. The results of bacterial cultures started during his hospitalization indicated Nelyn had died from pertussis.

The CDC's "Pink Book" describes the onset of pertussis as "insidious," meaning it develops "so gradually as to be well established before becoming apparent." Studies indicate pertussis accounts for approximately 20-30 percent of instances of coughs lasting more than two weeks in adults and adolescents, and that adults are often found to be the first case in a household with multiple pertussis cases. This seems to have been what happened in the Baker household: Lynne believes she not only passed the disease to her newborn son but spread it to her two teenage children, her mother, and several members of her extended family in Michigan.

For adults, the disease is usually mild. For infants, however, it is anything but. During 1997-2000, 63 percent of infants under six months of age diagnosed with pertussis required hospitalization, and infants this age accounted for 90 percent of pertussis deaths. It is for this reason that it is imperative that all physicians, not just those who provide primary care for children, become knowledgeable about the diagnosis,

treatment, and reporting requirements for pertussis. Had pertussis been suspected as the cause of Lynne's persistent cough during labor and the weeks following, it's likely she and her immediate family would have been treated with antibiotics at once. Nelyn might now be alive.

Physicians now have new adolescent and adult vaccines that can indirectly help protect infants from pertussis. The Food and Drug Administration recently approved two single-dose tetanus-diphtheria-pertussis booster vaccines. GlaxoSmithKline's Boostrix was approved in May 2005 for use in persons ages 10-18 years; sanofi-pasteur's Adacel was approved in June 2005 for use in those 11-64 years of age.

M.A.J. McKenna reported the Bakers' ordeal in her article "Long-ago bane of whooping cough making a stealthy resurgence," which was published in the Atlanta Journal-Constitution September 23, 2004. Copyright 2004, the Atlanta Journal-Constitution. Reprinted with permission from the Atlanta Journal-Constitution. Further reproduction, retransmission, or distribution of these materials without the prior written consent of the Atlanta Journal-Constitution, and any copyright holder identified in the material's copyright notice, is prohibited.

Long-ago bane of whooping cough making a stealthy resurgence

By M.A.J. McKenna

On the edge of the woods behind their house in Alpharetta [Georgia], Lynne and Phil Baker have made a garden for their son Nelyn.

Phil piled up the rock wall enclosing it. Friends brought the dark red chrysanthemums and brilliant marigolds, and Lynne planted them.

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In the center is a tiny Japanese maple. The parents chose it in tribute to their baby son because it is a species that will always stay small.

As will Nelyn. He died April 25 [2004]. He was 18 days old.

He was killed by a disease that his family did not know still existed, one that 60 years of vaccination has failed to suppress.

Because of his death, the Bakers have become crusaders. They are driven to tell others about his brief life and quick illness, hoping that no other parents will be taken by surprise.

Nelyn Frend Theodore Baker died of whooping cough.

"I never," said Lynne, "never, never, never want this to happen to another child."

Signature Symptom

Whooping cough—the clinical name is pertussis—is a severe bacterial infection of the airways. It is highly infectious, lasts for weeks, and has one overwhelming symptom: It causes uncontrollable coughing fits. In the midst of a spasm, sufferers can crack ribs, vomit, and turn blue from lack of oxygen.

Its name comes from the first breath patients take when a paroxysm ends, an urgent crow that sounds like nothing else in medicine.

The signature sound of whooping cough has passed out of most Americans' memory. Once, though, the disease was one of the most common causes of death in childhood. Before a vaccine was introduced in the 1940s, there were more than 175,000 cases every year in the United States.

The vaccine had an immediate, dramatic effect, cutting adult and child cases of the disease to about 1,000 a year by 1976. Then, in the 1990s, the number of cases began to inch upward again.

Last year [2003], according to the Centers for Disease Control and Prevention, there were 11,647 known U.S. cases, a 30-year high. One-fifth of the cases last year were in children less than a year old. Nineteen [persons], almost all [of them] children, died.

