

Message from Jenny's Parents

We, Barb and Phil, know of no better way to honor Jenny's memory than to help the neurologists and immunologists who continue to investigate the causes of her death. If you know of any cases of young people between the ages of 9 and 30 who have experienced weakening and/or prolonged paralysis, please send a note to this blog. We will forward the information to medical professionals who are investigating these cases. Please note that we are interested in all such cases, regardless of whether they are male or female, or possibly linked or not linked to the HPV vaccine.

Posted by [Jenny's family and friends](#) at [12:38 PM](#) 10 comments:

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Jenny Is Dead, But Her Question Stands

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On a sunny afternoon in May 2007, a tearful Jenny told her mother how her seventh-grade gym class laughed when she tripped on a hurdle that everyone else cleared easily. A few weeks later came the odd limp. Gradually, weakness spread; her muscles atrophied; her world shrank.

Jenny's parents frantically rushed her to an ever wider range of specialists, to no avail. By spring 2008, Jenny was a quadriplegic who could breathe only with machine support. She clung to life for almost a year but she never made it to see another spring.

No one knows exactly when Jenny's disease began—or what disease she had. World-class neurologists suspect Lou Gehrig's disease, or amyotrophic lateral sclerosis (ALS). This relentless killer spares the mind, while methodically destroying the body's motor neurons until the patient body slips into total, irreversible paralysis.

Yet medical opinion is not unanimous. The CDC estimates the odds of ALS among teenage girls at 1 in 3 million, less than those of being struck by lightning. A far more common cause of paralysis among teenage girls is autoimmune disease.

This is why world-class immunologists suspect that Jenny had a potentially treatable autoimmune disorder mimicking ALS, possibly triggered by the Gardasil vaccination - for protection against the virus that causes cervical cancer - that she got in March 2007, just weeks before her hurdle accident.

As if the anguish over Jenny's condition weren't enough, we are now inviting added trouble. As you might imagine, merely suggesting a link between a vaccination and subsequent illness polarizes people into feuding camps. So, we hasten to add that we are not anti-vaccine zealots (would we have been so quick to give Jenny a new vaccine if we were?). As professors who use statistics in our everyday research, we know that correlation does not mean causation. We agree that cost-benefit ratios generally favor vaccines. Jenny might be an isolated case in a capricious universe.

But we also see the other side. Jenny could be the tip of a growing cluster of grimly similar cases thus

far invisible to regulatory watchdogs. That is why we reported Jenny's case in spring 2008 to the Vaccine Adverse Event Reporting System (VAERS), the federal database for monitoring adverse events. And that is why we have tried repeatedly—and unsuccessfully—to persuade the Center for Disease Control (CDC) to investigate how many Jennys are out there. Thus far, the CDC insists that Jenny is just an isolated statistical blip. They might be right. But wouldn't it be important to confirm that hunch?

Remarkably, the CDC drew confident conclusions before it had conducted a rigorous study. It limited its search to the VAERS database—even though its shortcomings are well known to insiders. For one thing, it is a voluntary reporting system that almost certainly undercounts adverse events. Many doctors have even never heard of it. And the rest are busy people who are wary of vaccine kooks. Second, VAERS data are also poorly organized, notably, the reporting form does not even offer an entry for diagnosis.

Finally, the accuracy of VAERS data is questionable. It is the rare entry that says “further information requested”; most entries contain no follow-up information on what happened to the patient including whether she lived or died. It is unclear who, if anyone, is tracking the adverse events and sorting cases into similar clusters. And it is impossible to compute how many of all the vaccinated girls are now ill if the government refuses to reveal how many vaccinations in each lot number were administered (such information is proprietary!).

The CDC does not inspire confidence, so we conducted our own shoe-string search to determine whether Jenny was alone. We created a website (jenjensfamily.blogspot.com). Although this website has only drawn 40,000 visitors, it has out-performed the federal government in finding girls ominously similar to Jenny (current score is: Jenny site 2; CDC's VAERS: 0).

One does not need to be a statistician to see how unlikely it is that these two other girls are the only cases out there—or how frightening it is that we already know of three documented cases of girls (those two plus Jenny) who developed ALS within several months after their vaccinations. After all, if the odds of ALS in teenaged girls are 1 in 3 million and we found 3 in only 40,000, it is very possible that many other of the 6 million girls vaccinated have already developed severe neurological collapse, like Jenny.

Surely, one does not need to be a conspiracy theorist to ask: How many catastrophic 1-in-3 million events, all within months of Gardasil vaccinations, will it take to get the CDC to launch a major investigation of possible causal connections?

Vaccination, like national defense, is a public good. Society asks citizens to make small sacrifices for our collective safety. Occasionally, some pay a horrific price. As in war, we should honor the fallen, including those fallen to friendly fire. But, by accident or design, our government has made it unduly difficult to identify the fallen in the war against infectious diseases. Without good data, we cannot have a serious policy debate—and we will never know how many Jennys are out there.

Author Note: Barbara Mellers and Philip Tetlock, the parents of Jenny Tetlock, are professors at the University of California - Berkeley. Barbara Shapiro, M.D., Ph.D. is an associate professor of neurology at Case Western University.