Hill Briefing Stresses Importance of Pediatric Medical Research

Senators Christopher Coons (D-DE) and Marco Rubio (R-FL) will speak at a policy briefing today on Capitol Hill, hosted by Nemours Children's Health System and the Children's Hospital of Philadelphia (CHOP). The briefing will highlight the urgent need to include children in pioneering cancer research and the precision medicine initiative that studies how differences in genetics, environment, and lifestyle can be identified to help develop tailored personalized treatments for critical diseases.

"I look forward to joining Sen. Coons to discuss the importance of pediatric medical research," said Sen. Rubio. "With today's advancements in medicine and technology, there is no excuse for leaving children out of pioneering cancer research and the precision medicine initiative. We must do everything we can to ensure there are more treatment options available for children."

"I am pleased to be able to join with Sen. Rubio to highlight the need to include children in our nation's cutting-edge research," said Sen. Coons. "Precision medicine holds promise for our future, but we must make sure that pediatric populations are included in this research so that we can offer a brighter future for children here and around the world."

The briefing will focus on the need for participation of children in the National Institutes of Health's All of Us Research Program and the Beau Biden Cancer Moonshot. Launched in 2015, the All of Us program, formerly known as the Precision Medicine Initiative Cohort Program, looks to build a national research cohort of at least one million volunteers to advance biomedical discoveries through participation in longitudinal studies to identify the molecular, environmental, and behavioral factors that contribute to major diseases and disorders. Pediatric researchers and families have developed a history of extensive collaboration to effectively safeguard private information, using the most rigorous standards in the research field. Nemours and CHOP are encouraging NIH to meaningfully enroll children in the All of Us Research Program.

"Precision medicine has enormous potential to change the face of medicine. We know that much of adult health is rooted in early childhood. To promote health and prevent disease throughout the lifespan, we need to ensure meaningful inclusion of children in important longitudinal research,"said panelist Vicky Funanage, PhD, Operational Vice President of Research at Nemours Children's Health System.

Joining Funanage on the panel are Christopher H. Lee, Esq., and Erin R. Lee, co-executive directors of Piper's Kidney Beans Foundation. The Lee family has experienced the benefits of precision medicine firsthand, through a specific genetic test for steroid-resistant nephrotic (kidney) syndrome that helped save their daughter's life. The foundation aims to make such tests more readily available for families in the U.S. by raising funds for research and for the cost of genetic testing for nephrotic disease in children.

"Genetic testing saved our daughter's life by allowing her team at Nemours/Alfred I. duPont Hospital for Children the information they needed to diagnose and treat her," said Erin Lee, mother of Piper, now 4, who underwent a kidney transplant from her father at 16 months to save her from Denys-Drash Syndrome. "Genetic testing is the next frontier in diagnostic medicine. Each year, scientists and doctors identify previously unknown spontaneous and inherited genetic illnesses which typically can only be detected via genetic blood tests. It is our belief that all children should have access to these tests to help identify genetic illnesses early and affordably."

Also joining the panel is Peter Adamson, MD, chair of The Children's Oncology Group at Children's Hospital of Philadelphia Research Institute. As a member of the Blue Ribbon Panel that guides pediatric recommendations for the Cancer Moonshot project, Dr. Adamson will emphasize the importance of ensuring pediatric participation in cancer research.

Nemours is an internationally recognized children's health system that owns and operates the Nemours/Alfred I. duPont Hospital for Children in Wilmington, Del., and Nemours Children's Hospital in Orlando, Fla., along with outpatient facilities in six states, delivering pediatric primary, specialty and urgent care. Nemours also powers the world's most-visited website for information on the health of children and teens, KidsHealth.org and offers on-demand, online video patient visits through Nemours CareConnect.

Established as The Nemours Foundation through the legacy and philanthropy of Alfred I. duPont, Nemours provides pediatric clinical care, research, education, advocacy, and prevention programs to families in the communities it serves.

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