Attractive Opposites

Lynne and Phil Baker are 36 and 39; they have been together since shortly after they met in high school. Their 17-year marriage is a union of opposites. He is from a small family whose roots in rural Pennsylvania go back 200 years; she belongs to a sprawling Michigan clan of Polish immigrants.

He designs information systems; she is a photographer. He is tall and sturdy and has a relaxed self-possession instilled by nine years in the Marines. She is fair and very slender, with a whimsical sense of humor.

Together they raised two children: Brandon, 16, and Lorren, 14. Lynne wanted a third for years, and in July 2003 she learned she was pregnant.

In March, about two weeks before her due date, Lynne went to her part-time job in a bookstore. A customer came to her register. She remembers he was typical for Alpharetta: white, well dressed, well off. And coughing.

"Oh great," she remembers thinking. "By the time I have this baby, I'm going to be sick."

She was right. But she had no idea how sick she would become.

Nationwide Outbreaks

Lynne had no way of knowing that, during her pregnancy, local newspapers around the country were reporting outbreaks of illness.

Children and teens were sick in 19 states: Oklahoma, South Carolina, Texas, New York, Pennsylvania, Illinois, Maine, Missouri, Wisconsin, Ohio, New Jersey, Tennessee, New Mexico, Massachusetts, Minnesota, Colorado, Arkansas, California, and Washington.

The outbreaks were all whooping cough, unrelated cases demonstrating the hidden persistence of a once desperately feared disease.

The last two months of Lynne's pregnancy were difficult, with early contractions suppressed with drugs. In the first week of April, she felt a catch in

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her throat. On the day of her delivery, the raspiness bloomed into a cough.

"She coughed all through labor," Phil said. "Overnight, it got worse and worse."

Nelyn was born April 7. He had a perfectly round head, abundant dark hair, and eyes that seemed to focus immediately. Lynne and Phil happily took him home. But Lynne was still coughing so hard she feared her episiotomy stitches would burst. A week after the birth, on a day when her sisters Julie Conway and Lisa Ginter arrived to celebrate, she went back to the doctor.

She had only a low fever, she seemed well between coughing bouts, and a chest X-ray showed nothing. Her illness looked like a cold, or an asthma-like condition related to the drug that had stopped her contractions.

Five days later, still coughing, she went back to her family physician. He gave her antibiotics. Lynne was nursing; the doctor warned that Nelyn might not like the taste of the drug in her breast milk.

Four days later, Nelyn started to fuss after feeding. Then he was listless. In the evening, he began to cough.

In the middle of the night, his fingers and toes turned blue.

The next morning, Phil and Lynne took their son to his pediatrician. Within an hour, they were in an ambulance, speeding down [Georgia 400 freeway] to Children's Healthcare of Atlanta's Scottish Rite Hospital. Nelyn was rushed upstairs to intensive care.

"They told us at first he would be in the hospital for two days," Lynne said, her voice breaking. "And then he got sicker, and they said maybe five days. And then seven days.

"The next morning, as the sun was rising, Nelyn died. His cause of death was recorded as pneumonia.

A Time to Mourn

The families—Lynne's parents and seven siblings, Phil's mother and sister, and dozens of cousins—

arrived almost immediately. Some drove through the night. Others traded in tickets they had bought for trips to meet the baby. They bunked throughout the house.

Phil's employer sent a vanload of food and flowers. Neighbors came to mourn. Lynne's sisters crept through the gathering, picking up baby gifts and stashing them out of sight.

It was the end of April. The subdivision was coated with pollen. So no one found it unusual that Lorren and Brandon came down with respiratory infections, or that Lynne's mother was hospitalized briefly with breathing problems.

On April 28, more than 100 people crammed into the house for a wake. Two days later, the family set off slowly for the Detroit suburbs, where Lynne and Phil met and most of Lynne's family still live. Lisa did not go with them; she flew home early with what she thought was a cold.

