

TESTIMONY OF
U.S. REPRESENTATIVE BRIAN FITZPATRICK. (PA-01)

HOUSE COMMITTEE ON APPROPRIATIONS
SUBCOMMITTEE FOR LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION

PUBLIC WITNESS HEARING
MARCH 27, 2019

Chairwoman DeLauro, Ranking Member Cole, members of the committee, thank you for hosting today's hearing and giving me the opportunity to discuss one of my priorities for FY 2020 appropriations.

On September 15, 2016, at the age of seven, Philomena "Bean" Stendaro was diagnosed with Diffuse Intrinsic Pontine Glioma, or DIPG. DIPG is one of the most devastating cancers with a zero percent survival rate and median survival of nine months from diagnosis.

Bean was an exceptional athlete and mastered every sport she participated in. Like most of us at age seven, she was full of energy, loved playing with friends and family, and perhaps unlike some of us at age seven, she loved going to school.

Just ten months after her diagnosis, on July 23, 2017, Bean lost her battle to DIPG – she was eight years old.

The research of the National Institutes of Health (NIH), a collection of America's preeminent medical research centers, is a critical part of meeting health care challenges, strengthening our economy, inspiring the next generation of scientists, and maintaining our nation's leadership in innovation.

NIH has provided funding and support for some of the world's best and most important medical research. The NIH has, since its beginning, been the best hope for finding cures, improving treatments, and gaining better understanding of the diseases and conditions that affect millions of Americans.

I encourage the committee to double the amount of funding for cancer research at the NIH – but to reach a minimum of \$10 billion in FY 2020 for the National Cancer Institute – with a significant percentage of those funds focused on pediatric cancers and specifically to research for an effective treatment and cure for DIPG.

I also encourage the committee to increase funding to the Pediatric Brain Tumor Consortium – and specifically a 25 percent increase in funding aimed at homerun cancer strategies through pediatric brain tumor research. Investing in research for a homerun cure type cancer like DIPG will lead to curing other pediatric brain cancers, and eventually to nearly all cancers.

As the committee looks for ways to increase the speed of research – especially with respect to data sharing – I encourage you to look to organizations which have already developed systems and methods which can expand and scale accordingly. For example, in 2011 organizations and researchers identified a need to better understand DIPG and other brain cancers. Frustrated with a lack of information and collaboration, they started a partnership which now consists of 110 institutions in 14 countries and over 80 foundations and chapters representing hundreds of patient families working together to share data. Out of a patient diagnosis rate of approximately 250 per year, this partnership is already sharing 1,400 patient data sets. Before the DIPG registry, the largest sampling was around 70 patient data sets. With data sharing comes the need to protect patient privacy and standards for uniform collection. There should be a standard process for collecting and inputting data in order to protect the integrity of research and increase the speed and effectiveness of cancer research. It is also important we avoid duplication and that we are using every taxpayer dollar wisely. If a successful registry already exists, any taxpayer dollars going towards data sharing should bolster the registry and use it for other cancers. By using the best existing models, we can promote collaboration and potentially save more lives quicker.

The fight against cancer is one that transcends politics. By working together, we can pass common sense bills that increase the quality of life and care for patients, and ultimately put an end to this despicable disease. And as co-chair of the Cancer Caucus, I'm committed to finding and implementing solutions which will help us find treatments – and eventually a cure – for cancers of all types.

Thank you again for holding today's hearing. I yield back.