



The way to faster cures

As the father of a child with recurrent medulloblastoma, and as a cancer survivor myself, I was deeply moved by the May 27 Health article “For children with cancer, surviving is the first fight,” in which Amy McHugh shared her daughter Emily’s story and explored the lifelong complications that can result from current cancer treatments.

Right now, our society — across the private, public and philanthropic sectors — is woefully failing kids with cancer. According to the Pediatric Cancer Foundation, less than 4 percent of the U.S. federal cancer research budget is allocated to the study of pediatric cancer. And within that meager percentage, brain tumors — which are the leading cause of cancer-related death in children — receive an even smaller fraction.

This neglect occurs because of a perverse market logic. Because brain tumors affect relatively few children, they do not attract the interest of the pharmaceutical industry, which prioritizes research and development for diseases that offer a greater financial return. Thus, families like mine — and thousands of others around the world — are forced to fight not only against the disease, but also against the structural indifference that hinders research progress and the development of new therapeutic alternatives.

As a result, children diagnosed with these tumors face a devastating scenario: few therapeutic options, highly toxic treatments and, for many, a severely limited life expectancy. Even among those who survive, the side effects of outdated therapies impair their neurological, physical and emotional development.

We need research to move more quickly, and we need new funding models that aren't constrained by the need to turn a profit. At the Medulloblastoma Initiative, we've tried to marry a philanthropic financial structure to a start-up mindset, and in the 2 ½ years since our launch, we've been able to take one of our experimental treatments, Matchpoint, to clinical trials. Similar efforts that rely on public funding can take as long as 10 years.

Children with cancer are counting on us. We should act quickly to give more of them a fighting chance and the healthy, bright futures they deserve.

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