

----- Stacey a True Hero -----

We doubt she ever wanted to be a hero, but that is how everyone will remember Stacey Vorpahl.

The 19-year-old Fort Atkinson woman who died Oct. 9, 2004, probably would have preferred being known as “that freckled-faced kid” or “the girl with curly red hair” or simply “Stacey,” but fate changed her life early on and she became the heroic poster child for a rare and fatal disease.

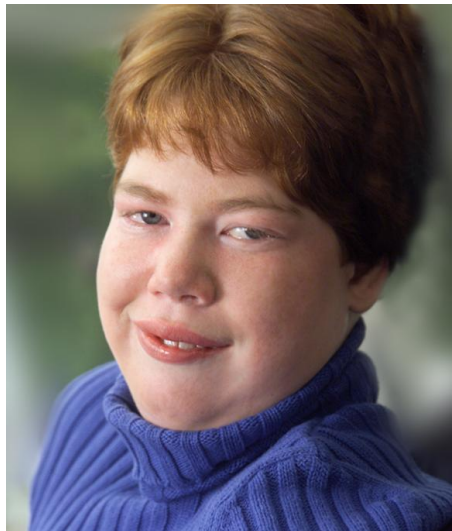
Stacey was only 18 months old when she was diagnosed with Niemann-Pick Disease-Type C, an illness that causes progressive deterioration of the nervous system by blocking the movement of cholesterol within the body’s cells. Cholesterol builds up in the vital organs, causing an enlarged spleen and liver, clumsiness, problems with balance, poor muscle control, impaired eye movements, slurred speech and dementia.

She began showing some symptoms in first grade and started experiencing seizures about age seven. Stacey needed a feeding tube at nine, slowly lost her ability to walk and, by age 10, was confined to a wheelchair. Most recently, her eyesight had dimmed.

Yet, despite the many medications, despite the regimen of physical therapy, Stacey never gave up. Even when she could no longer talk, she

retained an infectious smile. Even when her vision began to fail, she kept a twinkle in her eye.

It was that spirit, we think, that took Stacey far past the life expectancy for a Niemann-Pick Type C patient ... that, along with personal attention and care, and the morale and financial support of an entire community.



And it was that spirit, we think, that pushed Barb and Gary Vorpahl to join the families of six other Niemann-Pick children to create a foundation that has raised \$3.4 million to help fund 36 research projects, including more than \$305,000 from Fort Atkinson residents alone. Many strides have been made, including the identification of the gene that causes Niemann-Pick Disease Type C, and most recently, its help in learning about the basic causes and early progress of Alzheimer’s and cardiovascular disease.

With only 1,500 people in the entire world having been diagnosed with Niemann-Pick Disease, it would not be a stretch to say that Stacey’s infliction and her family and friends’ commitment vaulted an otherwise unknown — and unfunded — illness into the public eye.

Yes, Stacey Vorpahl was, indeed, a hero. For nearly two decades, she faced illness and certain death with a joyful smile, courageous heart and hopeful outlook. In turn, Stacey spread that joy, courage and hope to others near and far ... and she continues to do so yet today.