After Tragedy, Measles Warning For Adopted Kids

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One of the most joyous days of their lives was when Erica and Dr. Brian Parker took home Emmalee Madeline Snehal from an orphanage in India. They had waited 2 1/2 years for a child of their own and fell in love with Emmalee as soon as they saw her picture.

From the beginning, Emmalee — who was adopted when she was 2 1/2 — was an energetic child. She was outgoing, with a smile for everyone. She loved animals, ballet and singing. She attended Beth Israel Religious School, services at Moses Montefiore Anshe Emunah Congregation and Chabad of Owings Mills. She loved being Jewish.

Life was not perfect for Emmalee, a Littlestown, Pa., youngster who had behavioral problems and learning challenges. She was diagnosed with attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder and fine motor skill issues. She was on Ritalin and saw a psychiatrist, pediatric neurologist and occupational therapist.

It wasn’t until later that the Parkers would begin to connect the dots. They would make a connection that these diagnoses were probably the result of a rare disease called subacute sclerosing panencephalitis (SSPE), which later would take Emmalee’s life.

According to the National Institute of Neurological Disorders and Stroke, SSPE is a “progressive neurological disorder ... that affects the central nervous system.” Most individuals who develop SSPE have a history of measles infection before age 2. Its incidence is highest in developing countries, particularly India and Eastern Europe.

Difficult as it is, the Parkers said they are sharing their story about Emmalee because they want to ensure all families inoculate their children against measles. They also want other families who have adopted or are planning to adopt children internationally to understand the possibility that their child may have contracted measles at some point.

The Parkers had a medical dossier from the Maine adoption agency they went through that indicated Emmalee was vaccinated from the measles and there was no history of the disease. But when they learned her diagnosis, they discovered Emmalee may have contracted measles pre-natally or before she was vaccinated. There was also the possibility that the inoculation in India was ineffective.
According to Beth Lutton, executive director of adoptions services at the Rockville-based Jewish Social Service Agency’s Adoption Options, which has a partnership with Jewish Community Services of Baltimore, “Depending on the country, the child may have been abandoned, there may be no background information, or no history of prenatal care.”

Ms. Lutton said families looking to adopt internationally should share medical records with physicians at international adoption medical clinics, such as the one at Baltimore’s Kennedy Krieger Institute. These physicians can review medical information and suggest additional medical testing before the adoption takes place.

For Emmalee, the decline came rapidly. It was last August that her feet began slapping the ground and her ankles became floppy. When eating, her head involuntarily dropped to the table.

After visits to several doctors and neurologists, the family found its way to Children’s Hospital of Pennsylvania in Philadelphia. Mrs. Parker still recalls the moment when Dr. Sudha Kilaru Kessler of CHoP’s division of neurology, saw Emmalee. “I saw her expression. She looked at us, she looked at Emmalee and she asked us, ‘When did she have measles?’” Mrs. Parker said.

Several days later, after extensive testing, including a spinal tap that would provide the definitive diagnosis, the family learned the devastating news. Most individuals die within one to three years of a SSPE diagnosis.

During the next few months, the Parkers did everything they could while watching their daughter’s rapid decline. They consulted with experts, other families with SSPE children and Turkish physician Dr. Banu Anlar, a leading researcher on the disease.

Despite everything, other than a brief spell, Emmalee’s condition worsened. “She would get tired at the end of the day and her head would drop at the dinner table,” said Dr. Parker. “I had to hold her head up so she could eat or put a bumper on the table so she wouldn’t hurt herself.”

On the Sunday before Thanksgiving, shortly before her 8th birthday, Emmalee slipped into a coma. She died Jan. 2.

For her parents, who grieve every day, there is hope that others will learn from their tragic experience. For those adopting internationally, Mrs. Parker said, make sure you thoroughly review any records you get with your doctor. “If you don’t see anything about measles,” she said, “specifically ask what they know about measles history, and not just about whether they had the vaccine.”

Mrs. Parker added, “Not inoculating your kid is not funny. SSPE is fatal. There is no treatment.”