

## Rare disease leaves girl with fragile skin

by Dean Olsen

Gabrielle Ladage soaps up her hands, rubs her slick palms together, looks at them and smiles while a steady trickle of warm water flows from a faucet into her tub.

**HANDLE WITH CARE** - Heather Ladage, 24, hugs her daughter, Gabrielle, after finishing a two-hour bathing and bandaging process to protect the girl's skin. Gabbie has a rare skin disorder called epidermolysis bullosa, which makes her skin susceptible to blisters and bruises. CNS Photo by Shannon Kirschner. The cycle repeats itself over and over as the 1 1/2-year-old delights in her morning bathtub ritual. It's relaxing for Gabbie. And it's one of the few times her mother doesn't have to worry much about the rambunctious girl damaging her fragile skin.

Caring for a child with a rare skin disease known as epidermolysis bullosa is especially tiring for Heather Ladage, who spends 1 1/2 to two hours every other day meticulously cleansing her daughter and changing the yards of gauze and bandages wrapped around her arms and legs. But Heather, a 24-year-old unwed mother who lives with Gabbie in a government-subsidized apartment in Pawnee, Ill., is not looking for pity.

Heather is unemployed and could use more respite care for her only child, but mostly she wants to expand public awareness about EB, a genetic and sometimes fatal skin disorder that affects an estimated 12,000 to 25,000 Americans - at least one out of every 50,000 births.

There is no cure for the disease, which has several forms and can cause chronic, painful blistering inside the body and on the skin. Some people have milder forms and never are treated or diagnosed.

Many people wonder if Gabbie - who also has blisters and wounds on her face, arms and legs - has been abused or is accident-prone.

"We get a lot of staring and a lot of gawkers," Heather said. "That's the worst part of the disease."

Heather's success in keeping Gabbie healthy thus far is a testament to her persistence, according to her mother, Patricia Ladage, 54, who farms with her husband, Wayne, in nearby rural Virden.

All parents worry about their children, but the emotional and physical toll of caring for a child with EB "just multiplies it times 10 or more," Patricia Ladage said. She said she worries about Heather "losing it." Heather, a petite but wiry former high school softball and volleyball player, said she gets depressed and frustrated at times but is determined not to fail her daughter. "You just can't be careless with this disease," she said, "and I have lived carelessly in the past."

Heather was born in Springfield and grew up in Divernon before turmoil in her family led to her and her sister being adopted by Patricia and Wayne Ladage. Heather attended high school in Springfield before running away from home to live with her biological mother and eventually graduating in 2000. She said the next few years were chaotic and included her living with a boyfriend while working at a factory while the two abused marijuana, alcohol and heroin in their off hours. Heather said she spent time at a drug abuse treatment center in Jacksonville and briefly attended Lincoln Land Community College before getting a job at a Springfield collection agency, where she met and began dating Gilbert Smith, the man who would become Gabbie's father.

Smith, an Army soldier stationed in Virginia, couldn't be reached for comment. Heather said they are no longer emotionally close, but Smith does pay child support.

Heather said neither she nor Smith knew of anyone in their families with EB. When Gabbie was born in July 2005 at Memorial Medical Center, there was no sign of the disease. A month later, a big blister formed on one of her ears. Then a blister formed on an elbow, and on her cheek. But local doctors never told Heather that the sores might be signs of EB.

That's not surprising, because most doctors never see a case of the disease and know little about it, according

to Suzanne Cohen, executive director of the New York-based Dystrophic Epidermolysis Bullosa Research Association of America, or DebRA.

Gabbie eventually was diagnosed with the disease at 4 months of age by a pediatric dermatologist at St. Louis Children's Hospital. Heather said several of Gabbie's worst sores developed before the diagnosis, when Heather was unaware of precautions recommended for EB children.

Since then, Heather has found a pediatric dermatologist in Springfield. And with help from her adopted parents, she traveled to Nashville, Tenn., to learn the latest wound-care techniques at a conference conducted by DebRA.

Because Heather knows of no other families of children with EB in central Illinois, she seeks peer support from EB families throughout the world on the Internet.

## DAILY CARE

Most of Heather and Gabbie's days are spent inside their one-bedroom apartment, where they each sleep in single beds. They support themselves on the \$623 a month that Gabbie receives in federal disability benefits, \$255 a month in child support and \$200 a month in food stamps - for a total of about \$13,000 a year.

Rent costs \$86 a month, which is why Heather said they live in Pawnee, a small town, although she would like to live in Springfield and be closer to supermarkets and other amenities. They don't travel much because of the price of gas, and Heather said she finds it hard to stretch her income.

Gabbie's sores often bleed while she's sleeping, which leaves Heather with more laundry to do in the

morning. "Her bed will be covered in blood," Heather said. "It looks like someone was murdered in her bed."

The baths, in water treated with bleach, give Heather a chance to prevent Gabbie's sores from becoming infected. Heather sometimes dreads the baths because they take so long, and her back gets sore from leaning over the tub.

After Gabbie's bath, Heather sets up a card table as a changing table, complete with five rolls of gauze and a variety of high-tech bandages that grip the skin without adhesives. Regular bandages can pull off layers of skin when they are removed. "The more she's wrapped up, the less actual contact her skin has with anything else," Heather said.

Gabbie doesn't complain when the bandages are changed even though Heather knows that the sores are painful. Heather slathers her daughter's skin with lotion to prevent chafing. "Raise your arm up," Heather told her while wrapping Gabbie's left elbow. Gabbie complied and seemed to enjoy the attention. "Such a smart girl - you're so smart, Gabbie," Heather said.

Heather estimated that the gauze and bandages cost \$1,000 a month. She said she is grateful to have the supplies covered by Illinois' Medicaid program for children - All Kids - which also covers Gabbie's medical care.

Some states' Medicaid programs, and some private insurance plans, don't pay for bandages, which can create major financial headaches for EB families, according to Cohen. Heather said she takes Gabbie with her when they go shopping for food at Wal-Mart and Meijer. The mother and daughter also play outdoors, though Heather won't take Gabbie outside their air-conditioned apartment when the temperature exceeds 70 or 75 degrees because the heat weakens the skin and causes her sores to bleed.

"The weather's too crazy," Heather said. "We need to move to a colder climate. We feel like we're quarantined in our house."

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