Documents for the Record

U.S. House Committee on Energy and Commerce
Markup of Seven Bills
September 17, 2025

Majority:

1. September 10, 2025, letter from the National Organization for Rare Disorders and the EveryLife Foundation for Rare Diseases submitted by Rep. Carter (GA).
2. September 15, 2025, letter to Chairman Guthrie and Ranking Member Pallone from the Praxis Precision Medicines Incorporated.
3. September 16, 2025, letter to Chairman Guthrie, Ranking Member Pallone, Rep. Morgan Griffith, and Rep. Diana DeGette from the Rare Disease Company Coalition.
4. September 16, 2025, letter to Chairman Guthrie and Ranking Member Pallone from the Alliance for Regenerative Medicine.
5. September 16, 2025, letter to Chairman Guthrie and Ranking Member Pallone from the Foundation Fighting Blindness.
6. September 17, 2025, statement from Rep. McCaul on H.R. 1262, Give Kids a Chance Act, submitted by Rep. Bilirakis.
7. September 16, 2025, letter from the American Farm Bureau Federation to Chairman Guthrie and Ranking Member Pallone.
8. September 15, 2025, letter from undersigned coalition of public safety and first responder associations to Speaker Johnson, Majority Leader Thune, and Minority Leader's Jefferies and Schumer.
9. September 16, 2025, letter from undersigned coalition of organizations to Speaker Johnson, Majority Leader Scalise, and Whip Emmer.

Minority:

1. April 2, 2025, letter from Ranking Members Pallone and DeGette to Chairman Guthrie, submitted by Rep. DeGette.
2. September 4, 2025, letter from undersigned Minority Members of Energy and Commerce to Chairmen Guthrie and Griffith, submitted by Rep. DeGette.
3. September 16, 2025, article from the New York Times titled "Trump Is Shutting Down the War on Cancer," submitted by Rep. DeGette.
4. September 9, 2025, letter to Rep. Fletcher from the Greater Houston Partnership submitted by Rep. Fletcher.
5. September 15, 2025, letter to Houston's Congressional Delegation from the Houston Hospital Leaders submitted by Rep. Fletcher.
6. September 17, 2025, Bronx Healthy Start Partnership Participants Unedited Stories submitted by Rep. Ocasio-Cortez.

NORD National Organization for Rare Disorders
EveryLife Foundation for Rare Diseases
Dysautonomia Foundation, Inc
NTSAD National Tay-Sachs & Allied Diseases Association
United Porphyrias Association
HCU Network America
Foundation for Prader-Willi Research
Cure Epilepsy
LGS Foundation Lennox-Gastaut Syndrome
Galactosemia Foundation Linked for Life
CureLGMD2i
Sarcoidosis of Long Island
Myositis Support & Understanding
KrabbeConnect Connecting Patients & Research
epilepsy advocacy network
Little Hercules Foundation
The Hope Project for Kids
Canavan Foundation
LGMD Awareness Foundation
IWMF International Waldenstrom's Macroglobulinemia Foundation
IFCR International Foundation for CDKL5 Research
FRAXA Research Foundation
SCN8A Alliance Collaborating for a cure
BDSRA foundation
LCC Foundation
KPTN Alliance
HypoPARAthyroidism Association, Inc.
NTM Info & Research, Inc.
DEE-P Connections
CAL RARE California Action Link for Rare Diseases
Hydrocephalus Association
Vasculitis Foundation
The Jansen's Foundation
Fighting H.A.R.D. Foundation Helping kids who Have A Rare Disease or chronic Illness
Immune Deficiency Foundation
Cure ARS
Mellie J Foundation
HAEA US Hereditary Angioedema Association
National MPS Society Support for Families. Research for a Cure
Alpha-1 Foundation
Dion Foundation
nnpdf National Niemann-Pick Disease Foundation, Inc.
PSC Partners Seeking a Cure
Adrenal Insufficiency United
amda
cure SMA
AfPA Alliance for Patient Access
Muenzer MPS Research & Treatment Center
GACI Global
Patient Empowerment Network
Wiskott-Aldrich foundation
Firefly Fund
National Alliance for Caregiving
Lymphoma Research Foundation
ACD Association for Creatine Deficiencies
KARES Foundation
The Rory Belle Foundation
epilepsy alliance America
GNB1
pmsf Phelan-McDermid Syndrome Foundation
KCNT1 Epilepsy Hope is on the horizon
South Carolina Advocates for Epilepsy
Epilepsy Foundation
Alliance to Cure Cavernous Malformation
Epilepsy Support Network of Orange County
BrainWarriors.org You are not alone
American Liver Foundation
The Cute Syndrome Foundation
National Kidney Foundation
flok
UnitedMSD Foundation Multiple Sulfatase Deficiency
My Kool Brother
LGMD2D Foundation
CMT Research Foundation
ifopa
MLD Foundation
Haystack Project
Parent Project Muscular Dystrophy
Project Alive
The LAM Foundation
Tough Genes
CDH International
NEC Society
EB Research Partnership
KDVS
NBIA Disorders Association
wynder nation
Nare Rolle & Bruce Reed Foundation
sat b2 gene foundation
TSC Alliance
GABA-A Alliance
Family Heart Foundation
INADcure Foundation
CureGM1 Foundation
Cure KCNH1 Foundation
angelman Syndrome Foundation
Hemophilia Foundation of Southern California
DART Dana's Angels Research Trust
United Mitochondrial Disease Foundation
MSUD Family Support Group
CVSA
The Bonnell Foundation
Barth Syndrome Foundation
WI Rare
Krishnan Family Foundation
indousrare
Prader-Willi Syndrome Association | USA
AH #CaringForRare
NADF National Adrenal Diseases Foundation
FARA Friedreich's Ataxia Research Alliance
AIMED Alliance
CURED www.CuredFoundation.org
fast Foundation for Angelman Syndrome Therapeutics
PROS Foundation
National Health Council
Dravet Syndrome Foundation
cure CMD a cure is among us
Pompe Alliance
ZTTK
NephCure
Fondazione Telethon
Mississippi MMF Metabolics Foundation
GLUT1 Deficiency Foundation
SCAD Alliance
The Mended Hearts, Inc.
Cure Lowe
Rett Syndrome Research Trust
FD/MAS Alliance
Organic Acidemia Association
Wilson Disease Association
SynGAP Research Fund
CCC Coalition to Cure CHD2
NAF National Ataxia Foundation
CHI Congenital Hyperinsulinism International
MGA
GFPD Global Foundation for Peroxisomal Disorders
Hope for HIE
MDA Muscular Dystrophy Association
Raymond A. Wood Foundation
NPKUA national PKU alliance
International Rett Syndrome Foundation
KIF1A KIF1A.ORG
YAYA Foundation Fighting for People Affected by all Leukodystrophy
CACNA1A Foundation
nfxf National Fragile X Foundation
FSIG
Jack Bear Foundation
Child Neurology Foundation
Bubba's Light
Spina Bifida Association
Wake Up Narcolepsy
Mackenzie's Mission
Family Connection, Inc
Global Genes
Cooley's Anemia Foundation
ARRE
cureSHANK
STXBP1 foundation
Center for Innovation & Value Research
CSNK2A1 Foundation
Sickle Cell Association of Kentuckiana
Superior Mesenteric Artery Syndrome
Cure GABA A
Rare Rising
Hope in Focus Seeing a cure for blindness
Rare Trait Hope Fund
noah's hope hope4bridget
Guthy Jackson Charitable Foundation
KCNQ2 Cure
Epilepsy Foundation Texas - Houston/Dallas-Fort Worth/West Texas
The Louisa Adelyn Johnson Fund for Complex Disease
CFRI Cystic Fibrosis Research Institute
AA-MDS International Foundation
Kabuki Syndrome Foundation
HPS
GCA Gaucher Community Alliance
USTMA
littlest Tumor Foundation
CancerCare
The Children's Medical Research Foundation, Inc. A Cure for Kirby
FAM177A1 Research Fund
REN Rare Epilepsy Network
Eosinophilic & Rare Disease Cooperative

September 10, 2025

The Honorable John Thune
Majority Leader
United States Senate
511 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Mike Johnson
Speaker of the House
United States House of Representatives
568 Cannon House Office Building
Washington, DC 20515

The Honorable Chuck Schumer
Minority Leader
United States Senate
322 Hart Senate Office Building
Washington, DC 20510

The Honorable Hakeem Jeffries
Minority Leader
United States House of Representatives
2267 Rayburn House Office Building
Washington, DC 20515

Dear Majority Leader Thune, Minority Leader Schumer, Speaker Johnson, and Minority Leader Jeffries, Chair Guthrie, and Ranking Member Pallone,

On behalf of the 30 million Americans living with a rare disease, the undersigned 190 organizations write to express strong support for the Give Kids a Chance Act of 2025 (H.R. 1262/ S.932) and urge its swift passage by Congress. This urgent legislation would reauthorize the highly effective Rare Pediatric Disease Priority Review Voucher (PRV) program for five years. As many as half of the individuals living with a rare disease are children, and this program offers a crucial incentive to develop therapies for this particularly challenging-to-study patient population living with devastating and often life-threatening rare conditions.

Nearly 70% of rare diseases start in childhood[1] and most have no approved treatments. The Rare Pediatric Disease PRV program, created by Congress in 2012, has been a vital catalyst for developing therapies for these vulnerable populations. Thanks to this program, treatments have reached children suffering from nearly 40 rare diseases, many of which previously had no FDA-approved options and led to severe disability or death before adulthood.[2]

The program's impact is accelerating – more than half of all Rare Pediatric Disease designations occurred in just the past four years,[3] demonstrating its growing importance in addressing urgent unmet medical needs. Yet despite this progress, over 95% of rare diseases still lack an FDA-approved therapy.

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[1] Nguengang Wakap S, Lambert DM, Olry A, Rodwell C, Gueydan C, Lanneau V, et al. Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. Eur J Hum Genet. 2020;28(2):165–73. https://www.nature.com/articles/s41431-019-0508-0

[2] See: https://rarediseases.org/wp-content/uploads/2024/05/NORD_PRV-white-paper_FINAL.pdf

[3] Mease, C., Miller, K. L., Fermaglich, L. J., Best, J., Liu, G., & Torjusen, E. (2024). Analysis of the first ten years of FDA's rare pediatric disease priority review voucher program: designations, diseases, and drug development. Orphanet J Rare Dis. 2024;19(1):131. https://pubmed.ncbi.nlm.nih.gov/38403586/

The Rare Pediatric Disease PRV program's authorization expired on December 20, 2024. Without reauthorization, newly designated investigational therapies are ineligible for PRVs. Those promising therapies that received Rare Pediatric Designation before the December 20th expiration, but do not receive FDA-approval before September 30, 2026 are also ineligible for a PRV. Allowing this program to lapse not only eliminates a proven pathway for future innovation and hope, but it also creates uncertainty for scientific work currently underway that will not meet the September 30, 2026 deadline.

Importantly, the PRV program is a market-based incentive that comes at no cost to taxpayers. The data shows that the Rare Pediatric Disease PRV program is working to address unmet needs and will continue to do so for years to come when reauthorized.

We urge Congress to act quickly and pass the Give Kids a Chance Act of 2025 (H.R. 1262/S. 932) to restore this life-saving program and ensure continued progress in rare pediatric drug development. Our communities are counting on you. We look forward to working with you on this important issue.

For any questions or concerns, please contact Allison Herrity at the National Organization for Rare Disorders, at aherrity@rarediseases.org and Jamie Sullivan at the EveryLife Foundation for Rare Diseases, at jsullivan@everylifefoundation.org.

Thank you for your leadership and commitment to improving the lives of children with rare diseases.

