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Shuster and Platts Introduce Legislation to Help Children Receive Life Saving Medical Treatment

Washington, D.C. – **Congressman Bill Shuster**, is pleased to announce that he has introduced legislation with **Congressman Todd Platts (PA-19)** seeking to provide continuous medical care to children who are transitioning out of research studies with the National Institutes of Health (NIH).

In many instances, children experiencing rare or life threatening illnesses take part in medical research studies through the NIH to gain access to new and emerging medications and therapies. Very often, the medications used by NIH are experimental and have either not been approved by the Food and Drug Administration or have not been cleared to treat a specific illness. When children leave an NIH study, they are at risk of losing access to these life saving therapies because their private insurance won't cover them.

Shuster and Platt's legislation seeks to close this gap in care by allowing children transitioning out of NIH medical studies to continue to receive medication through Medicaid if private insurance refuses to cover the treatment.

"The NIH does ground breaking work to evaluate new medical treatments for juvenile diseases," Shuster said. "For many children, these studies are the only way to take advantage of cutting-edge treatments that would otherwise be out of their reach. Children who respond to these therapies should not have their hopes and health crushed once they leave the NIH. Medicaid should be there to fill the gap."

Nino Todaro of Newville, Pennsylvania is an example of why this legislation needs to be enacted. In 2003, Nino was selected to take part in an NIH study for Undifferentiated Auto Inflammatory Periodic Fever Syndrome. The treatment received through the NIH allowed Nino to live a normal life. However, when he exited the study, his parent's private insurance would not cover the treatment. They relented only after a long and drawn-out battle by Nino's mother, Lori.

"No family should have to endure what Nino went through," Shuster added. "Sick children should not fall through the gaps of our healthcare system."

Shuster and Platts introduced their legislation in the House as a companion bill to S.2629, "Nino's Act;" legislation introduced this week by Senators Specter and Casey.

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