

THE PROGRESSION OF NIEMANN-PICK DISEASE

Stacey Lynne Vorpahl

1/3/85 - 10/9/04 NPC



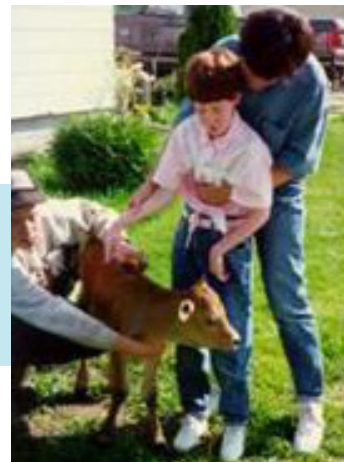
Stacey Lynne our daughter, was born on January 3rd, 1985. She was jaundiced at birth but otherwise seemed happy and healthy.

Stacey was only 18 months old when she was diagnosed with NPD due to an enlarged liver and spleen. She exhibited no other symptoms other than slight balance problems.



By about age five, Stacey was exhibiting vertical gaze palsy, slurred and repetitive speech, learning problems, and cataplexy (sudden loss of muscle tone).

When Stacey was seven, seizures began and her falls increased in frequency and severity. She was no longer able to speak, had difficulty swallowing, and walked only with assistance.





By age nine, Stacey was confined to a wheelchair and was completely incontinent. Her arm strength and control was diminished, and the seizures increased in frequency. Stacey was now unable to swallow, and so was fed solely through a stomach tube.

Chronic respiratory problems had set in by the time Stacey was thirteen. She had lost all motor control and the frequency of seizures had increased to 15-20 per day.



By 18 years of age, Stacey had lost her sight, a tracheotomy was needed and 24-hour skilled nursing care was necessary to keep her airway clear.



***Stacey passed away on October 9, 2004
at the age of 19 years.***