Sincerely,

EveryLife Foundation for Rare Diseases
National Organization for Rare Disorders (NORD)
Adrenal Insufficiency United
Aimed Alliance
Akari Foundation
Alliance for Patient Access
Alliance to Cure Cavernous Malformation
The Alpha-1 Foundation
AMDA
American Liver Foundation
Angelman Syndrome Foundation
Aplastic Anemia and MDS International Foundation
Association for Creatine Deficiencies
ASXL Rare Research Endowment Foundation
Avery's Hope
Barth Syndrome Foundation
BDSRA Foundation
BPAN WARRIORS
Bubba's Light, Inc.
CA Action Link for Rare Diseases (CAL RARE)
CACNA1A Foundation
Canavan Foundation
CancerCare
CDH International
Center for Innovation & Value Research
Child Neurology Foundation
CMT Research Foundation
Coalition to Cure CHD2
Congenital Hyperinsulinism International
Cooley's Anemia Foundation
CSNK2A1 Foundation
Cure CMD
CURE Epilepsy
CURE GABA-A
Cure GM1 Foundation

Cure KCNH1 Foundation
Cure LGMD2i Foundation
Cure Lowe Foundation
Cure SMA
CureARS
CURED Nfp
CureSHANK
Cyclic Vomiting Syndrome Association
Cystic Fibrosis Research Institute
Dana's Angels Research Trust
Developmental and Epileptic Encephalopathies - DEE-P Connections
Dion Foundation for Children with Rare Diseases
Dravet Syndrome Foundation
EB Research Partnership
Eosinophilic & Rare Disease Cooperative
Epilepsy Advocacy Network
Epilepsy Foundation of America
Epilepsy Foundation Texas
Epilepsy Support Network of Orange County
Epilepsy Alliance America
Fabry Support & Information Group
FAM177A1 Research Fund
Familial Dysautonomia Foundation
Family Heart Foundation
FD/MAS Alliance
Fighting H.A.R.D. Foundation
Firefly Fund
flok Health
Fondazione Telethon
Foundation for Angelman Syndrome Therapeutics
Foundation for Prader-Willi Research
FRAXA Research Foundation
Friedreich's Ataxia Research Alliance (FARA)
GABA-A Alliance
GACI Global
Galactosemia Foundation
Gaucher Community Alliance
Gene Giraffe Project
Global Genes
GNB1 Advocacy Group, Inc
Haystack Project
HCU Network America
Hemophilia Foundation of Southern California
Hermansky-Pudlak Syndrome Network Inc.
Hnrnp family foundation
Hope for HIE
Hope in Focus
Hydrocephalus Association
HypoPARAthyroidism Association
Immune Deficiency Foundation
INADcure Foundation
Indo US Organization for Rare Diseases
International Fibrodysplasia Ossificans Progressiva (FOP) Association
International Foundation for CDKL5 Research
International Rett Syndrome Foundation
International SCN8A Alliance
IWMF
Jack Bear Foundation
Joanna Sophia Foundation
Juju and Friends CLN2 Warrior Foundation
Kabuki Syndrome Foundation
KARES Foundation
KCNQ2 Cure Alliance
KCNT1 Epilepsy Foundation
KIF1A.ORG
Koolen-de Vries Syndrome Foundation
KPTN Alliance
KrabbeConnect
Krishnan Family Foundation
Lennox-Gastaut Syndrome (LGS) Foundation
LGMD Awareness Foundation, Inc
LGMD2D Foundation
Little Hercules Foundation
Littlest Tumor Foundation
Lymphoma Research Foundation
Mackenzies Mission
Melanie J Foundation
Mississippi Metabolics Foundation
MLD Foundation
MPS Research & Treatment Center
MSUD Family Support Group
MTM-CNM Family Connection
Muscular Dystrophy Association
My Kool Brother
Myasthenia Gravis Association
Myositis Support and Understanding
National Alliance for Caregiving

National Ataxia Foundation
National Fragile X Foundation
National Health Council
National Kidney Foundation
National MPS Society
National Niemann-Pick Disease Foundation
National PKU Alliance
National Tay-Sachs & Allied Diseases Association, Inc.
NBIA Disorders Association
Necrotizing Enterocolitis (NEC) Society
Neev Kolte & Brave Ronil Foundation
NephCure
Noah's Hope - Hope4Bridget
NTM Info & Research, Inc.
Organic Acidemia Association
Parent Project Muscular Dystrophy
Pathways for Rare and Orphan Studies
Patient Empowerment Network
Phelan-McDermid Syndrome Foundation
Pompe Alliance
Project Alive
PSC Partners Seeking a Cure
PWSA | USA - Prader-Willi Syndrome Association
Rare Epilepsy Network
Rare Trait Hope Fund
RareRising
Raymond A. Wood Foundation
Rett Syndrome Research Trust
Sarcoidosis of Long Island
SATB2 Gene Foundation
SCAD Alliance (spontaneous coronary artery dissection)
Sickle Cell Association of Kentuckiana
South Carolina Advocates for Epilepsy (S.A.F.E.)
Spina Bifida Association
Stronger Than Sarcoidosis and Sarcoidosis of Long Island
STXBP1 Foundation
Superior Mesenteric Artery Syndrome Research Awareness and Support
SynGAP Research Fund dba CURE SYNGAP1
The Bonnell Foundation: Living with cystic fibrosis
The Children’s Medical Research Foundation, Inc.
The Cute Syndrome Foundation
The Global Foundation for Peroxisomal Disorders
The GLUT1 Deficiency Foundation
The Guthy-Jackson Charitable Foundation
The Hope Project For kids
The Jansens's Foundation
The LAM Foundation
The LCC Foundation
The Louisa Adelynn Johnson Fund for Complex Disease
The Mended Hearts, Inc.
The National Adrenal Diseases Foundation
The Rory Belle Foundation
The Sturge-Weber Foundation
Tough Genes
TSC Alliance
United Mitochondrial Disease Foundation
United MSD Foundation
United Porphyrias Association
US Hereditary Angioedema Association
USTMA Consortium and Alliance
Vasculitis Foundation
Wake Up Narcolepsy, Inc.
WI Rare Disease Alliance
Wilson Disease Association
Wiskott Aldrich Foundation
Wylder Nation Foundation
Yaya Foundation for 4H Leukodystrophy
ZTTK Son-Shine Foundation

Praxis Precision Medicines Incorporated
99 High Street, 30th Floor, Boston, MA 02110
www.praxismedicines.com

September 15, 2025

The Honorable Brett Guthrie
The Honorable Frank Pallone
House Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

Chairman Guthrie, Ranking Member Pallone, and Members of the House Energy Commerce Committee,

I am writing on behalf of Praxis Precision Medicines to urge you to support the reauthorization of the Rare Pediatric Disease Priority Review Voucher (PRV) program and to advance H.R. 1262, the Give Kids a Chance Act, out of Committee without delay.

Praxis Precision Medicines is a U.S.-based, clinical-stage biopharmaceutical company translating genetic insights into novel therapies for common and rare brain disorders with the highest unmet medical need. Our pipeline includes multiple programs with Rare Pediatric Disease designations. PRAX-222 (elsunersen) has received Rare Pediatric Disease designation for treatment of SCN2A Developmental and Epileptic Encephalopathy (DEE). PRAX-562 (relutrigine), which has received Rare Pediatric Disease designations in three different indications, recently received Breakthrough Therapy Designation for the treatment of SCN2A and SCN8A DEEs. This recognition underscores the urgent need to bring therapies like relutrigine to children living with catastrophic epilepsies.

Rare diseases collectively affect approximately 10% of the U.S. population, and half of those affected are children. Alarmingly, 30% of children with a rare disease will not survive beyond their fifth birthday.[1] Of the more than 10,000 known rare diseases, 95% have no FDA-approved treatment.[2] Drug development for rare diseases is complex, slow, and risky; averaging over 15 years from "bench to bedside" and requiring significant financial investment.[3]

The PRV program represents a critical mechanism to accelerate and expand development in rare diseases. Without it, progress will undoubtedly stall, and many companies may abandon promising programs, leaving children and families behind.

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[1] Rare Disease Company Coalition. *Impact of the Priority Review Voucher Program on Rare Pediatric Disease Drug Development*. May 2024. Rare Disease Company Coalition. https://www rarecoalition.com/wp-content/uploads/Impact-of-the-Priority-Review-Voucher-Program-on-Rare-Pediatric-Disease-Drug-Development-1-1.pdf.
[2] National Organization for Rare Disorders. (2025). *Impact of the Rare Pediatric Disease Priority Review Voucher Program on Drug Development*, 2012–2024. NORD. https://rarediseases.org/rare-pediatric-disease-prv-program.
[3] Rare Disease Company Coalition, *supra* note 1.

Since its creation in 2012, the PRV program has been a catalyst for innovation[4]:

- 53 PRVs have been awarded, spurring development across 39 diseases and 47 novel indications, many of which had no prior approved therapies.
- More than 200,000 patients have directly benefited from therapies supported by the program.
- Over 350 new rare pediatric disease designations were granted between 2020–2022 alone, a clear signal that the program is driving robust R&D pipelines.
- Importantly, over 90% of PRVs were awarded for indications with no existing approved therapy.

PRVs also enable small biotech companies like Praxis to raise capital for continued research, essential given that only one-third of commercial-stage rare disease companies are profitable, despite reinvesting over 40% of revenue into research and development.

Without Congressional action, the PRV program will sunset in 2026. For Praxis, this means that even if PRAX-562 or other programs in our rare pediatric epilepsies pipeline achieve FDA approval, we could be ineligible to receive a PRV. The inability to redeem or sell a voucher would directly limit our ability to reinvest those funds into further expanding our pipeline, slowing progress toward new treatments for children living with other devastating rare conditions.

If Praxis can serve as a resource to help the Committee understand the real-world impact of this program, on both patients and the biotechnology ecosystem, we would welcome the opportunity to engage with you further.

Thank you for your commitment to supporting rare disease patients and advancing treatments that can change and save lives. We look forward to working together to ensure that innovation continues to reach those who need it most.

Sincerely,

DocuSigned by:
Marcio Souza
357C35131E07456...

Marcio Souza
Chief Executive Officer
Praxis Precision Medicines

[4] Rare Disease Company Coalition, *supra* note 1.

BY ELECTRONIC DELIVERY

September 16, 2025

The Honorable Brett Guthrie
Chair
House Committee on Energy & Commerce
United States House of Representatives
2161 Rayburn House Office Building
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
House Committee on Energy & Commerce
United States House of Representatives
2107 Rayburn House Office Building
Washington, DC 20515

The Honorable Morgan Griffith
Chair
Subcommittee on Health
United States House of Representatives
2110 Rayburn House Office Building
Washington, DC 20515

The Honorable Diana DeGette
Ranking Member
Subcommittee on Health
United States House of Representatives
2111 Rayburn House Office Building
Washington, DC 20515

RE: Rare Disease Company Coalition Urges Lawmakers to Support the Restoration of the Rare Pediatric Disease Priority Review Voucher (PRV) Program Through H.R. 1262, The Give Kids a Chance Act

Dear Chair Guthrie, Ranking Member Pallone, Chair Griffith, and Ranking Member DeGette,

I write on behalf of the Rare Disease Company Coalition (RDCC) and the 1 in 10 Americans living with a rare disease to urge you to champion the swift reauthorization of the rare pediatric disease priority review voucher (PRV) program through supporting H.R. 1262, the Give Kids a Chance Act. We greatly appreciate your consideration of this legislation in the full House Committee on Energy and Commerce markup on Wednesday, September 17. As you may know, the Give Kids a Chance Act would restore the critical PRV program through September 30, 2029, and without urgent Congressional action, hope for millions of children may vanish.

RDCC members are dedicated to discovering, developing, and delivering treatments for patients living with a rare disease. Collectively, RDCC members invested more than $20 billion in research & development (R&D) in 2024 and continue to reinvest over two thirds of annual expenditures back into R&D. Our members have brought over 50 rare disease treatments to market and have more than 200 promising programs currently in development, underscoring our unwavering commitment to transforming patients' lives.

Reauthorization of the rare pediatric PRV program would benefit hundreds of thousands of patients living with a rare disease. The program has received broad, bipartisan, and bicameral support since its inception in 2012. Most recently in the 118th Congress, the program enjoyed unanimous passage through the House of Representatives. Additionally, the Food and Drug Administration (FDA) supports the reauthorization of the program. A diverse array of stakeholders, from policymakers to patient advocates, from the

investor community to rare disease innovators, understand that the PRV program is a proven innovation-driving and cost-effective policy that spurs research & development (R&D) in rare pediatric diseases.

In the United States, a rare disease is defined as a condition that affects fewer than 200,000 people.[1] Approximately 30 million Americans are affected by one of the over 10,000 rare diseases,[2] and only 5% of those rare diseases have an FDA-approved treatment.[3] Further complicating this unmet need, rare disease drug development is extraordinarily challenging, and these challenges are further amplified in pediatric populations. One in 2 patients diagnosed with a rare disease are children – and a third of those children will not live to see their fifth birthday.[4] Tailored policy is needed to ensure that these children have access to innovative therapies that can slow, stop, or even reverse the progression of their disease or condition.

The rare pediatric disease PRV program enables innovative companies to provide hope to children living with a rare disease while reinvesting critical dollars into additional R&D for rare disease treatments. The program has zero cost to taxpayers and remains a critical incentive to attract investment into rare disease drug development.

Programs like the rare pediatric disease PRV are crucial to mitigating the risks associated with investment in the rare disease space. Without tools like the PRV program, investors may view rare disease drug development as too risky – and for small and emerging companies that rely on capital markets for funding, that could make the difference between bringing a product to market and shuttering a program. Research shows that many rare disease companies are struggling to survive in the current policy and funding ecosystems,[5] and policies like the PRV program are necessary to attract investors that are fundamental to rare disease drug development.

