



THE PLAIN DEALER

Dakota Bihn now going to school

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How is Dakota Bihn, the Olmsted Falls youngster who underwent a controversial and grueling umbilical cord-blood transplant 2 1/2 years ago to try to arrest her juvenile Tay-Sachs disease, an extremely rare and fatal inherited condition?

The good news is that 9-year-old Dakota is going to school — special education classes at Falls-Lenox Primary School — and she loves it, says mother Julie Bihn.

The first year after her January 2006 transplant at Duke University Medical Center in North Carolina, Falls-Lenox sent a teacher to work with Dakota at home. Last year, she got to go to school all year. This fall, Dakota will enter the third grade, Bihn said, spending most of her day in special ed.

But the bad news is that the debilitating disease, which destroys the central nervous system, hasn't gone away. And Dakota is very much showing the effects. The transplant, which some medical ethicists described as experimental and scientifically unjustified, may have slowed the disease in the beginning, Bihn said, although she and her husband, Ken, are not even sure of that.

“At this point, we're not really seeing any progress,” Bihn said. “She's regressing some now. Her seizures are getting a little worse. And she's pretty much stopped talking. She doesn't talk very much at all.”

Still, she and her husband have “absolutely no regrets whatsoever” about proceeding with the transplant because the alternative — doing nothing — was unbearable, Bihn said.

The rest of the family, meanwhile, is coping, she said. “It's not easy, because the disease is still there. But for the most part, she still smiles and gives kisses and that gets us through our days.”

And to help wrest something more positive from their ordeal with Dakota, the Bihns started their own foundation last year, called the Cure Tay-Sachs Foundation (curetay-

sachs. org) to raise money for research. A year old in August, the foundation has already raised more than \$400,000, Bihn said.

“We don’t think that we can necessarily find a cure to help Dakota,” Bihn said. “But there has to be something that can be done to help these kids.”

— Bob Paynter

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