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JOSH GOTTHEIMER

New Jersey's 5th District

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PRESS RELEASES

RELEASE: GOTTHEIMER LEADING BIPARTISAN LEGISLATION TO BOOST INVESTMENT IN PEDIATRIC CANCER RESEARCH TO FIND MORE CURES, SAVE LIVES

BIPARTISAN "FAIRNESS TO KIDS WITH CANCER ACT" WILL INVEST IN MORE R&D

HACKENSACK, NJ, May 25, 2021



Above: Gottheimer announces bipartisan legislation to boost pediatric cancer research.

Left to right: Aubrey Reichard-Eline, brain cancer survivor Grace Eline, Gottheimer, HUMC President & Chief Hospital Executive Mark Sparta, and Christine FitzPatrick, who lost her 6-year-old son Tommy to brain cancer.

HACKENSACK, NJ – U.S. Congressman Josh Gottheimer (NJ-5) joined North Jersey medical experts, families, and cancer survivors to announce [bipartisan legislation](#), the *Fairness to Kids with Cancer Act*, to increase federal investment in pediatric cancer research – so that we can invest in more clinical trials and save more children’s lives.

Right now, only 4 percent of federal cancer research investment is allocated to pediatric cancer. The *Fairness to Kids with Cancer Act* will adjust federal investment in pediatric cancer research to match the percentage of American citizens under the age of 18. According to new 2020 Census data, 22 percent of the U.S. population is under the age of 18, meaning the allocation would increase the funding rate to 22 percent.

Cancer is the number one cause of death of children from any disease. According to the CDC, New Jersey has the third highest

rate of pediatric cancer in the country.

“It’s heartbreaking, because there are children behind every statistic. Pediatric cancer has touched far too many families, including my own. With the bipartisan Fairness to Kids with Cancer Act, we will pave the way for more cures and we will save lives,” **said Congressman Josh Gottheimer (NJ-5)**. “I’m looking to pave the way for New Jersey, and great centers like here at Hackensack Meridian, to be leaders in finding that hope, not just for kids in North Jersey, but nationwide, and around the world.”

“Being able to represent those that are in the fight now, those that have passed away, and those that will be in the fight tomorrow is such an honor and I am grateful to be able to do this for the childhood cancer cause,” **said 12-year-old brain cancer survivor Grace Eline**.

“Cancer is not something you want in your vocabulary and especially not in your home with your child. Adult research is important, but what about kids? It is critical to fund childhood cancer research and improve outcomes for children with lifetimes ahead of them,” **said Grace’s mother, Aubrey Reichard-Eline**.

“Pediatric cancer research is woefully underfunded at the federal level. We are grateful for and supportive of Representatives Gottheimer and Fitzpatrick and their colleagues for their efforts to address that with this bill. We lost our six-year-old son, Tommy, to pediatric brain cancer in 2019. The awareness and funding that this bill will bring to the cause will make a difference in the lives of so many children who are bravely fighting this disease just as Tommy did,” **said Fifth District residents Christine and Andrew FitzPatrick**.

“It is heartbreaking that only 4% of the annual government funding for cancer research is directed towards childhood cancer research. Hackensack Meridian Children's Health is grateful to Congressman Josh Gottheimer for paving the way for our hospitals and so many

others in this state to continue our cutting-edge research and life sciences development providing hope to children, not just in New Jersey, but around the world,” said **Mark Sparta, FACHE, President, Hackensack University Medical Center.**

“Cancer is the number one cause of death by disease among children and it does not have to be. We need to increase funding for pediatric cancer research, it is critical to accelerating the progress. We owe it to the children in our pediatric ward and their families who deserve to live happy and healthy lives,” said **Alfred Gillio, MD, Pediatric Hematologist-Oncologist, Hackensack University Medical Center.**

“We desperately need more treatments that are dedicated to childhood cancer. Many people may not even know that the drugs we use to treat children were in fact developed for adults,” said **Dr. Stacey Rifkin-Zenenberg, Pediatric Hematologist-Oncologist, Hackensack University Medical Center.**

Every year, about 12 drugs are developed in the U.S. and approved by the FDA to treat adult cancers. However, since the 1950s, there have only been a total 47 drugs developed and approved by the FDA for pediatric cancers.

For example, while brain cancer is the leading cause of disease related death in people under the age of 20, there has not been a child-specific drug developed for brain cancer since the 1970s. In fact, some children receive the same treatment that Neil Armstrong’s daughter received in the 1960s.

Gottheimer made the announcement at Hackensack University Medical Center’s John Theurer Cancer Center, alongside Hackensack University Medical Center (HUMC) President & Chief Hospital Executive Mark Sparta, Ramsey residents Andrew & Christine FitzPatrick, who lost their 6-year-old son Tommy to brain cancer; Aubrey Reichard-Eline and her daughter, 12-year-old brain cancer survivor Grace; Director of HUMC’s Children’s Cancer

Institute Dr. Alfred Gillio, HUMC Chief of Pediatric Pain & Palliative Care Dr. Stacey Rifkin-Zenenberg, and HUMC Children's Cancer Institute Licensed Clinical Senior Social Worker Jane Watson.

Watch the announcement [here](#).

Below: Andrew & Christine FitzPatrick (right) speak about their 6-year-old son Tommy, who passed following a battle with brain cancer.



Below: Gottheimer with 12-year-old brain cancer survivor Grace Eline.