A recent study has shown that the PRV program is an effective and proven policy that spurs new rare disease treatments and cures. Innovation driven by the program has benefited over 200,000 rare disease patients across 47 unique indications.[6] And this innovation is meeting previously unmet needs. More than 90 percent of all PRVs were awarded to therapies for indications with no approved therapy on the market.[7] Furthermore, uptake of the program is still expanding, as more than half of all vouchers were granted in the last four years alone.[8] Rare disease treatments take longer than prevalent disease treatments

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1 Orphan Drug Act, Public Law 414, U.S. Statutes at Large 96 (1982): 2049-2066.

2 National Center for Advancing Translational Sciences (NCATS). Delivering Hope for Rare Diseases. January 2023.

3 Fermaglich LJ, Miller KL. A comprehensive study of the rare diseases and conditions targeted by orphan drug designations and approvals over the forty years of the Orphan Drug Act. Orphanet J Rare Dis. 2023 June 3;18(1):163

4 Global Genes. Rare Disease Facts.

5 Masia, Neal. Health Capital Group. Rare Disease Companies in the Public Markets: Challenging Performance Against a Backdrop of Policy Uncertainty. October 2023.

6 Rare Disease Company Coalition (RDCC). Impact of the Priority Review Voucher Program on Rare Pediatric Disease Drug Development. May 2024.

7 Ibid.

8 Ibid.

to move from bench to bedside. On average, the development timeline for rare disease treatments is 15 years.[9,10] As the program has only been operational for 12 years, its true impact is still being realized.

Immediate restoration of the rare pediatric disease PRV program is critical to achieving our important mission to address the unmet medical needs of the rare disease community. Every minute the PRV program remains expired jeopardizes investment in critical innovations that could transform the lives of children living with rare, often fatal and progressively debilitating, diseases.

On behalf of the Rare Disease Company Coalition, we urge you to support H.R 1262, the Give Kids a Chance Act to ensure the urgent restoration of the rare pediatric disease PRV program.

If you have any questions or would like to discuss further, please contact me at stacey@rarecoalition.com.

Signed,

Stacey Frisk
Executive Director
Rare Disease Company Coalition

[9] Brown DG, Wobst HJ, Kapoor A, Kenna LA, Southall N. Clinical development times for innovative drugs. Nat Rev Drug Discov. 2022 Nov;21(11):793-794.
[10] HHS ASPE. Examination of Clinical Trial Costs and Barriers for Drug Development.

Alliance for Regenerative Medicine

September 16, 2025

The Honorable Brett Guthrie
Chairman
Committee on Energy & Commerce
U.S. House of Representatives
2161 Rayburn House Office Building
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
Committee on Energy & Commerce
U.S. House of Representatives
2107 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Guthrie and Ranking Member Pallone:

The **Alliance for Regenerative Medicine (ARM) wishes to express its strong support for the *Give Kids a Chance Act of 2025*** (H.R. 1262) and thank you for including it in the upcoming Energy and Commerce Committee markup. This crucial, bipartisan legislation would reauthorize the highly effective Rare Pediatric Disease Priority Review Voucher (PRV) Program for five years and **will meaningfully improve access to life-changing and lifesaving treatments.**

ARM is the leading international advocacy organization championing the benefits of engineered cell therapies and genetic medicines for patients, healthcare systems, and society. With more than 400 member organizations - including biotechnology companies, academic and medical research institutions, and patient organizations - ARM works to engage key stakeholders to enable the development of advanced therapies and to modernize healthcare systems so that patients benefit from durable, potentially curative treatments.

Background

Children comprise as many as half of those living with rare diseases, yet their treatment options are extremely limited. Because a significant number, nearly 70 percent, of rare pediatric disorders have genetic causes, they are increasingly being addressed by the growing number of cell and gene therapies (CGTs).[1] This includes the life-saving options for children diagnosed with acute lymphoblastic leukemia, Duchenne muscular dystrophy, and sickle cell disease.

Rare Pediatric Disease PRV Program

The Rare Pediatric Disease PRV Program is a cost-neutral Food and Drug Administration (FDA) initiative that incentivizes manufacturers to develop products for rare pediatric indications. The Rare Pediatric Disease PRV program, created by Congress in 2012, has been a vital catalyst for developing therapies for these vulnerable populations.

A PRV is awarded at the time of approval and allows for the priority review of future human drug application. Vouchers are often sold between companies to raise the capital needed to commercialize newly approved rare disease therapies.

Since 2011, more than 50 PRVs have been awarded across 39 different rare

pediatric diseases. A recent NIH analysis found that half of all PRVs were granted in just the last four years, a wide range of diseases have seen development—from rare pediatric cancers to rare genetic disorders since the program's inception, and more than 90 percent of all PRVs have been awarded for treatments for indications with no approved therapy on the market.[2]

Last year's expiration of the Rare Pediatric Disease PRV Program is already hampering investment in new CGTs for life-threatening conditions. Without reauthorization, newly designated therapies are ineligible for PRVs. Biotech companies are having to make difficult decisions regarding their product pipeline, and without a PRV, some may be unable to afford to continue working on new CGTs and other treatments for rare diseases, particularly those indicated for a limited patient population. An RPD PRV is a financial lifeline for smaller companies where the funds earned from the transfer of a voucher and the funding they can attract from investors thanks to the potential to receive a PRV enable them to make research investments and, in some cases, continue operations. ARM has heard from multiple members concerned about the viability of their CGT programs if the FDA's authority to award RPD PRVs is not reauthorized. It takes years and considerable resources to bring new rare disease therapies to market; ensuring the continuation of the Rare Pediatric Disease PRV Program is critical for preserving incentives to invest in the development of new cell and gene therapies. The *Give Kids a Chance Act* ensures the PRV incentive is preserved for all future patients.

In summary, the Rare Pediatric Disease PRV Program has injected hope and innovation incentives into the pediatric drug development pipeline, and **failure to pass the *Give Kids a Chance Act* before the end of the year will delay – or worse halt – the development of new treatments for children living with rare diseases.** The fact that H.R. 1262 has been cosponsored by more than half of the House of Representatives demonstrates that there is broad, bipartisan recognition of the importance and urgency of this legislation.

We look forward to working with you and the Committee to advance this important bill and ensure its passage before the end of the year. Thank you for your consideration, and if you have any questions, please contact me at ecischke@alliancerm.org.

Sincerely,

Erica Cischke, MPH
Vice President, Government Affairs

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[1] Nguengang Wakap, S., Lambert, D.M., Olry, A. et al. Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. Eur J Hum Genet 28, 165–173 (2020). https://doi.org/10.1038/s41431-019-0508-0

[2] Mease, C., Miller, K. L., Fermaglich, L. J., Best, J., Liu, G., & Torjusen, E. (2024). Analysis of the first ten years of FDA's rare pediatric disease priority review voucher program: designations, diseases, and drug development. Orphanet J Rare Dis. 2024;19(1):131. https://pubmed ncbi.nlm.nih.gov/38403586/

FOUNDATION FIGHTING BLINDNESS
Together, we're winning.

September 16, 2025

The Honorable Brett Guthrie
Chairman
House Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Frank Pallone, Jr.
Ranking Member
House Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Guthrie and Ranking Member Pallone,

On behalf of the Foundation Fighting Blindness and the millions of Americans impacted by inherited retinal diseases (IRDs), we urge you to advance H.R.1262, the Give Kids a Chance Act, and reauthorize the Rare Pediatric Disease Priority Review Voucher (PRV) Program.

Why this matters now: Many IRDs manifest in childhood and are progressive — meaning each year without treatment can bring irreversible vision loss. Families do not have the luxury of time. The PRV Program has been a market-based, taxpayer-neutral incentive that helps close the investment gap for rare pediatric conditions with small patient populations and high R&D costs. When the PRV lapsed in 2024, the pipeline for children with rare blinding diseases was put at risk.

What the PRV enables:

- **Accelerated access:** PRVs help speed FDA review without compromising safety standards.
- **Investment signal:** The voucher creates a tangible return that attracts private capital to pediatric programs that would otherwise not move forward.
- **No taxpayer cost:** The program advances innovation without new appropriations.

Vision is a pediatric health priority. For children facing conditions like Leber congenital amaurosis or early-onset retinitis pigmentosa, delayed therapy can mean the permanent loss of functional sight, and with it, academic, social, and economic opportunities. Reauthorizing the PRV can help ensure that more children access sight-preserving treatments faster.

For over 50 years, the Foundation Fighting Blindness has been the world's leading private funder of research into retinal degenerative diseases, advancing prevention, treatments, and cures across the spectrum of blinding retinal diseases. We collaborate closely with scientists, clinicians, companies, and patients to de-risk promising approaches and responsibly accelerate development.

We respectfully ask the Committee to:

1. Advance H.R.1262 out of markup with strong bipartisan support; and

2. Preserve the PRV Program's pediatric focus, safety rigor, and taxpayer-neutral design.

We stand ready to support the Committee with technical expertise, patient perspectives, and data as you consider this legislation.

Thank you for your leadership on behalf of children and families living with rare diseases.

Sincerely,

Jason Menzo
Chief Executive Officer
Foundation Fighting Blindness
JMenzo@FightingBlindness.org

cc: The Honorable Michael McCaul

Remarks from Chairman Emeritus Michael McCaul on Give Kids a Chance, H.R. 1262

Chairman Guthrie, Ranking Member Pallone, and Members of the Committee,

I want to express my appreciation to the committee for marking up the Give Kids a Chance Act, H.R.1262. This bill has a considerable history and has been close to my heart for a long time.

The Give Kids a Chance Act combines legislation that will tackle pediatric cancer and bring hope to those children - not to mention the parents, family members, and friends - who face these terrible diseases. This bill will reauthorize the Food and Drug Administration's Priority Review Voucher System (PRV). The PRV was an effective program that allowed drugs targeting pediatric cancers to be expedited for approval, and as a result, we have seen 63 new cancer fighting drugs approved using this mechanism since 2015. The bill also requires drug companies making new cancer cures and treatments to test any product for pediatric cancer applicability.

This legislation is vital to the cause of pediatric cancer care. Every year, nearly 16,000 children in the United States are diagnosed with cancer. Around 1,800 of these children will unfortunately pass from the disease. Those who survive often face life-long health complications.

However, we have come a long way from the 1970s, when the five-year survival rate for pediatric cancer was 58% in the U.S. Today, in part due to drugs that were approved by the PRV, the survival rate is now 85%. Legislation like the Give Kids a Chance Act will empower the healthcare industry to further invest in treatments and cures for pediatric cancers. In doing so, it will lend greater hope for a day when pediatric cancers will be a thing of the past.

American Farm Bureau Federation®
600 Maryland Avenue, SW | Suite 1000W | Washington, DC 20024

ph. 202.406.3600
www.fb.org

September 16, 2025

The Honorable Brett Guthrie
Chairman
Energy and Commerce Committee
U.S. House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
Energy and Commerce Committee
U.S. House of Representatives
2322A Rayburn House Office Building
Washington, DC 20515

Dear Chairman Guthrie and Ranking Member Pallone:

On behalf of the American Farm Bureau Federation — the nation's largest general farm organization representing nearly six million member families across all 50 states and Puerto Rico — we express our support for H.R. 979, the AM Radio for Every Vehicle Act of 2025.

AM radio remains a critical lifeline for our members, delivering essential information they rely on every day. From weather forecasts and commodity reports to updates on national farm policy, AM radio keeps America's farmers and ranchers informed and connected. Its importance becomes even more dire during emergencies. Farmers and ranchers spend long hours working outdoors — often far from home — and timely information can mean the difference between safety and danger. Whether it's a developing thunderstorm, an approaching tornado, or a rapidly spreading wildfire, our members need dependable communication to stay ahead of threats and protect their livelihoods.

We appreciate your leadership in protecting access to AM radio and urge the committee to advance H.R. 979. Thank you for your attention to this matter.

Sincerely,

Sam Kieffer
Vice President, Public Policy

September 15, 2025

The Honorable Mike Johnson
Speaker
U.S. House of Representatives
The Capitol, Room H-232
Washington, DC 20510

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
The Capitol, Room H-204
Washington, DC 20510

The Honorable John Thune
Majority Leader
United States Senate
The Capitol, Room S-221
Washington, DC 20515

The Honorable Chuck Schumer
Minority Leader
United States Senate
The Capitol, Room S-230
Washington, DC 20515

Dear Speaker Johnson, Leader Thune, Leader Jeffries, and Leader Schumer:

We are writing to express our strong support for the AM Radio for Every Vehicle Act (H.R. 979/ S. 315). As firefighters, law enforcement officers, and representatives of the emergency medical service, we rely upon the critical importance of reliable means of communications, particularly during emergencies and crises. Reliable means of communications help first responders save lives, as is the case with the important information citizens receive via AM radio.

AM radio continues to serve as a dependable means of communication, especially in situations where other forms of communication may be unavailable. As we have seen, regardless of whether it is a natural disaster, a severe accident, or a public safety threat, AM radio provides a lifeline for disseminating crucial information to the public and coordinating our emergency response efforts.

