

Bill Would Speed Process to Create More Child Cancer Drugs

By ALEXANDRA JAFFE, HOUSTON CHRONICLE

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Five-year-old Delaney "Laney" Starcher (right) who is diagnosed with Diffuse Intrinsic Pontine Glioma (tumor in brain stem) is fingerprinted as her sister Bailey Starcher (right 7yrs.) looks on as Laney has her wish to be a cop granted by Harris County Sheriff Adrian Garcia at the the sheriff department 1301 Franklin location Saturday, June 13, 2009, in Houston. (James Nielsen / Chronicle) Photo: James Nielsen / Houston Chronicl

This was supposed to be the year for Jacob Froman's bar mitzvah, except that a rare and fatal brain cancer reached out for him first.

Just 10, Jacob died in 2009, two years after a diagnosis of medulloblastoma, a rare brain cancer with no drug designed specifically to treat it.

During the arduous months of ultimately unsuccessful treatments, his mother, Nancy Goodman, discovered that few pharmaceutical companies are fully invested in developing drugs specifically targeted toward children's cancer and other rare diseases.

She established Kids v. Cancer, her hope for children suffering from pediatric diseases that lack drug treatments. A national organization, it aims to create a pediatric brain cancer tissue bank for researchers as well as a specific pediatric cancer subsection of the National Cancer Institute to provide funding for pediatric cancer research and incentives to pharmaceutical companies to create more drugs.

Her persistence led her to Texas Republican Rep. Mike McCaul, who has sponsored the Creating Hope Act that, if passed, would offer drug companies the ability to expedite more profitable drugs through the Food and Drug Administration review process in exchange for the creation of new drugs to combat rare pediatric diseases.

"Until we change the culture of drug companies to find a cure, we're never going to win this battle," McCaul declared.

Market not lucrative

According to Texas Children's Hospital, only about 12,000 children and teens are diagnosed with cancer each year, so the market for pediatric cancer drugs isn't very lucrative.

"There's no profit in childhood cancer," McCaul said. "You would think childhood cancers would get the most attention, but just the opposite. It's been neglected for decades."

With cancer, the drugs and therapies used to treat adults often don't affect children the same way, and can lead to health issues or new cancers down the road. Because children's cells multiply at a quicker rate than those in adults, chemotherapy - which attacks rapidly multiplying cells to stamp out the malignant ones - tends to affect children negatively in ways that adults don't experience.

"There are kids with scores of other neurological diseases and they need help, too," said Goodman. The legislation is designed not only for children with cancer, but for "kids with other terrible rare diseases who ... have no new drugs developed for their diseases."

Texas resident Shannon Hayes, of Spring, stood behind McCaul last week when he announced the bill. Baring a bald head in memory of her daughter, she is part of 46 Mommas, a group of women touched by pediatric cancer who shave their heads to raise awareness and money for the St. Baldrick's Foundation.

Bill's prospects good

Hayes' daughter, Delaney Starcher, died in 2008 at age 5 from a rare brain cancer. The disease builds around the brain stem like a "handful of sand thrown into a field of grass," she said, making it difficult to treat.

McCaul is founder of the Childhood Cancer Congressional Caucus; his wife sits on the board of Houston's University of Texas M.D. Anderson Cancer Center, one of the world's foremost cancer treatment centers. He and 19 other House members, including Texas Reps. Michael Burgess, Henry Cuellar and Pete Olson, co-sponsored the bill, which McCaul said he expects will pass easily.

And Goodman hopes that, eventually, every child with cancer will have the chance to throw a big bash when he or she turns 13.

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