Gottheimer's full remarks as prepared for delivery are below.

Thanks to all the incredible doctors, experts, and North Jersey families here today – who are all fighting for cures and to raise awareness for the work we still have to do.

Thanks also to everyone at Hackensack University Medical Center for their incredible work over this past year throughout the pandemic and beyond – to keep our community safe and healthy, and to continue the lifesaving work you do each and every day.

I'm also especially glad to be here at Hackensack Meridian's John Theurer Cancer Center, which U.S. News & World Report recognized just this past year as the single best cancer center in New Jersey – a testament to the great work that takes place here in Fifth District.

I'm here today to announce bipartisan legislation to boost federal investment in pediatric cancer research – because, right now, we're not getting the cures we need to help our kids.

Cancer is the number one cause of death of children from any disease. Here in New Jersey, according to the CDC, we have the third highest rate of pediatric cancer in the country. Only New

Hampshire and Washington, D.C. have higher rates.

According to the American Childhood Cancer Organization, each year in the U.S., approximately one in 285 children will be diagnosed with cancer before they turn 20.

It's heartbreaking, because there are children behind every statistic.

Pediatric cancer has touched far too many families, including my own. We lost our Karyn from leukemia when she was just fourteen. My aunt and uncle tried everything to save her, but, despite all the doctors they went to, a cure just didn't exist.

My family isn't alone. There are families like the FitzPatrick's, who lost their six-year-old son Tommy after he bravely fought a two-year battle with brain cancer.

It's clear that we need more research and cures, and that we just aren't making the progress we should be, fast enough, for our children.

As we've seen over the course of this pandemic, we know that investment and innovation can lead to real solutions.

For instance, our COVID-19 vaccines were developed by companies like Moderna, Pfizer, and Johnson & Johnson using a new and potentially revolutionary technology called Messenger RNA or mRNA. Researchers have been studying and working with mRNA vaccines for decades, including for many rare diseases, but it took this pandemic to create the urgency to fully develop and utilize this capability. Pfizer and Moderna have even publicly stated that they developed the design of their vaccines in just a few days.

So, it's clear that new possibilities can be at our fingertips.

But, right now, only four percent of federal cancer research funding is allocated to pediatric cancer research. Just **FOUR** percent — of

ALL federal investment in cancer research. As a member of the Childhood Cancer Caucus, I know that I'm not the only one who thinks this is unacceptable.

A group of us in Congress wants to change that. Along with my fellow Problem Solvers Caucus Co-Chair, Congressman Brian Fitzpatrick of Pennsylvania, and a small but mighty bipartisan group from around the country, I'm helping lead the introduction of the bipartisan "Fairness to Kids with Cancer Act."

This bipartisan bill will adjust the level of federal investment in pediatric cancer research to match the actual percentage of Americans under the age of 18 – so that we can bring more hope to children and their families in New Jersey and across our country.

This calculation will be based off of the federal Census, and – according to the recent 2020 Census numbers – 22 percent of the U.S. population is under the age of 18. That means, when this bill becomes law, we would boost the level of federal investment in pediatric cancer research from 4 percent to 22 percent – a 450 percent increase.

In time, our bipartisan bill will help find cures, change lives, and – most importantly – save lives.

This increase would change things for the better, because, every year, about twelve drugs are developed in the U.S. and approved by the FDA to treat adult cancers.

But, since the 1950s, there have only been forty-seven drugs, TOTAL, developed and approved by the FDA for pediatric cancers.

For example, while brain cancer is the leading cause of disease related death in people under the age of 20, there has not been a child-specific drug developed for brain cancer since the 1970s. In fact, some children receive the same treatment that Neil Armstrong's daughter received in the 1960s.

I want to turn that around, and, here in New Jersey, I know that we can lead the way.

A remarkable young lady – from right here in Jersey – Grace, and her mom Aubrey know just how great our state can be at these treatments: at just nine-years-old, Grace beat brain cancer – after months of chemotherapy and proton radiation. Throughout it all, she remained strong and optimistic – and now, cancer-free as of 2018, she’s a fierce advocate for other children affected by cancer. She and her family have even met with me to discuss what initiatives we need to focus on, so that we can find more cures.

Grace is a success story – but, as we all know, there are families who aren’t as lucky, which is why we’re all fighting together to save more lives.

Jersey is the medicine cabinet of the world and we’re a leader in bio-pharma R&D, which supports more than 300,000 Jersey jobs and produces \$83 billion in economic output every year.

With so much cutting-edge research and life sciences development, boosting pediatric cancer R&D investment will mean that our research centers, right here in Jersey, will play a key role in helping find the cures these kids need.

Beyond just pediatric cancer, I’m fighting in a bipartisan way to restore the Orphan Disease Tax Credit to find cures for rare diseases. And we must also maintain our commitment to curing cancers and diseases for adult populations too.

When it comes down to it, families like these – joining me today – they need hope.

With our bipartisan Fairness to Kids with Cancer Act, we will pave the way for more cures and we will save lives.

And I’m looking to pave the way for New Jersey, and great centers like here at Hackensack Meridian, to be leaders in finding that

hope, not just for kids in North Jersey, but nationwide, and around the world.

Together, working across the aisle, and working with the experts we have here today, I know that we can get this done, and I know that our best days will always be ahead of us.

Thanks again for joining me for today's roundtable; God bless you, your families, and the work you do.

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