By ensuring the inclusion of AM radio receivers in all new vehicles, this legislation ensures that drivers and passengers have access to vital emergency broadcasts, including areas with limited or disrupted cellular or internet connectivity. Through the Integrated Public Alert and Warning

System (IPAWS), AM radio is one of the broadcast methods relied upon after a hurricane when cell service is unreliable. In fact, AM radio repeatedly proves a very reliable source of providing information to communities in times where other forms of communication may have been impacted.

A proven example of the usefulness of AM radio happened last year in North Carolina during the landfall of Hurricane Helene. There, AM radio operators stayed on the air to ensure their listeners and community stayed informed as the event unfolded. AM radio provided crucial evacuation and shelter information to citizens when other public communications networks were inoperable.

We urge you to join us in advocating for this important legislation and to ensure its swift passage. Together, we can enhance public safety, improve emergency preparedness, and save lives.

Sincerely,

International Association of Fire Chiefs
National Association of Emergency Medical Technicians
National Volunteer Fire Council
International Association of Chiefs of Police
Major County Sheriffs of America
International Association of Fire Fighters
National Sheriffs' Association

cc:

The Honorable Brett Guthrie, Chair, House Committee on Energy and Commerce
The Honorable Frank Pallone, Ranking Member, House Committee on Energy and Commerce
The Honorable Ted Cruz, Chairman, Senate Committee on Commerce, Science and Transportation
The Honorable Maria Cantwell, Ranking Member, Senate Committee on Commerce, Science and Transportation
The Honorable Rand Paul, Chairman, Senate Committee on Homeland Security and Government Affairs
The Honorable Gary Peters, Ranking Member, Senate Committee on Homeland Security and Government Affairs
The Honorable Andrew Garbarino, Chairman, House Committee on Homeland Security
The Honorable Bennie Thompson, Ranking Member, House Committee on Homeland Security
The Honorable Sam Graves, Chairman, House Committee on Transportation and Infrastructure
The Honorable Rick Larsen, Ranking Member, House Committee on Transportation and Infrastructure

:sa

The Honorable Mike Johnson
Speaker of the House
H-232, The Capitol
Washington, D.C. 20515

The Honorable Tom Emmer
H-150, The Capitol
Washington, D.C. 20515

The Honorable Steve Scalise
The Capitol
Washington, D.C. 20515

The Honorable Brett Guthrie
2125 Rayburn House Office Building
Washington, D.C. 20515

September 16, 2025

Dear Speaker Johnson, Leader Scalise, and Whip Emmer:

We write today as a coalition of organizations committed to preserving American traditions, ensuring public safety, and protecting the foundations of free expression. At a moment when powerful interests push for centralized, digital-only platforms, we urge Congress to act swiftly in defense of a time-tested institution: AM radio.

The AM Radio for Every Vehicle Act (S. 315/H.R. 979) represents a simple yet vital safeguard for consumers – requiring automakers to keep AM radio accessible in every vehicle sold in the United States. This legislation is not about nostalgia; it is about national resilience and safety, free expression, and the communities that depend on this critical means of communication.

The trend of removing AM radio from newer car models, specifically electric vehicles, is not only unnecessary, it is dangerous. It severs Americans from a free, over-the-air public safety tool, while undercutting one of the few remaining sources of locally rooted media in a world of algorithm-driven content.

For generations, AM radio has been the unfiltered voice of local communities, from small businesses and farmers to high school football games and Sunday morning church services.

In times of emergency, AM radio is more than a platform – it's a lifeline. The federal emergency alert system, including FEMA's hardened Primary Entry Point (PEP) stations, depends on radio to reach Americans when the electric grid crashes or Internet service fails. No satellite system, podcast platform, or mobile phone app can replicate its reliability or geographic coverage. As seven former FEMA administrators have warned, sidelining AM would cripple the National Public Warning System (NPWS) and leave many Americans in the dark during a disaster.

This is also a matter of free speech. AM radio has long been a battleground of ideas – a venue where Americans of all backgrounds and beliefs can speak, challenge, and persuade. Some of the most powerful cultural and political voices – from Ronald Reagan to Rush Limbaugh – built their audiences through AM's humble crackle. We should be wary of any shift that narrows the diversity of voices or funnels all discourse through Big Tech gatekeepers.

As conservatives, we believe in preserving the institutions that serve everyday Americans – especially when they are free, local, and resilient. The effort to erase AM radio from modern vehicles is not market-driven; it is a top-down decision that marginalizes working-class listeners, rural families, and first responders who rely on AM in their daily lives.

We strongly urge you to support the AM Radio for Every Vehicle Act and bring it to a full vote without delay. In doing so, you will be defending more than a technology – you will be defending the connective tissue of our republic.

Thank you for your consideration.

Sincerely,

Tiffany Justice
Executive Vice President
Heritage Action

Jordan Sekulow
President & CEO
ACLJ Action

Terry Schilling
President
American Principles Project

Nic Anderson
Vice President, Public Policy
National Religious Broadcasters (NRB)

David Santrella
Chief Executive Officer
Salem Media Group

Aiden Buzzetti
President
Bull Moose Project

Andrew Langer
President
Institute for Liberty

Ziven Havens
Policy Director
Bull Moose Project

George Landrith
President
Frontiers of Freedom

BRETT GUTHRIE, KENTUCKY
CHAIRMAN

FRANK PALLONE, JR., NEW JERSEY
RANKING MEMBER

ONE HUNDRED NINETEENTH CONGRESS
Congress of the United States
House of Representatives
COMMITTEE ON ENERGY AND COMMERCE
2125 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515-6115

Majority (202) 225-3641
Minority (202) 225-2927

April 2, 2025

The Honorable Brett Guthrie
Chairman
House Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Guthrie:

We are writing regarding your commitment during yesterday's Energy and Commerce Subcommittee on Health hearing to hold a hearing on the Trump Administration's cuts and reorganization at the Department of Health and Human Services (HHS) and its components. We are concerned that these cuts have been made indiscriminately, without regard to the impact that they will have on the ability of HHS and its operating divisions to meet its statutory responsibilities and its obligations to the American people.

As you know, last week, Secretary Robert F. Kennedy, Jr. announced HHS would undergo a restructuring including consolidating HHS operating divisions with specific missions. He also announced that HHS would eliminate 10,000 jobs on top of the 10,000 public servants who have already been terminated or who have taken the deferred resignation program. Yesterday, "reduction in force" notices began going out to affected employees. Many HHS employees did not know they had been terminated until they attempted to scan their badge to enter the office for the day and were denied entry.

Congress created HHS's operating divisions such as the Health Resources and Services Administration, the Substance Abuse and Mental Health Services Administration, and the Agency for Health Research and Quality in statute and gave them specific statutory mandates. It is up to Congress to authorize and oversee any changes to those mandates. It is also up to Congress to hold the Executive Branch accountable for its responsibility to faithfully execute the laws and maintain workforces that can fulfill agencies' missions as established in statute.

At yesterday's Health Subcommittee hearing, in reference to the Trump Administration's actions, you stated, "we have to have the proper oversight to make sure the things that Congress directs the Administration is in place." You went on to say that "it is also our responsibility…to make sure that our mission's accomplished and have the proper oversight to do that."

We call on you to fulfill this responsibility of Congress and of the Energy and Commerce Committee to exercise its oversight and hold hearings on the Trump Administration's unauthorized restructuring of HHS and termination of tens of thousands of civil servants. We believe this is of utmost importance and request you hold a hearing immediately with Secretary Kennedy to give him the opportunity to explain his plan to Congress, which holds the sole authority to undertake such a vast reorganization of HHS. The top bipartisan leaders of the Senate HELP Committee requested Secretary Kennedy to appear at a hearing next week, and our Committee must also have him before us to get answers on these massive layoffs and reorganization. We note that our multiple efforts to get HHS to provide a briefing on this matter and responses to our letters and questions have been ignored.

Moving forward, it is essential that the Committee conduct oversight of recent actions by HHS Secretary Kennedy and the Trump Administration to ensure we are maintaining and vigorously exercising Congress' Article I powers.

Sincerely,

Frank Pallone, Jr.
Ranking Member
House Committee on Energy and Commerce

Diana DeGette
Ranking Member, Subcommittee on Health
House Committee on Energy and Commerce

Congress of the United States

Washington, DC 20515

September 4, 2025

The Honorable Brett Guthrie
Chairman
House Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Morgan Griffith
Chairman
Subcommittee on Health, House Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Guthrie and Chairman Griffith:

As you know, last Wednesday, August 27, the Department of Health and Human Services (HHS) announced that Dr. Susan Monarez was no longer Director of the Centers for Disease Control and Prevention (CDC).[1] Dr. Monarez was confirmed by the Senate to the position on July 29, 2025, and had served in the position for less than a month when this announcement was made.[2]

The same day, three other senior CDC leaders announced their resignations. They include the two senior-most executives responsible for emerging infectious diseases, respiratory infections such as measles and influenza, vaccine policy, and vaccine safety research. The substantial chaos at the agency and the simultaneous departure of the nation's experts in critical infectious disease topic areas leaves the agency weakened and our nation's public health infrastructure extremely vulnerable to potential biosecurity threats.

Dr. Monarez was forced out for refusing to rubber stamp unscientific guidance related to vaccines and for refusing to fire respected senior CDC staff.[3] It is Dr. Monarez's role, as Director of CDC, to oversee the Advisory Committee on Immunization Practices and determine whether to approve vaccine recommendations made by members of the Advisory Committee. She was extensively asked about her position on vaccines during her confirmation hearing and has remained consistent in her approach to upholding evidence-based policymaking. The fact that she was forced out for following the evidence and the science is disturbing, to say the least, and is part of a clear pattern of Secretary Kennedy's direct attack on scientific integrity in favor of his extremist unscientific views.

Dr. Monarez and the other leaders left the CDC just weeks after a deadly shooting occurred at the CDC main campus by an individual who blamed the COVID-19 vaccine "for making him depressed and suicidal."[4] The shooting resulted in the death of a responding police officer and nearly two hundred rounds fired into CDC buildings. In the wake of the CDC shooting, over 750 current and former federal health employees signed a letter describing Secretary Kennedy as fueling vaccine mistrust that contributed to the violence and called upon

[1] See https://www nytimes.com/2025/08/28/health/rfk-jr-susan-monarez-cdc-vaccines.html

[2] *Id.*

[3] https://www.politico.com/news/2025/08/28/monarez-cdc-vaccines-rfk-trump-00533358

[4] https://abcnews.go.com/world-news-tonight-with-david-muirT/video/cdc-shooter-believed-covid-vaccine-made-suicidal-sources-124529774

him to denounce the attack and stop spreading inaccurate health information.[5] His response has been grossly inadequate. While CDC buildings are still undergoing repairs and clean-up from bullet holes and shattered windows, the Trump Administration saw fit to terminate the head of the CDC.

Dr. Monarez is an experienced scientist and senior executive leader in federal government. She most recently served as Deputy Director of the Advanced Research Projects for Health (ARPA-H), where she led initiatives in artificial intelligence and health technology.[6] She has held multiple positions in the White House, including in the Office of Science and Technology Policy and on the National Security Council, where she led efforts to combat antimicrobial resistance and improved pandemic preparedness.[7] President Trump posted on Truth Social regarding her nomination that "Dr. Monarez understands the importance of protecting our children, our communities, and our future."[8] Notably, Dr. Monarez was confirmed with the full support of Senate Republicans.

Congress has an obligation to the Constitution and to the American people to conduct rigorous oversight of the activities of the executive. It is imperative that we, as the Committee with jurisdiction over HHS and CDC specifically and the public health of the nation broadly, ensure public health is protected. So far, despite numerous Democratic requests for oversight hearings into Secretary Kennedy's dangerous leadership of HHS, this Republican majority has abdicated its responsibility. This Committee should immediately call the following individuals to testify regarding the departure of Director Monarez and the place of scientific expertise and evidence-based policymaking at HHS under Secretary Kennedy:

- Robert F. Kennedy, Jr., in his capacity as Secretary of Health and Human Services
- James O'Neill, in his capacity as Deputy Secretary of Health and Human Services
- Matt Buckham, in his capacity as HHS Chief of Staff
- Stefanie Spear, in her capacity as HHS Principal Deputy Chief of Staff
- Dr. Susan Monarez
- Dr. Debra Houry
- Dr. Demetre Daskalakis
- Dr. Daniel Jernigan

Congress and the American people deserve to hear directly from these individuals regarding the circumstances that led to the departure of Director Monarez and other senior CDC leaders. We are alarmed by reports that Dr. Monarez was directed to resign for refusing to engage in regulatory actions driven by ideology rather than science and what is best for public health. The Committee on Energy and Commerce must immediately hold hearings to gain a full picture of this matter, the state of CDC, and the risks to Americans' health and lives if scientific competence is not restored.

