

Lydia Giordano

Where do I begin... Steve had issues with his learning When he was a toddler so I had Special education services to help him. I knew something was wrong I thought maybe ADHD but doctors told me he was too young to be Diagnose. Steve was very sickly.. asthma at 6 months.. allergic to dairy until 5 years old..i was always stuggling with steve s energy.,My doctor says usually around 6 years old the boys tend to mellow down. At six I took him to see someone and they told me he had ADHD and we put him on conserta.. He was only on it for about four months because I felt I can control him during the summer months.. He was not a disrespectful boy he was just very hyper all over the place. Summer is over and now he's going to first grade and Stevie was called into the principal office almost every other week for something he was doing in class.. He didn't do that well that year he was going to repeat first-grade once again but in the new school For learning disabilities.. September 28, 2006 was his first day and his last We were in the Van and his head had dropped ..I asked him are you okay Steve picked his head up and said I ok mommy.i called my pediatrician.. That same night she had sent me to the emergency room. She did not know what was wrong with Steve but she felt something was different. She had order a CAT scan at the emergency room Sitting there with his father Steve playing as always.. Waiting for results from the CAT scan .The doctor came towards us.The look was like the kiss of death on his face.. I said was Steve CAT scan.. bad. He said mom is not good. it was confirmed two days later he had X-linked Adrenoleukodystrophy. Within two weeks Steve stop walking. Steve was in a wheelchair one month later for Halloween ..two weeks after that Steve could barely talk by the second month. And by the third month we went to see if Steve could recieve bone marrow transplant at duke in north carolina and I did not know Steve was blind by then.. duke said Steve Was not a candidate for bone marrow transplant I asked the doctors how long does he have to live? I was told 3 to 6 months .. So I took him home got a feeding tube and the trache eventually when he almost died in December 2007 since then Steve has a trache g tube and no mobility.. I was in a happy and healthy relationship for 18 years this disease devastated his father Steve Conley Sr.one day he didn't come home he just stayed at his mothers .I was taking care Steve jr alone with home health aides and then I got nurses We lost our house his father own in new jersey..financially he could not afford the Mortgage .because of loss income from me.. Steve father became depressed & gave up hope.. September 28, 2009 three years exact to the day my son got sick his father dies of a heart attack 43 years old and my life has never been the same since.. Steve has live now 6 years.. And life has been hard.. This was not how I thought I would spend my golden years.. I asked of you please pass this bill so no other families would have to go to the pain that I go through every day..