



COALITION FOR PEDIATRIC MEDICAL RESEARCH

July 22, 2020

The Honorable Lamar Alexander
Chairman
Committee on Health, Education, Labor
and Pensions
United States Senate
428 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
Committee on Health, Education, Labor
and Pensions
United States Senate
428 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Frank Pallone
Chairman
Committee on Energy & Commerce
United States Congress
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Greg Walden
Ranking Member
Committee on Energy & Commerce
United States Congress
2322 Rayburn House Office Building
Washington, DC 20515

Dear Chairmen Alexander and Pallone and Ranking Members Murray and Walden:

On behalf of the Coalition for Pediatric Medical Research which is comprised of the nation's most research-intensive children's hospitals, we are writing to express our support for the **Creating Hope Reauthorization Act (S. 4010 and H.R. 4439)**. This bipartisan legislation seeks to make permanent the Pediatric Rare Disease Priority Review Voucher (PRV), which incents the development of drugs to treat pediatric rare diseases.

First enacted in 2012 via the Food and Drug Administration Safety and Innovation Act (FDASIA), the transferable voucher was reauthorized via the 21st Century Cures Act. The Creating Hope Reauthorization Act seeks to make the voucher permanent law. Making the incentive permanent will send an important message to developers of therapies that the nation will continue to prioritize development of therapies to treat children impacted by rare pediatric diseases.

As a coalition of children's hospitals that treat our nation's sickest children, we know first-hand the need for continual development of new therapies and treatments. The incentive created by the PRV helps make this possible. Congress has recognized the value of the voucher by creating it and reauthorizing it once before. We urge you to act one more time – this Congress – to make this powerful tool permanent law. If you have any questions, please do not hesitate to contact the Coalition through Nick Manetto at 202.312.7499 or nicholas.manetto@faegredrinker.com.

Sincerely,

The Coalition for Pediatric Medical Research Steering Committee

Dr. Tom Curran
Children's Mercy Kansas City

Dr. F. Bruder Stapleton
Seattle Children's

Dr. Carolyn Russo
St. Jude Children's Research Hospital

Dr. Calvin Williams
Children's Wisconsin

Dr. Jeff Shenberger
Brenner Children's Wake Forest Baptist
Health

Dr. David Williams
Boston Children's Hospital

Dr. Alex Huang
Rainbow Babies & Children's Hospital

CC: The Honorable G.K. Butterfield
The Honorable Michael McCaul
The Honorable Robert Casey
The Honorable Susan Collins

Ann & Robert H. Lurie Children's Hospital of Chicago	Cleveland Clinic Children's Hospital
Boston Children's Hospital	Columbia University
Brenner Children's Wake Forest Baptist Health	Helen DeVos Children's Hospital
Cincinnati Children's Hospital Medical Center	Intermountain Primary Children's Hospital
Children's Hospital Colorado	LeBonheur Children's Hospital
Children's of Alabama	Lucile Packard Children's Hospital at Stanford
Children's Healthcare of Atlanta	MUSC Children's Hospital
Children's Hospital of Los Angeles	Nationwide Children's Hospital
Children's Hospital of Philadelphia	Nemours Children's Health System
UPMC Children's Hospital of Pittsburgh	Rainbow Babies & Children's Hospital
Children's Mercy Kansas City	Seattle Children's
Children's Wisconsin	St. Jude Children's Research Hospital
	Texas Children's Hospital