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[5] https://www npr.org/sections/shots-health-news/2025/08/20/nx-s1-5507208/after-shooting-cdc-workers-demand-more-protections-from-hhs-secretary

[6] https://www npr.org/sections/shots-health-news/2025/07/29/nx-s1-5484124/cdc-director-monarez-confirmed-senate

[7] *Id.*

[8] https://truthsocial.com/@realDonaldTrump/posts/114219231809224627

It is long past time for Committee Republicans to join us in conducting vigorous oversight of the nation's public health system in service of our constituents.

Sincerely,

Diana DeGette
Ranking Member
Subcommittee on Health
Committee on Energy and Commerce

Frank Pallone, Jr.
Ranking Member
Committee on Energy and Commerce

Raul Ruiz, M.D.
Member of Congress

Debbie Dingell
Member of Congress

Robin L. Kelly
Member of Congress

Nanette Diaz Barragán
Member of Congress

Kim Schrier, M.D.
Member of Congress

Lori Trahan
Member of Congress

Marc A. Veasey
Member of Congress

Lizzie Fletcher
Member of Congress

Alexandria Ocasio-Cortez
Member of Congress

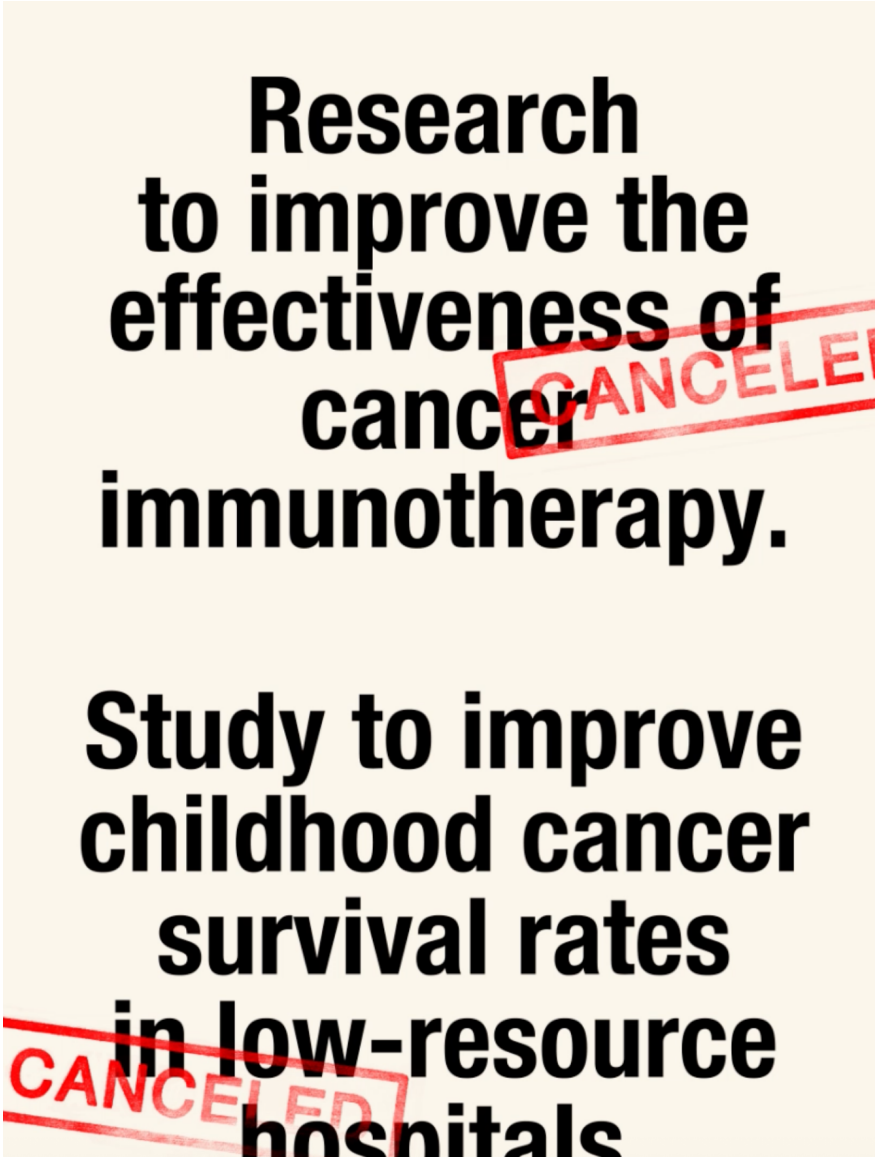
Jake Auchincloss
Member of Congress

Troy A. Carter, Sr.
Member of Congress

Greg Landsman
Member of Congress

Trump Is Shutting Down the War On Cancer

America's cancer research system, which has helped save millions of lives, is under threat in one of its most productive moments.



By Jonathan Mahler

Sept. 14, 2025

Rachael Sirianni first learned her lab might be in trouble just a few weeks into the new year. A professor at the University of Massachusetts Chan Medical School, in Worcester, Sirianni focuses primarily on an aggressive form of pediatric brain cancer known as medulloblastoma. Researchers have made great strides in treating these tumors, but they are still often fatal, and even successful treatments can come with devastating side effects. Sirianni had spent the last several years working on a potentially transformative approach to treating the most malignant type of medulloblastoma and was making real progress.

Pediatric brain cancer research is expensive. UMass Chan pays for some of Sirianni's work, but most of her funding comes from the federal government. Entering 2025, she had three active grants at the National Institutes of Health that were all set to expire either this year or in 2026. She was prepared. In 2024, she submitted two new applications to continue her research. Both proposals had cleared the first hurdle at the N.I.H., earning strong scores from a panel of independent experts in the field. They were scheduled for another review at the agency in late January.

But then, in the days after Trump's inauguration, Sirianni started hearing rumors that he was planning to disrupt the N.I.H.'s grant-making process. As it turned out, he did much more than that. In late January, his administration ordered the N.I.H. to cancel meetings to consider pending grant applications.

Sirianni received her first federal research grant more than a decade earlier and had never even had an application-review meeting postponed. She scrambled to learn anything she could about the status of her proposals. This turned out to be difficult, because the new administration had ordered the N.I.H. to temporarily cease all external communications. Scientists were unsure whether they could even speak with program officers at the agency.

Sirianni, who is now 40, started college when she was 13. For more than two decades, she had spent as many as 12 hours a day in a lab, hunched over microscopes, computer monitors and lab mice. Now she was spending much of her time on the phone, talking and texting with equally anxious peers around the country. "Many of us had been in uncertain situations in the past — that's the nature of the game for academic scientists," she says. "But this was unlike anything we'd ever felt before."

Sirianni was lucky in that she had a modest buffer: When UMass Chan recruited her from the University of Texas in 2022, the school's chancellor, Michael Collins, gave her a generous start-up fund to get her new lab up and running and to pay her postdoc researchers, trainees and technicians. She had spent only half the money, so she could use what was left to help carry her and her staff through this period of uncertainty; she needed to keep the momentum going for her most promising studies and pay the researchers overseeing them.

On March 11, though, Sirianni received a troubling email from UMass Chan's administration. The disruptions at the N.I.H. were creating so much uncertainty around the school's financial future that it had to indefinitely pause all discretionary spending and freeze all hiring. The money from Sirianni's start-up fund was now effectively frozen, and she had no choice but to shrink her lab. When a researcher and her lab manager left, she was unable to replace them. Nor could she offer positions to two undergraduates whom she had been mentoring and was planning to retain. More devastating still, she had to suspend one of her most promising pediatric brain cancer studies and eventually lay off the postdoc who was helping her run it.

'When you remove me from the ecosystem, you are removing something that can't be replaced.'

Rachael Sirianni

There was a sliver of hope, though: The two grants that Sirianni applied for in 2024 were pending, and they were finally scheduled for their reviews at the N.I.H. in April and May. The delay had at least allowed her to add more compelling data to one application, strengthening her case for funding.

Both proposals received strong scores from the N.I.H. program directors who analyzed and discussed them. But as of the beginning of September, neither one had been funded. "I believe I am one of only a small handful of labs in the country that specializes in drug-delivery barriers in pediatric brain cancer," Sirianni told me when I visited her over the summer at her lab. "When you remove me from the ecosystem, you are removing something that can't be replaced."

Rachael Sirianni, a professor at the University of Massachusetts Chan Medical School. Her research into pediatric brain cancer was derailed by changes to federal grant programs. Matthew Monteith for The New York Times

When America declared war on cancer more than 50 years ago, there was a misguided assumption outside the scientific community that it would be only a matter of years before the disease was eradicated — that defeating cancer would be no different than building an atomic bomb or putting a man on the moon. But there would be no miracle cure: As of this writing, some 40 percent of Americans will be diagnosed with cancer at some point in their life.

What there would be, however, was decades of minor breakthroughs that would accrue over time, transforming both our understanding of the disease and our ability to treat it. One way to measure the cumulative effect of those breakthroughs is with statistics: In the mid-1970s, America's five-year cancer-survival rate sat at 49 percent; today, it is 68 percent. You can also correlate America's sustained investment in cancer research directly with these returns: According to a recent study in The

Journal of Clinical Oncology, every $326 that our government spends researching cancer extends a human life by one year. Now an extraordinarily successful scientific research system — one that took decades to build, has saved millions of lives and generated billions of dollars in profits for American companies and investors — is being dismantled before our eyes.

In a matter of months, the Trump administration has canceled hundreds of millions of dollars in cancer-related research grants and contracts, arguing that they were part of politically driven D.E.I. initiatives, and suspended or delayed payments for hundreds of millions more. It is trying to sharply reduce the percentage of expenses that the government will cover for federally funded cancer-research labs. It has terminated hundreds of government employees who helped lead the country's cancer-research system and ensured that new discoveries reached clinicians, cancer patients and the American public. And the president's proposed budget for the next fiscal year calls for a more-than-37-percent cut to the National Cancer Institute — the N.I.H. agency that leads most of the nation's cancer research — reducing it to $4.5 billion from $7.2 billion. Adjusting for inflation, you have to go back more than 30 years to find a comparably sized federal cancer-research budget.

President Trump made a less ambitious attempt to defund America's scientific research system during his first term, proposing a 22-percent across-the-board cut to the N.I.H. in his inaugural budget and seeking to reduce institutions' reimbursement rates for some of their overhead expenses. Congress flatly rejected both efforts. To Republicans and Democrats, biomedical research — and cancer research, in particular — was sacrosanct.

But a very different attitude toward American science now prevails on the right wing of American politics. The Covid epidemic is largely responsible. Caught between a deadly pandemic and the government's oppressive countermeasures, many Americans sought someone to blame. A variety of vaccine skeptics, antigovernment MAGA types and wellness influencers and a discrete cohort of doctors and medical experts offered them a candidate: the scientific establishment. Their collective disaffection soon congealed into a powerful political force of its own, and a fringe movement to undermine the credibility of America's scientists went mainstream.

This force has become institutionalized in Trump's second administration. Defending the government's ongoing cuts to scientific research last May, Robert F. Kennedy Jr., a prominent vaccine skeptic who now leads the Department of Health and Human Services, told Congress that the N.I.H. was plagued by "corruption." Trump's N.I.H. director, Jay Bhattacharya, a co-author of the Great Barrington Declaration, a scientific treatise assailing America's Covid policies, made his name attacking the agency that he is now running.

Trump himself defended the cuts to biomedical research in a testy exchange with a Time magazine reporter last spring. "I could give you a list of abuse and waste and fraud," he said, "and you don't have any interest in hearing it." But neither he nor anyone inside his administration has spoken explicitly about its intention to radically rethink how America funds and directs cancer research, let alone laid out a plan for doing so.

In the absence of any such plan, it's hard not to see the ongoing dismantling of the cancer research system as collateral damage in a larger, partisan war against both the predominantly Democratic scientific establishment and the predominantly Democratic academic institutions where much of the country's biomedical research takes place. And yet the term "collateral damage" suggests a lack of agency; this has been a deliberate and targeted attack. "They have studied how N.I.H. works, studied it hard and learned it well," says Sarah Kobrin, head of the Health Systems and Interventions Research Branch at the National Cancer Institute. "And they have put sand in the gears in ways that are very effective, devastating." (The White House referred a detailed request for comment to the Office of Management and Budget, which said in a statement that the administration's "efforts to focus N.I.H. spending will establish a more sustainable and accountable fiscal path for N.I.H., while ensuring that resources are managed effectively and in a manner that best supports America's biomedical-research enterprise." An N.I.H. spokesperson said, "N.I.H. continues to invest significantly in bold and innovative cancer research.")

I spoke to 50 members of America's biomedical research establishment for this article — medical-school administrators; N.I.H.- and N.C.I.-funded researchers; former directors and current and former program officers and officials at the two agencies. As a group, they were hardly averse to change: Most acknowledged that the cancer-research system and the biomedical-research system more broadly had become too unwieldy and risk-averse. Before last year's election, both House and Senate Republicans circulated N.I.H. reform proposals on Capitol Hill, and the leaders of the National Institutes of Health and the National Cancer Institute were expecting — and even looking forward to — some new policies. "We didn't have our heads in the sand," says Michael Lauer, who retired in February as a deputy director of the N.I.H. and the agency's head of grant-making.

