Getting Big Pharma to Treat Childhood Cancers

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Sept. 23, 2011

At age five, some kids have won pee-wee sports championships or perhaps a class spelling bee, but for Luke Fochtman of Okemos, Mich., his fifth birthday marked his victory over a much larger foe -- in a life-or-death battle with childhood cancer, Luke has come out on top.

"Through 72 weeks of treatment, chemotherapy, 105 fevers, he never said 'no' to us," says Luke's mom Monica Fochtman, 36. "That to me was very inspiring and humbling. To be in the presence of that kind of grace gave me the courage to keep going," she says. Though Luke's type of pediatric sarcoma has a high recurrence rate, he is currently cancer free.

In honor of her little hero, Fochtman shaved her head this week alongside 45 other mothers of children with cancer as part of a larger effort to raise awareness for pediatric cancer. This "Shave for the Brave" event took place on Wednesday in the nation's capital as part of a series events leading up to Friday's the Second Annual Childhood Cancer Summit and meeting of the Congressional Pediatric Cancer Caucus.

One of the biggest issues on the docket this year is the dire need for better pediatric cancer treatments. Because there are so many different types of pediatric cancers, the market for any particular drug would be small, making it highly unlikely that pharmaceutical companies will take up the cause. As a result, the vast majority of drugs

used on pediatric cancer patients today were created for adults 30 or even 50 years ago.

Luke's chemotherapy was developed 25 years ago, says Fochtman, and was so harsh that it caused repeated bacterial infections in her son as his immune system was completely knocked out by the chemo rounds.

"We are desperate for new treatments. We have not had a single meaningful improvement in pediatric cancer medication in decades and the children have paid the price," says Dr. Peter Adamson, chief of the Division of Clinical Pharmacology & Therapeutics at The Children's Hospital of Philadelphia. "Even though we cure four out of five pediatric cancer patients, even those who survive often go on to have lifelong side effects from the treatment we give them."

Adamson will be presenting to the Caucus Friday, arguing for changes in legislation to make developing pediatric cancer drugs more financially appealing to pharmaceutical companies.

Getting Big Pharma to Fund Pediatric Cancer Drugs

Friday's summit will be geared towards members of congress, hill staff, and pediatric cancer advocates with a panel on "The Future of Childhood Cancer Drug Development."

Two previous legislations concerning pediatric drugs are up for modification and a new legislation, known as the Creating Hope Act, will be presented to the caucus. The bill will constitute the first federal incentive to pharmaceutical companies to specifically research and market pediatric cancer drugs.

"We live in the country with the world's leading researchers and scientists, and yet almost none of that talent is being directed toward drugs for our children. The problem is that the size of the drug markets for pediatric cancer drugs is too small for drug companies to enter," said Nancy Goodman, founder and director of Kids v Cancer in a statement for the Summit. Goodman, whose son Jacob passed away five years ago from pediatric brain cancer, has been instrumental force in the creation of the Creating Hope Act.

"There have been a number of legislative efforts to promote new drug development, but frankly, they have not been effective for pediatric cancer drugs," Goodman said.

The previous laws, the Best Pharmaceuticals for Children Act (BTCA) and the Pediatric Research Equity Act (PREA), both deal with encouraging pharmaceutical companies to do clinical trials for their adults drugs on kids to see if there are important pediatric applications of a new drug. The Creating Hope Act however, will allow companies that research and develop a pediatric cancer drug to expedite the FDA review of another drug they are developing.

The idea, explains Adamson, is that selling a pediatric cancer drug is not very lucrative, because a single type of pediatric cancer may only have a few hundred new patients each year, as opposed to, say, a diabetes drug which would have millions. This act would make investing in pediatric cancer research more economically viable by allowing them to get another, more lucrative drug they produce, to market faster.

"Instead of nine months in FDA review, it will happen much faster," says Adamson.