

For the love of Jennifer

TURNING TRAGEDY INTO HOPE, A GRIEVING FAMILY COPES WITH THEIR LOSS BY RAISING MONEY AND AWARENESS FOR MENINGITIS RESEARCH AT CHILDREN'S / BY LYNN SAGRAMOSO



Jennifer's mother, Cindy Payne (at far right), and Cindy's four sisters (l-r) Suzanne Collier, Wendy Passerell, Barbara Rickards and Jamie DeVore, pose together at the 2007 Jennifer Leigh Wells moonlight fundraiser run in Charlottesville, Va. The run raised more than \$15,000 each year in 2007 and 2008. (Opposite page) Jennifer Leigh Wells at 17.

JENNIFER WELLS DIED A WEEK AFTER HER 21ST BIRTHDAY. It was a sudden death that devastated her close-knit family, her friends, and her entire hometown community of Charlottesville, Va.

"She was complaining of a really bad headache, so she decided to stay home from classes that morning," recalled Jennifer's mother, Cindy Payne. "I called later that afternoon to see how she was feeling, but she didn't answer the phone." Cindy drove home and found her only daughter unconscious, her breathing labored and erratic.

"I was terrified. I remember kneeling beside her, crying hysterically, calling her name to wake her," Cindy said. An emergency response team rushed Jennifer to the hospital, but she never regained consciousness and died two days later of bacterial meningitis.

"It happened so quickly," shared Cindy. "She was a healthy, vibrant

young woman, in her senior year at the University of Virginia. Then she was gone. We were all in shock. My husband and I still feel totally lost without her."

Every year nearly 3,000 people nationwide are diagnosed with bacterial meningitis. Although relatively rare, it is an extremely dangerous, rapidly progressing infection that can become life-threatening within hours after the first symptoms appear. Symptoms are often flu-like, and may include a sudden fever, headache, stiff neck, nausea, vomiting and sensitivity to light.

Even with proper intravenous antibiotic treatments, 10 to 14 percent of meningitis cases are fatal. Among those who survive this serious disease, about 20 percent suffer long-term effects such as brain damage, paralysis, hearing loss or limb amputation.

THE LONG ROAD TOWARD HEALING

Cindy's four sisters and their families, all living in the greater Charlottesville area, pulled together to mourn Jennifer's death and try to make sense of their loss. "Part of our family's grieving process was to learn more about this disease," said Cindy. "We needed to understand how something like this could happen."

They learned that bacterial meningitis is contagious—transmitted through sneezing, coughing, sharing drinking containers, or direct contact with people sick with the disease or who carry the bacteria. Adolescents in high school and college are at the highest risk of encountering the bacteria.

Fortunately, a vaccine is available that protects against four of the five different strains, or groups, of meningitis. The Centers for Disease Control and Prevention recommend children receive

this vaccine when they reach 11 or 12 years of age.

“Jennifer did receive the vaccination, which affords short-term (three to five years) protection that is 83 percent effective for four strains of the disease,” Cindy explained. “Ironically, Jennifer had the B-strain of meningitis, for which there is no vaccine.”

“We called a family meeting and decided that we should do something to help ensure that this wouldn’t happen to anyone else,” Cindy continued. “Jennifer was a very caring person who loved animals, volunteered at a local elementary school to help kids learn to read, and planned to become a social worker. We felt that she would want us to try to make a difference.”

Three of Cindy’s sisters had participated in “fun run” fundraisers before, so the family decided to make their event a moonlight, family-style run at Jennifer’s old high school race track. They wanted to raise money and awareness about meningitis, and to celebrate Jennifer’s life.

“Jennifer’s passing was reported in several local and state newspapers, because hers was the first student death from meningitis at the University of Virginia in about 25 years,” explained Jennifer’s aunt, Jamie DeVore. “People were understandably alarmed and saddened. So, the event we planned was something that would not only help our family



cope with Jennifer's loss, but could also help the whole community heal."

The next concern was how to direct the funds raised by the Jennifer Leigh Wells Moonlight Walk/Run event. "We felt it was crucial that a vaccine be found for the B-strain bacteria," Jamie noted. "This is a devastating disease that affects thousands of children annually in developed countries, and tens of thousands throughout the world. We decided to support research that would provide this needed immunization."

The family enlisted the aid of a local physician who specializes in infectious diseases to help them find scientists trying to develop a vaccine for B-strain meningitis. After conducting a thorough review of scientists' work from across the country, the family decided the most innovative research was being done by a team of scientists led by Gregory Moe, PhD, at Children's Hospital Oakland's research center.

A STRONG VACCINE CANDIDATE

"Dr. Moe's research is very promising—and we are so excited to be able to support his work," Jamie said enthusi-

astically. Cindy and three of Jennifer's aunts flew to Oakland to visit Dr. Moe and his team. "You couldn't meet a nicer person," Jamie said. "And the caliber of his research is stunning. He took us on a fascinating tour of Children's research center, and keeps us updated on his team's progress. We really feel a close partnership."

"Group B bacteria are tricky, because they masquerade as normal human cells," Dr. Moe explained. Virtual wolves in sheep's clothing, the bacteria are encapsulated in a sugar called polysialic acid, also found on the surface of many human cells. "Because of this similarity, our immune system doesn't recognize the potentially deadly bacteria as being foreign to the body—so it evades our natural defenses."

After careful analysis, Dr. Moe's team discovered that group B bacteria also have a small amount of another form of sugar on their surface, called de-N-acetyl sialic acid. "This sugar is not found on normal human cells, which makes it an attractive focus for the development of a vaccine. We believe that targeting this specific sugar will allow

us to construct a 'universal' vaccine that will provide immunity to all the group B bacteria substrains found in various parts of the world," Dr. Moe continued.

Dr. Moe presented his new vaccine results at an international scientific conference on meningitis in Rotterdam, Netherlands in September. The conference is held every two years to discuss the latest developments in combating this devastating disease.

"This is just such awesome news," exclaimed Jamie. "Not a day goes by that I don't think about Jennifer, and what she might be doing if she were alive. I think she'd be proud of what's been accomplished."

It will take several more years of research and clinical trials before Dr. Moe's vaccine candidate can be released for human use. "We are so grateful for the commitment of Jennifer's family," said Dr. Moe. "It is a great honor to have the financial support of the generous, compassionate people of Charlottesville who participate each year in the Jennifer Wells fundraiser. They have done an incredible thing—they've turned a terrible tragedy into hope."

"I feel that Jennifer will always be with me, and that keeps me going," Cindy said softly. "Doing this fundraiser every year brings her closer, and helps me feel that I am still taking care of my child, as every mother strives to do." ■

To learn more about Dr. Moe's work and all of the amazing research at Children's, visit www.chori.org.

If you are interested in setting up your own community fundraiser for Children's, please contact the Children's Hospital Foundation at 510-428-3814 or foundation@mail.choi.org.



(Left) Gregory Moe, PhD. (Above) Colonized electron micrograph of meningococcus.