But no one was expecting this. "It's an absolutely unmitigated disaster," Lauer told me. "It will take decades to recover from this, if we ever do."

Frozen tissue samples and other materials used during Sirianni's research. Federal grant money supports laboratories in many ways, including supplies and facilities costs as well as staff salaries. Matthew Monteith for The New York Times

America's cancer-research system is sprawling and diffuse, beginning with Sirianni and the rest of America's tens of thousands of cancer researchers and continuing up through UMass Chan and the other research universities and cancer centers across the country that support their work. These institutions depend on the grant money their faculty members bring in to help cover their individual salaries and also to create and support their infrastructures — like the buildings that house the labs, the doctoral students and postdocs who help run them and the supplies they need to conduct experiments. This is the economic structure that built these institutions, and it's one that they have come to rely on to function.

UMass Chan is a short drive from some of the most prestigious cancer-research centers in the world. It may not have the reputation or resources of a Harvard or Dana-Farber, but it does have 234 principal investigators doing frontline, government-funded research. When Michael Collins took over as the school's full-time chancellor in 2008, one of his priorities was to expand its research program, and he has been unambiguously successful at doing so. On his watch, the school's annual research budget has nearly doubled, to $352 million from $157 million, some $45 million of which goes toward cancer-related work. "If you have great scientists, you are going to win your share of grants," he says.

Last year was the high point of his 18-year tenure: He opened a new, $350 million, 350,000-square-foot research building, and one of his scientists was part of a duo that won a Nobel Prize. This year has been a very different story. Collins has spent much of it in urgent meetings with his finance team trying to figure out how to deal with the reality that tens of millions of dollars were suddenly disappearing from his institution's anticipated revenues.

Collins suspected that trouble was coming even before the new administration took office in Washington. One of the most important federal funding mechanisms for UMass Chan and other research institutions is what's known as their indirect cost reimbursements. In short, the government covers a portion of their facilities and administrative costs. How much institutions are entitled to receive is known as their indirect-cost rate, a fixed number that corresponds to a percentage of the direct costs associated with specific research projects.

Every institution has its own indirect rate, negotiated with the government and determined by a variety of factors, like the cost of labor in its geographic region. UMass Chan has a high indirect rate — 67.5 percent — which means it is heavily dependent on these reimbursements. As Collins is quick to point out, though, the number is misleading. Because of certain caps and other limitations, the government reimburses the institution only for the indirect expenses associated with 44 percent of its direct costs. Those indirect expenses include the cost of administering the school's grants and the debt service on its research buildings.

During his first term, Trump tried to cap all indirect-cost reimbursements at 10 percent, which would have had dire consequences for UMass Chan. Congress not only rejected the effort but also added a rider to the budget bill preventing the administration from modifying indirect rates in the future. That same rider had been attached to every budget bill enacted since then.

Still, Project 2025 had called for the new administration to cut reimbursement rates, and Collins was worried that Trump would try again. A few days after the election, he flew down to Washington and met with Representative Lori Trahan, a Massachusetts congresswoman who sits on the committee that oversees the N.I.H., to remind her about the rider. Trahan was reassuring.

Collins's worries proved prescient. On a Friday evening in early February, the N.I.H. unilaterally amended its grant policy, ordering that all indirect-reimbursement rates be capped at 15 percent. Collins spent the weekend on the phone with his finance team, which calculated that the cut could cost UMass Chan somewhere between $50 and $60 million in expected revenues for the fiscal year. On Monday morning, Massachusetts and 21 other states sued the Trump administration to block the change. That afternoon, a federal judge in Boston issued a temporary restraining order halting the implementation of the new policy until its lawfulness had been adjudicated.

'We could lose a generation of scientists in a very short time.'

Michael Collins

Collins was safe, but not for long. Soon after, he got a call from his finance team informing him that the federal grant payments for the week were not available. There was little explanation from the government. The money simply wasn't accessible. The way the federal grant-making process works, researchers apply for funding through their respective institutions and the money is then disbursed through those institutions. Collins relies on those funds to help pay the salaries of his professors. Now he would need to find the money elsewhere to make up the difference.

Weeks passed, and there was still no money from the N.I.H., nor any clear explanation for why it had disappeared. At the same time, Collins had numerous faculty members who, like Sirianni, had grant applications pending at the N.I.H. that were completely stalled.

Already down some $30 million and with anticipated future revenues in jeopardy, Collins had to take some sort of action. In March, UMass Chan furloughed 200 employees and sent out the email to Sirianni and the rest of the school's faculty members freezing all discretionary spending. It also rescinded the offers to all 87 students whom it had admitted to its graduate school of biomedical science for the 2025-26 academic year. (The school would partly reverse this decision several weeks later, offering spots to 14 students for the current academic year and accepting the rest for the following one.)

Collins was not alone. Chancellors and medical-school deans at research institutions across the country had all had their government funding disrupted, and they were by now comparing notes during a weekly Thursday night Zoom meeting. UMass Chan had not been targeted by the Trump administration for political reasons, but other institutions had been. Harvard, Columbia, Northwestern, Cornell, Brown and the University of Pennsylvania were among those whose N.I.H. funding was cut off because the White House claimed that they had violated the civil rights of their Jewish students. Like UMass, these institutions had also received little or no warning.

In April, Collins finally got some good news: The N.I.H. had resumed meetings to discuss pending grant applications. He had his finance team run some more numbers, calculating how many proposals UMass Chan had before the agency that had already cleared the first round of N.I.H. review and had received what is considered a fundable score. They determined that the school could expect between $30 million and $40 million in new grant payments for the remainder of the fiscal year. As of the end of June, however, very few of these applications had been approved.

Michael Collins, chancellor of UMass Chan. In March, the absence of promised federal grant money forced the school to furlough 200 employees and freeze discretionary spending. Matthew Monteith for The New York Times

By that point, the N.I.H. had started resuming some payments for existing grants to UMass Chan, but the flow of money was still just a trickle — no more than a few hundred thousand dollars a week. By the middle of July, Collins was facing a research-budget shortfall for the fiscal year of $93 million. Collins told me that he planned to take stock again at the end of September, at the close of the federal government's fiscal year, and decide what additional cuts he needs to make. In the meantime, he's doing everything he can to raise money from individuals, private foundations and the state of Massachusetts. "I'm trying to get people to be worried about this," he says, "and it's hard. We could lose a generation of scientists in a very short time."

The broad framework for America's cancer-research system can be traced back many decades, to the waning days of World War II. The scientific community had played a critical role in the war effort, and President Franklin Delano Roosevelt commissioned the head of his wartime Office of Scientific Research and Development, a former M.I.T. scientist named Vannevar Bush, to draft a

report — “Science: The Endless Frontier” — that would argue for carrying the partnership between government and academia into peacetime. Bush made the case that basic scientific research was critical to maintaining America’s global leadership role and economic vitality, and he argued that this research should be funded by the federal government and carried out by universities.

It would be many years, though, before the government would make a large and sustained investment in fighting cancer. The individual most responsible for prodding the government into action was not a politician but a New York philanthropist and socialite, Mary Lasker. Lasker started lobbying for a sweeping government-funded effort to fight cancer in 1952, after her husband died of colon cancer, and pretty much never stopped. In 1969, she turned her lobbying campaign into a public crusade that included a series of full-page newspaper ads challenging President Richard Nixon to invest the same sort of resources and energy into fighting cancer that the government had put into the Apollo space program. Two years later, Nixon signed the National Cancer Act into law, committing $1.5 billion — about $12 billion in today’s dollars — over the next three years to fighting cancer. Thus began the War on Cancer, the most ambitious public-health initiative ever undertaken.

Before scientists could begin to figure out how to defeat cancer, they first had to learn how little they knew about its biology, starting with the fact that it was not a single disease but an infinite number of them, with hundreds of subtypes that don’t just originate in different parts of the body but also behave differently in different people. The process took decades and is ongoing. Not until the late 1990s did all of the accumulated knowledge about the molecular biology of cancers begin to yield transformative treatments, in the form of targeted therapies designed to attack specific types of cancer. Since then, progress has accelerated. Between 1991 and 2022, the death rate from cancer in the United States fell by 34 percent; 4.5 million fewer people died of cancer than otherwise would have.

As scientists’ understanding of the disease deepened and new paths to treat it proliferated, the cancer-research system expanded. It now reaches into just about every medical specialty, subspecialty and scientific discipline. It is diffuse but also interconnected, with researchers sharing their findings in peer-reviewed medical journals and at scientific conferences. Cancer research seldom has a clear, monetizable endpoint — it is often work, in other words, that private industry would never support. The system’s extraordinary success is most clearly observed in retrospect, by looking at cancers that were fatal just a couple of decades ago and that doctors can effectively treat today. This progress is a validation of a slow but patient process that requires time — and the gradual accretion of shared knowledge — to prove its value.

‘This is one of the most productive periods in the history of cancer research. At the same time, my colleagues are experiencing something between malaise and terror.’

Norman Sharpless

America’s investment in cancer research has rippled out far beyond cancer. Investigating the molecular biology of one disease can naturally lead to discoveries about other ones — a phenomenon that scientists call convergence. It was cancer research that led to the creation of treatments for H.I.V. and hepatitis C, and to a vaccine for hepatitis B. When the Covid pandemic struck, technologies that had been developed for cancer enabled scientists to quickly sequence the virus and then develop a vaccine for it. The Cancer Genome Atlas, which collected and analyzed DNA samples from 11,000 cancer patients over 12 years, didn’t just become a model for the mapping of other diseases; it also accelerated the evolution of the emerging interdisciplinary field of data science. America’s prodigious investment in cancer research also helped jump-start the biotechnology industry, a powerful engine of medical innovation in its own right.

Sirianni’s story speaks to both the short- and long-term benefits of America’s cancer-research system. Her work builds on that of other drug-delivery scientists and is both costly and labor-intensive. Pediatric cancer cells can’t easily be grown in vitro in a lab; they are typically harvested from operating rooms and then cultivated in lab animals — most commonly, an expensive strain of

mouse. Pediatric brain cancer is also a highly specialized field, so it can take a while to train doctoral students and postdocs to become comfortable in the lab. Sirianni is targeting a specific subset of a relatively rare cancer; about 300 or so children are diagnosed with medulloblastoma every year. It is the kind of work that is unlikely to attract private investment at this early stage. And yet if she succeeds in developing a more effective method of moving therapeutic molecules into the interior of the brain to attack this particular form of cancer, she might not only save or improve the lives of many children; the technique could very well transform how doctors treat other neurodegenerative diseases like A.L.S., Alzheimer's and traumatic brain injury.

Government-funded cancer researchers across the country are engaged in work with similarly groundbreaking potential. At Ohio State University, investigators are experimenting with a so-called flash-radiation treatment that lasts just a few tenths of a second, killing cancer cells and causing significantly less harm to the surrounding healthy tissue. At Stanford, scientists are using machine learning and mathematical modeling to more accurately predict the evolution and outcome of tumors. At Johns Hopkins, researchers recently discovered a way to detect cancer-derived mutations in the bloodstream up to three years before clinical signs or symptoms — advancing progress toward the development of a routine blood test that will be able to screen for a range of cancers. At the University of Washington and elsewhere, researchers are developing cancer vaccines. (Some, however, are mRNA vaccines, which could be threatened by Robert F. Kennedy Jr., who has already halted funding for the development of mRNA vaccines for infectious diseases.) "This is one of the most productive periods in the history of cancer research," Norman Sharpless, who served as the director of the National Cancer Institute during the first Trump administration and for part of Biden's presidency, told me. "At the same time, my colleagues are experiencing something between malaise and terror."

As might be expected of any complex, multibillion-dollar entity that has been growing and evolving over decades, America's cancer-research system has developed structural problems that need to be addressed. Because there is no mandatory retirement age for academics, the research field has aged sharply; between 1980 and 2008, the average age for an N.I.H.-funded principal investigator rose from 39 to 51, and it has slightly increased since. This has crowded out a lot of younger scientists with fresh ideas. It has also made the grant-application process enormously competitive, which means principal investigators have to spend a disproportionate amount of their time not doing research but writing grant applications. To secure funding in such a cutthroat environment, investigators are often inclined to propose safer, more incremental projects, rather than more cutting-edge ones. The top-heaviness of the research field and the time-consuming nature of the grant process is holding back progress and making it difficult to attract the most talented American students, which explains why so many postdoctoral researchers in American labs are from other countries, principally China and India.

It's perhaps no surprise that the Trump administration's attack on America's biomedical research system has been embraced by the disruption-addicted tech right. A government-run research system of sustained investment, collaboration and incremental progress no doubt looks anachronistic to a culture of individual visions, competitive silos and overnight growth — and all the more so with the leaders of various generative-A.I. companies making far-fetched promises to cure cancer in a matter of years.