In Michigan, there was a larger wake, and then the funeral. Nelyn was buried with his cousin Machiej, who had died at the age of 2. They placed the baby's ashes over the toddler's heart.

On May 5, the Bakers made the 12-hour drive back to Georgia. They found a message asking them to call the Fulton County Department of Health and Wellness.

Back in Michigan, Lynne's sister Julie had developed a racking cough since the funeral. She was coughing so hard when her phone rang the morning of May 6 that she could hardly answer it.

The caller was Lynne, crying and gasping for breath.

"They know what killed Nelyn," she wailed. "He died of whooping cough."

Julie was stunned, and then angry.

"That can't be right," she snapped. "We were immunized. We can't get whooping cough."

She was right: All eight children in their family had been vaccinated in childhood, and each had had their own children vaccinated in turn.

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But she was also wrong. They were not protected.

Protection Ends

Pertussis has a little-known trick. Immunity to the disease—from vaccination or infection—does not last.

A child who has had a full series of shots is protected roughly until puberty. But infants too young to be vaccinated, toddlers with one or two shots, and teenagers and adults are all undefended.

That vulnerability explains a small outbreak of pertussis among four teens in one school in DeKalb County [Georgia] last year. According to the DeKalb County Board of Health, their childhood shots had worn off.

In teens and adults, the disease can be a mild illness—with no coughing fits, no distinctive whoop, and no compelling reason to see a physician. No doctor's visit means no lab test, no formal diagnosis, and no notification to authorities. As a result, even though every state requires pertussis to be reported, the CDC estimates that nine-tenths of cases go unrecognized. Absent strong symptoms or a confirmatory test, patients have no idea what they may be carrying and spreading. Whooping cough is kept alive by those who never realize they have it and accidentally pass it on to others, many of whom develop severe cases.

A Dire Discovery

Fulton County's discovery, made from bacterial cultures started by the hospital during Nelyn's treatment, triggered an emergency.

Pertussis symptoms can be slow to develop, and patients are infectious for weeks once symptoms start. The Bakers' friends, co-workers, and extended family in four states—Georgia, Michigan, Pennsylvania, and Texas—were at risk of developing the disease and passing it on.

In Alpharetta, the Bakers pulled Lorren and Brandon from school and took them immediately to the doctor. In Michigan, Julie and her husband and children were taken through the back door of their pediatrician's office, sent to a hospital, and then closed in an isolation unit inside an emergency room.

Both families were ordered by health departments to stay home for a week.

Each extended-family member was put on powerful antibiotics, but it was not enough. The young children were protected by their immunizations, but at least seven of the teens and adults fell ill.

Julie was hit the hardest. She still cannot exercise or draw a deep breath, and regularly doubles over in coughing fits that leave her retching.

The Bakers have no way of knowing how the disease entered their family, or who infected whom. The drugs given to Lynne, Brandon, and Lorren before Nelyn fell ill wiped the bacteria from their systems before they were tested.

But Lynne believes she knows. She thinks she gave the disease to her sisters when they came to celebrate the birth; she suspects they passed it to their mother in Michigan and that it spread among her family at the wake. She is sure she gave it to her children, including her newborn son.

"I don't blame myself," she said. "Someone gave it to me. But I am haunted by how many people we may have given it to before we realized what was going on."

Special Places

Before Nelyn was buried, Lynne and Phil held back part of his ashes. They took some to Phil's mother, who lives on the family land in northwest Pennsylvania, and spread some by a creek on the property where Phil takes the children every year. They kept the rest, tucked into a cherrywood vessel carved by Lynne's father.

When they are ready, they will add Nelyn's ashes to the garden built in his memory.

"He will be in all the places that have special importance for us," Phil said. "It will help, I think."

Recently, Lynne sat by the garden, smoothing its carefully tended surface and thinking about the need to warn others about whooping cough.

"I never imagined this was possible, but I want people to know it is possible," she said. "This is out there, and it is spreading."