Last May, in the early months of the Trump administration's cuts, the venture capitalist and Palantir co-founder Joe Lonsdale took aim at America's biomedical-research establishment in a Substack post titled "Fix the N.I.H. to Fix American Science." Lonsdale bemoaned the lack of breakthroughs to treat many cancers and proposed some of his own solutions. In addition to a sweeping regime of cuts to "underperforming labs and scientists" that "fuel mediocrity" and advance political agendas, Lonsdale called for a new federal grant-making process that would reward risk-taking and embolden visionaries. "In too many ways, the N.I.H. embodies the Soviet model that should have been left to die in the 20th century," he wrote. "Centralization, top-down ideological control of processes and an extreme conviction by the bureaucrats that they know better than anyone about everything."

A desk in a cancer-research lab at UMass Chan. Decades of federally funded efforts have led to accelerating results: Between 1991 and 2022, the death rate from cancer in the United States fell by 34 percent. Matthew Monteith for The New York Times

Dismantling a structure as large and multifaceted as America's cancer-research system is much easier than building one, but it is not without its challenges. The system was designed to be insulated from politics. Traditionally, there were only two political appointees at the N.I.H.: its director and the director of the National Cancer Institute. What's more, it's not the executive branch but Congress — which has a long history of bipartisan support for cancer research — that allocates the grant money that funds the scientists and their institutions. Tearing down the system, then, would require moving quickly and aggressively, taking control of it from the top down, clearing out civil servants and scientists while choking off the flow of money to universities and research centers.

The administration was much better prepared to accomplish this during Trump's second term than during his first. Russell Vought, the director of the White House's Office of Management and Budget and the primary architect of the attack on the biomedical-research system, spent the Biden years getting ready for this moment, drawing up a detailed plan to markedly shrink the federal government and end what he has called "the woke and weaponized bureaucracy."

He and the new administration began executing their plan on Trump's first full day in office. The first step was to effectively paralyze the N.I.H. and N.C.I. by ordering them to pause all external communications. They accomplished this via the sweeping communications ban issued by the acting head of H.H.S., Dorothy Fink. The directive compromised the agencies' ability to interact with the scientific community. But it also stopped the publication of all scientific research and, crucially, of any information in The Federal Register, in which all new opportunities for funding and all meetings to consider new grant applications have to be listed. As long as the communications pause was in effect — and the order wasn't clear about when it would end — there would be no new opportunities for cancer researchers, and all pending proposals, like Sirianni's two applications at the N.I.H., would be indefinitely delayed.

More directives followed in the days ahead, first a suspension of travel for N.I.H. employees and then a memo from the White House's Office of Management and Budget freezing grant funding from all federal agencies. Now, in addition to the ongoing pause on new cancer-research grant applications, no existing grants could be paid. All of this was unprecedented. Given the nature of the N.I.H.'s work — supporting biomedical research — new administrations usually went out of their way to make sure that transitions were as seamless as possible. "I don't ever recall a gag order or a grant freeze in my time at N.I.H.," says Lauer, the former N.I.H. deputy director who spent 18 years at the agency.

A group of nonprofits sued the administration over the funding freeze and were granted a stay in late January, ensuring that grant money would continue to flow while the case was briefed. In response, the administration withdrew the memo announcing the freeze — seemingly lifting it, per the court's order. But then the new White House press secretary, Karoline Leavitt, announced on her social media account that the order was still in effect. No one at the N.I.H. was sure what to do. At N.C.I., the confusion was especially acute. The agency's director, Kimryn Rathmell, resigned the day of Trump's inauguration, and the president had not named an acting director to replace her, instead consolidating power at H.H.S.

The first round of layoffs came soon after, in mid-February. Some 1,200 N.I.H. employees were terminated, including 140 or so people at N.C.I. — senior leaders, scientists, grant administrators and many others. The O.M.B. order to freeze all grant payments had already disrupted the flow of money to research universities and centers. But in March, H.H.S. started formally canceling hundreds of active research grants.

This, too, was virtually unprecedented; Lauer recalled a total of two grants being unilaterally terminated by the government over the course of his career at the N.I.H. Now numerous grants that didn't comport with the administration's priorities, specifically as they concerned its D.E.I. policies, were being flagged for cancellation. At N.C.I., Sarah Kobrin, who focuses on cancer prevention, found herself trying to defend government-funded projects dedicated to increasing cancer screening in rural communities that happened to have large Black populations.

There was a more efficient way to stop the flow of money than terminating individual grants. Later in the winter, the Trump administration simply took control of the grant-payment system at H.H.S. — via Elon Musk's Department of Government Efficiency — and began freezing billions of dollars in N.I.H. funding for a group of universities that appeared on a target list compiled by the administration's new task force to combat antisemitism.

More layoffs followed in the spring. Pretty much the N.C.I.'s entire 70-person communications department, which was responsible for keeping the public and the medical and scientific communities abreast of the latest developments in the world of cancer research, was let go and not replaced. So was the N.C.I.'s acquisitions department, which purchased all the agency's office and lab supplies and issued all its contracts. A chief surgeon at the National Cancer Institute, Steven Rosenberg, who is leading a clinical trial testing the use of immunotherapy on acutely ill patients with gastrointestinal cancer, lost two of the scientists in his lab who produced the cells with which he injected his patients.

Another way to cancel grants in bulk was to go after grant programs. The new administration terminated one of the N.C.I.'s most prestigious ones, the Outstanding Investigator Award, a seven-year grant intended to give cancer researchers with a track record of success the freedom to explore more innovative approaches in their field. It also ordered the N.I.H. to overhaul its

approach to funding grants that weren't being canceled. The administration wanted half of all remaining funding for the fiscal year to be "forward-funded" — or paid out in full upfront. This would consume a large portion of the N.C.I.'s budget for the year, and translate into a significant cut to the number of new cancer-research grants that could be approved and funded. The National Cancer Institute recently informed the scientific community that it expected to be funding just 4 percent of all grant applications for the remainder of the government's fiscal year — less than half of last year's already-low 9 percent. In July, a public-policy professor at the University of Michigan, Donald Moynihan, posted an anonymous note on his Substack from an N.I.H. expert who described the abrupt shift to forward-funding as "a nuclear bomb dropped on cancer funding."

How was any of this even possible? The American people, through their representatives in Congress, had already allocated this money for research. When a president withholds congressionally appropriated funding, it is called impoundment, which Congress placed strict limits on in 1974. But Vought has insisted that the president is within his rights to refuse to disperse these funds. And he has argued that any money that hasn't been spent by the end of the fiscal year should be returned to the Treasury — a move known as a pocket rescission, which is considered illegal by the Government Accountability Office and other legal experts.

Whether the new administration's actions are legal or not, it has succeeded in blocking the disbursement of a lot of congressionally appropriated funds. Between Jan. 20 and Aug. 20, the N.I.H. paid out $4.31 billion less in grants than it did during the same period last year. The N.C.I., for its part, paid out $842 million less. And these numbers don't account for the many other billions of dollars in grants and funding that have been terminated or frozen since Trump took office.

Of course, withholding all of this money required a whole new structure inside the government. The N.I.H. no longer has two political appointees; it now has more than 20. The administration didn't so much tear down a top-down, ideologically controlled bureaucracy as it created a new one.

In the summer of 2008, my mother, who was 70 years old at the time, lost her appetite. She was a petite woman to begin with, but over the course of the next few months she lost at least 15 pounds. For a while, she refused to go to the doctor — she was also stubborn — but when she finally did, she was diagnosed with small-cell lung cancer that had spread to her liver. My mom was a lifelong smoker**,** so the diagnosis was devastating but not surprising. It was too late for radiation or surgery. The only option was a highly toxic course of chemotherapy. She survived for nearly a year, but her quality of life was terrible; her weekly chemo treatments left her nauseous and exhausted, unable to get out of bed or eat solid food for days. She was fully lucid and mentally sharp right up until 24 hours or so before she died, when the morphine pulled her into a state of semiconsciousness.

'Running a lab is not like running a clothing store, where if your sales are down you can bounce back. You are dealing with highly trained people and projects which, when stopped for a short time, are ruined.'

Harold Varmus

Last year, when I was suffering from a lingering respiratory infection, I went to see the pulmonologist who treated her, Daniel Libby. We talked a little bit about my mom, and he mentioned to me, almost as an aside, that if she were diagnosed today, he would be able to do a lot more for her. Over the summer, I gave him a call. Now that I was working on a story about cancer research, I was curious to hear more.

Libby told me that if he were to diagnose my mom with cancer today, her initial biopsy would include an oncogene test to see which one of the 75 known lung-cancer genes he was dealing with and what mutation could be occurring. Depending on the mutation, there might be a drug that would be effective in slowing the growth of the cancer cells. Even if there weren't, the test would provide him with actionable information about how to best treat her. Rather than chemo, he would use immunotherapy to

help her immune system recognize the cancer cells and fight them off, which would probably be both more effective and much easier on her body. It's impossible to know how she would have responded to the treatment, but he estimated that she might have lived an extra six months or even a year; maybe more important, her quality of life during treatment would have been vastly better than it was during her chemo.

It's too early to predict what the ongoing dismantling of America's cancer-research system is going to cost us — what lifesaving, life-extending or life-improving treatments will be slower to develop, if they develop at all. The White House's proposed budget, with its 37-percent cut to the N.C.I., is still awaiting congressional debate, and various court battles are still playing out. In June, a Reagan-appointed federal judge in Boston, William G. Young, reversed some of the Trump administration's grant terminations in a stinging decision, writing that in his 40 years on the bench, he had "never seen government racial discrimination like this." But the administration appealed, and in late August, a 5-to-4 majority of Supreme Court justices upheld the cancellations, while leaving the door open for individual grantees to bring their own challenges.

The researchers, meanwhile, are doing what they can to continue their work. At UMass Chan, the top student in the biomedical sciences Ph.D. programs — the winner of the school's Chancellor's Award — has made plans to return home to China to run his own lab at Peking University. And Sirianni is now spending much of her time in her small office across the hall from her lab, furiously writing grant applications. For the time being, she is shifting her primary focus away from medulloblastoma, and toward other fields like traumatic brain injury. The experiments are too expensive to run, and she now has fewer researchers with the necessary expertise to help her. And pediatric cancer had very low funding rates at the N.I.H. before the Trump administration's cuts. Even if one of her new applications on a different project finds traction inside the N.I.H., though, it could take at least a year from the time of submission for the money to begin to flow. And these are just two scientists at a single institution.

Joe Lonsdale's blueprint for overhauling the N.I.H. promised a "moonshot factory that unleashes a new era of discovery." But almost eight months into Trump's second term, we have seen no proposals to replace what his administration is tearing down. The cancer-research system may be big and sprawling, but its wholesale dependence on government funding also makes it almost uniquely precarious. It doesn't take much to disrupt its normal functioning, and in the realm of science, any sort of disruption can be devastating. "Running a lab is not like running a clothing store, where if your sales are down you can bounce back," Harold Varmus, a former N.I.H. director and Nobel Prize-winning cancer researcher, told me. "You are dealing with highly trained people and projects which, when stopped for a short time, are ruined."

Other countries are seeing opportunity in the chaos. Varmus is among a number of prominent U.S. scientists who have received solicitations from the governments of France and Spain to consider relocating there. America's 80-year run as the world's leader of biomedical research — and 50-year run as the global leader of cancer research — may very well be coming to a close, and for no apparent reason. Varmus seemed as puzzled as anyone by the development. "We are great in science," he said. "Why would we want to destroy one of our greatest assets?"

Read by Eric Jason Martin Narration produced by Krish Seenivasan Engineered by Ted Blaisdell

Jonathan Mahler, a staff writer for The New York Times Magazine, has been writing for the magazine since 2001.

GREATER HOUSTON PARTNERSHIP.
Making Houston Greater.

September 9, 2025

The Honorable Lizzie Fletcher
2004 Rayburn House Office Building
Washington DC, 20515

RE: Extending the Enhanced Premium Tax Credits

Dear Congresswoman Fletcher,

The Greater Houston Partnership, representing the business community and leading institutions of the 12-county greater Houston region, supports extending the enhanced premium tax credits (EPTC) for small businesses and self-employed Texans.

As you know, the Houston region boasts one of the largest and fastest growing economies in the nation, employing nearly 3.5 million residents in a variety of industries and business sizes. Nearly one third of these workers are able to remain healthy contributors to our economy because of their ability to access affordable health care coverage through enhanced premium tax credits. These tax credits have provided business owners and employees alike with much-needed stability, empowering entrepreneurship and economic growth.

Access to affordable health coverage is vital to sustaining our region's economic growth and fostering a thriving workforce. By extending these tax credits, Congress would continue a proven, market-driven solution that strengthens Houston businesses and helps us sustain a productive workforce.

As the 119th Congress considers its legislative priorities for the remainer of the year, the Greater Houston Partnership supports the economic and health advantages of extending the enhanced premium tax credits.

Sincerely,

Steve Kean
President & CEO

September 15, 2025

Honorable Members of the Houston Congressional Delegation
United States Congress
Washington, D.C. 20515

RE: Houston Hospital Leaders Support for Enhanced Premium Tax Credits

Dear Members of Houston's Congressional Delegation,

As leaders of Houston's major hospitals and health systems, including Harris Health System, HCA Houston Healthcare, Houston Methodist, Memorial Hermann Health System, and St. Luke's Health, we write to urge your support for extending the Enhanced Premium Tax Credits before they expire at the end of this year.

The tax credits have been critical in enabling nearly 3.4 million Texas residents, including more than 667,417 Harris County residents, to access affordable health insurance through the individual Marketplace. Many of these individuals are small business employees, self-employed individuals, working families, and pre-retirees who otherwise would not have access to affordable health coverage.

The consequences of the tax credits expiring would be devastating. If Congress does not act, a Texas couple in their early sixties could see their annual premiums rise by more than $17,500 — more than tripling their out-of-pocket costs and placing coverage out of reach. These affordability cliffs would lead to coverage losses, delayed care, and worsening health outcomes for our patients. There would be higher uncompensated care costs, overburdened emergency departments, and greater resource strain across our networks.

When individuals lose insurance, they delay treatment for chronic diseases, avoid screenings, and present with more advanced conditions. This undermines quality, increases overall costs, and strains the entire system, from primary care to specialty and hospital services.

The Enhanced Premium Tax Credits are an essential part of Houston's health infrastructure. They support working families, protect access in rural and underserved areas, and ensure hospitals can deliver high-quality care without compromise.

Allowing these health care tax credits to lapse would also harm our state's economy. Analysts estimate our state would lose more than 69,000 jobs and $8.4 billion in GDP by 2026, impacting the health care sector directly. As coverage rates fall, hospitals and other providers may be forced to cut services, delay improvements, or reduce staff. All of these consequences would limit access and widen health disparities across Texas.

Nearly 810,000 small business owners and self-employed workers in Texas rely on Marketplace coverage made more affordable by these tax credits. These Texans are the backbone of our

state's economy — entrepreneurs, sole proprietors, and independent contractors who power our local communities. Without the Enhanced Premium Tax Credits, many would face steep premium hikes that could threaten both their health and their livelihoods.

We strongly urge you to extend the Enhanced Premium Tax Credits. Doing so will ensure our patients have the care they need. We welcome the opportunity to share more about how these credits are impacting our patients, staff, and community health outcomes.

Sincerely,

Esmaeil Porsa, MD, MBA,MPH, CCHP-A
President and CEO, HarrisHealth System

Troy Villarreal, FACHE
President, HCA Healthcare Gulf Coast Division and HCA Houston Healthcare

Marc L. Boom, MD,MBA, FACP, FACHE
President and CEO, Houston Methodist

David L. Callender, MD, MBA
President and CEO, Memorial Hermann Health System

Michael Lawson, MBA Houston Market President,
St.Luke's Health, a member of CommonSpirit

Bronx Healthy Start Partnership Participants, unedited stories
Submitted for the September 17, 2025 hearing before the House Energy and Commerce Committee

(Participant A)
Healthy Start has truly been my lifeline during some of the most challenging and uncertain moments in my life. Two years ago, I gave birth to my son. I was overjoyed at becoming a mother, but reality hit me hard. I wasn't financially stable or emotionally prepared for what lay ahead. I felt overwhelmed, frightened, and isolated. Then, one day, I attended a community baby shower where several organizations had set up informational tables. That's where I first discovered Healthy Start. At the time, I didn't realize how significant that encounter would be. But looking back, I now see it as the turning point—the moment everything started to change.

Healthy Start embraced me with open arms. They provided so much more than just supplies. Yes, I received essentials like diapers, formula, a stroller, and breastfeeding support, but they also empowered me with knowledge. They taught me how to care for my baby, understand his needs, and keep him safe. I learned about safe sleep practices, developmental milestones, and how to advocate for my child's health. That guidance gave me something no material item ever could: confidence.

One of my biggest fears as a new mom was not being able to adequately provide for my children, not just physically, but also emotionally and mentally. That fear used to keep me awake at night. However, with Healthy Start walking beside me, I didn't have to navigate motherhood alone. They believed in me, and in turn, I started to believe in myself.

Most recently, I welcomed a beautiful baby girl into the world. She was born prematurely, and the fear I had experienced with my first child came flooding back—only this time, it was magnified. But once again, Healthy Start was there. They helped me understand the unique needs of a premature baby and offered constant support, answering my questions, calming my fears, and reassuring me that I could do this. Their team treated me with compassion and respect, never judging, only uplifting.

I am incredibly proud and deeply grateful to share my story today. If you are reading this and going through a tough time—wondering how you'll make it, how you'll care for your baby, or if anyone even sees your struggle—please know that you are not alone. Don't hesitate to ask for help. There is strength in reaching out. Healthy Start and MHHC were there for me, and they will be there for you, too. Every parent deserves support, every baby deserves a strong start, and every family deserves the opportunity to thrive.

(Participant B)
For those who may not know, Burkina Faso is a beautiful country in West Africa, rich in culture, vibrant communities, and strong traditions. Back home, I was a successful businesswoman, owning and operating a restaurant that made me proud of what I had built. Life was good—I enjoyed a sense of stability, purpose, and a strong community bond. I even had the opportunity

to travel back and forth to the United States several times, always returning home to continue growing my business and supporting my family. But then, like it did for so many, COVID-19 changed everything.

The pandemic disrupted my life in ways I couldn't have imagined. I went from having almost everything to starting over with nothing. The life I had carefully built was no longer there, and I found myself in a foreign country, trying to rebuild without the support system I had always known.

In 2023, I became pregnant. It was a joyful moment, but also a deeply challenging one. I was alone, uncertain, and far from home. I didn't know where to begin—but that's when I found Healthy Start, and everything began to shift.

Healthy Start gave me more than just material help—they gave me hope. Their team came to my home, arms full of baby gifts, but what they truly delivered was compassion, care, and connection. They took the time to listen, to understand my story, and to meet me where I was.

They didn't just see me as someone in need—they saw me as a woman, a mother, and a survivor.

Where I come from, when a woman goes through hard times, the entire village surrounds her with love, wisdom, and support. Here in the U.S., I was afraid I had lost that village. But I soon realized that Healthy Start became my village. They stood beside me during one of the most vulnerable periods of my life.

Healthy Start also encouraged me to invest in myself. I'm now enrolled at Mid-Manhattan Adult Learning Center, where I'm studying English and working toward my GED. I'm not just surviving anymore—I'm rebuilding. I'm dreaming again. I'm working toward a future filled with opportunity, stability, and pride.

To anyone who may be reading this and feeling lost or overwhelmed, please let me say this: Stay positive. Keep going. And always trust in God**.** Becoming the best version of yourself is not something you can do alone—and you don't have to. When life feels heavy and you're unsure of the next step, remember that MHHC and Healthy Start are here. Just like they stood beside me, they will walk beside you too. Because no matter where you're from, **we all deserve a village**, and we all deserve a chance to rise again.

(Participant C)

I have been enrolled with Bronx Healthy Start since May of 2024. I'm enrolled with my daughter, [redacted]. Ms. [redacted] has been such a tremendous support to myself and my child. I have attended a lot of workshops for like breastfeeding and childcare. Ms. [redacted] also connected me directly to a childcare application worker who helped me with the application and my child has been successfully attending daycare for almost a year now. I was grateful for this help because I wanted to return to work and be financially stable. With the help of this program and Ms. [redacted],

I have also successfully been able to apply for housing assistance and am very glad to share I will be moving into my own place next month. We were living with family in a small space, and I'm happy that I can now enjoy my space with my family in peace. This could not have happened without the support of Ms. [redacted]. I always try to tell her how grateful I am and how God will bless her. This program has been a blessing to my family.

(Participant D)
When I enrolled in Healthy Start back in March, I was in the hospital with pre-eclampsia and going through a hard time physically and emotionally. I was stressed because I couldn't prepare for my baby's arrival since I had to stay in the hospital for over a month before giving birth. My community health worker was able to provide me with a pack n' play and some clothes for my baby. When I speak to her, she always cares about me and my baby and asks how we are doing. She connected me with an opportunity to share my story with CBS News so that other mothers can know about pre-eclampsia. As a single mom with other children, this program helps me a lot, and I always tell my family and friends about it.

(Participant E)
During my time in Healthy Start with my daughter, who is almost 3 years old, I had the support of my community health worker, who would make time for me to check on us and my other children. I work long hours, so sometimes it is hard for me to join the workshops, but even then, they came to my job to drop off vegetables for Thanksgiving one year. This program is a blessing. I still have the BP cuff I received from Wendy to check my blood pressure because I have hypertension. I am now pregnant again and reached back out to Wendy because she told me I can always return if I wanted to have another baby. I am very happy and grateful for the support and education.

(Participant F)
In my journey as a mom, I've learned that a healthy family environment helps both my children and me thrive emotionally, physically, and mentally. Open communication builds trust and allows my children to express their feelings freely, while providing emotional support helps them feel valued and understanding. I've found that using positive discipline with clear boundaries and fair consequences teaches them responsibility and self-control. Spending quality time together strengthens our bond and gives them a sense of belonging. By modeling positive behaviors, this program has helped me. I look forward to sharing this with other moms. I appreciate my CHW for being here when I needed her support. Thank you.

(Participant G)
Attending this Healthy Start Program gave me valuable support and guidance in my parenting journey. I was able to learn more about child development, healthy routines, and ways to strengthen my bond with my kids. The program also connected me with resources and provided a safe space to share experiences, which made me feel more comfortable, confident, and supported as a parent. I also want to give a shout out to my CHW for helping me in times of need when I was so depressed and down, almost giving up, and she gave me that great speech, that energy that you can do speech, and it helped me a lot, so I also want to thank her for that.

(Participant H)
I am currently an active participant in the Bronx Healthy Start program. I initially enrolled in April 2023 with my older daughter, [redacted], and we successfully completed the program. During that time, my Community Health Worker (CHW) provided invaluable support, assisting me with baby essentials, employment opportunities, and guiding me through a fatherhood program that I proudly graduated from.

I am now enrolled again with my youngest child, [redacted]. As soon as I learned my partner was expecting, I immediately reached out to Tabitha to re-enroll. I was relieved and grateful to find that she was still with the program and willing once again to support me and my family. It has truly been an honor to be part of this program and to receive help from such dedicated and compassionate individuals.

Participating in the fatherhood classes in late 2023 was especially impactful. The classes allowed me to connect with other fathers and provided valuable insight and support. Though the commitment was significant—twice-weekly sessions—I was able to stay engaged and actually looked forward to them. One of the highlights was the "Dad and Kicks" event, where I had the opportunity to meet other fathers in person, as well as the incredible Bronx Healthy Start staff.

This program has had a profound influence not only on my life but also on the lives of my children. I now look forward to my regular check-ins and FaceTime calls with my worker. Even my son lights up with smiles and laughter when she calls. The program is deeply invested in both my child's development and my personal growth. Tabitha consistently checks in on my goals and future plans. Though it has been challenging this time around to secure employment, she provided me with a link to free online OSHA classes, which allowed me to earn a certificate that supports my career aspirations.

Additionally, I've had the opportunity to attend virtual classes and receive much-needed baby items, gift cards, and vouchers to help with food purchases. These resources have been incredibly helpful to my family, and we are sincerely grateful.

I hope this testimonial conveys just how appreciative my children and I are for the support we've received. Bronx Healthy Start is an amazing program that truly goes above and beyond to support families in every possible way.

(Participant I)
Bronx Healthy Start has been a great help to me and my baby. I have attended some of the events, such as one of the community baby showers, and participated in workshops via Zoom, and I would highly recommend the program. One of the services I really needed and that my worker provided was the donated diapers, but I am grateful for all the services, including the bags of vegetables that were delivered in November. I am very grateful to the program and to

my CHW (Suzette), because since I joined the program, she has always been attentive to me and my baby.

(Participant J)
As a new dad participating in the fatherhood initiative and enrolled in the Nurturing Fathers Program, my favorite session was “What Type of Father are you?” because I really enjoyed learning the different types of parenting styles and learning more about myself. I graduated from the Nurturing Fathers Program knowing how to communicate better with my family.

(Participant K)
Bronx Healthy Start was a very supportive resource in a lot of ways. They supported me emotionally, helped with resources for the baby, and were constantly checking in on my family to make sure we were fine. My CHW, Tabitha, was a great pillar for me and the baby. Keep doing what you’re doing, you guys are great!

(Participant L)
“The Bronx Healthy Start Partnership and my community health worker Tabitha have been amazing assets to me as a first-time mom,” said Bronx resident. “From doing educational workshops and learning about guided meditation for stress management, to accessing necessities like a travel crib and diapers, the Bronx Healthy Start Partnership has helped me to be a healthy and prepared parent.”