



COALITION FOR PEDIATRIC MEDICAL RESEARCH

Ann & Robert H. Lurie Children's Hospital of Chicago	Connecticut Children's
Boston Children's Hospital	Intermountain Primary Children's Hospital
Cincinnati Children's Hospital Medical Center	Nationwide Children's Hospital
Children's Hospital Colorado	Nemours Children's Health
Children's of Alabama	Rainbow Babies & Children's Hospital
Children's Healthcare of Atlanta	Seattle Children's
Children's Hospital of Los Angeles	Stanford Maternal & Child Health Research Institute
Children's Hospital of Philadelphia	St. Jude Children's Research Hospital
Children's Mercy Kansas City	Texas Children's Hospital
Children's Wisconsin	UPMC Children's Hospital of Pittsburgh
Cleveland Clinic Children's Hospital	Weill Cornell Medicine Pediatrics

October 27, 2023

The Honorable Bill Cassidy, M.D.
Ranking Member
Senate Committee on Health, Education, Labor and Pensions
428 Senate Dirksen Office Building
Washington, DC 20510

Dear Ranking Member Cassidy,

The Coalition for Pediatric Medical Research (the Coalition) is grateful for the opportunity to respond to your September 29th request for information (RFI) regarding the modernization of the National Institutes of Health (NIH). The [Coalition](#) – consisting of nearly two dozen of the most research-intensive children's hospitals in the United States – is deeply committed to and engaged in medical research to unlock the causes of diseases and disorders of childhood and improve the health and well-being of children and adults. Given the importance of NIH to this work and the need for an NIH that appropriately supports child health research, we are pleased to provide the following feedback that focuses on three key points:

- Adequately supporting early-career researchers focused on pediatric research.
- Preventing NIH policies and processes from limiting funding for meritorious pediatric-focused research proposals.

- Ensuring appropriate NIH leadership on the needs of children.

The following are our thoughts in response to specific questions in the document:

Extramural Research Program

Q7. What specific factors cause individuals to leave the biomedical research workforce? How could common NIH funding mechanisms be revised to better recruit and retain high-quality investigators, including young investigators?

The Coalition’s research-intensive hospitals have consistently warned that without a healthy and sustained commitment to developing and retaining the current/next generation of the pediatric-focused research workforce – particularly physician-scientists who bridge the research lab and clinical care – the pace of innovation will be slowed. The result will be fewer research breakthroughs and more diseases and conditions lacking treatments, therapies, or cures. While Congress and NIH have recognized these challenges in the past, the Coalition continues to witness firsthand how remaining barriers and inadequate investments to develop and retain pediatric-focused researchers undermine efforts to sustain our biomedical research workforce.

Myriad factors influence recruitment and retention of researchers to careers in pediatrics and other fields. These include the time and cost associated with training, particularly for physician-scientists, growing clinical demands, life-work balance, debt from college and medical school loans, and the potential for greater economic gain through clinical practice only or through a career outside of academia. Many of these factors were recently detailed in the National Academies of Science, Engineering, and Medicine’s (NASEM) September 2023 report, entitled “The Future Pediatric Subspecialty Physician Workforce: Meeting the needs of Infants, Children, and Adolescents.” Among its many findings, the study found that:

- Existing NIH career development funding levels are insufficient and, as a result, pediatric physician-scientists specifically are in need for targeted support to empower pediatric research.
- The lack of attention from NIH on providing career development grants to pediatric researchers – specifically institutional training awards – have contributed to a shrinking and aging biomedical research workforce of pediatric researchers that causes NASEM to have “concerns for the viability of the [biomedical research] workforce.”¹ We note that cuts to the Pediatric Scientist Development Program (PDSP) is a tangible example of this challenge to the field.
- The retention of mid-career physician scientists is a “major concern” to the sustainability of the pediatric research.²

Given these findings, a pillar of any effort to modernize NIH must include a robust and sustained commitment to developing and retaining pediatric physician-scientists to achieve research

¹ “The Future Pediatric Subspecialty Physician Workforce: Meeting the needs of Infants, Children, and Adolescents.” *National Academies of Science, Engineering, and Medicine*. September 2023. [Link](#). Page 218.

² *Ibid.*

breakthroughs which lead to treatments that improve health outcomes in children and adults alike. As pediatric researchers, we see firsthand how improved child health outcomes lay the foundation for healthier adults. Many prevalent adult-onset conditions – such as heart disease, diabetes, and mental health challenges – have their origins in early life. This reality, underscored by evidence from growing scientific and technological advancement, demonstrates the importance of improving societal health by intervening earlier in life.

To help address these urgent and persistent pediatric research workforce issues, the Coalition championed the introduction of the bipartisan and bicameral *Pediatricians Accelerate Childhood Therapies Act of 2023* (S. 2345 / H.R. 4714). Introduced by Reps. Joyce (R-PA) and Schrier (D-WA) in the House, and Sens. Ernst (R-IA) and Coons (D-DE) in the Senate, this legislation will help address pediatric research workforce challenges by establishing a new NIH career development award focused on early-career pediatric researchers, including those from populations who are historically under-represented in the field.

Recipients would use funds to offset the costs associated with activities they need to move to a state of research independence. For example, funds could be used to support laboratory operations, obtain mentorships, and conduct and present one's research activities. The legislative proposal aligns exceptionally well with the NASEM report and its recommendation that NIH increase support of pediatric career development awards. As part of any effort to modernize NIH, we strongly urge that you include the *Pediatricians Accelerate Childhood Therapies Act* as a meaningful way to help address pediatric research workforce development and retention.

In addition to strengthening early-career training resources focused on pediatrics, the Coalition supports expanding the Pediatric Loan Repayment Program to reduce the loan burden on young researchers. We recommend that NIH extend this program to more young investigators and increase the maximum dollar amount for loan repayment by at least 50 percent to child health researchers who remain in research. These actions will help this benefit keep pace with the costs associated with research education and training.

Statutory Structure and Functions

Q3. In your view, could NIH research dollars be better allocated within the agency's portfolio? Are there certain areas of research that are over-funded or under-funded? What strategy should Congress and NIH take in allocating resources to specific areas?

The Coalition has repeatedly voiced concern about NIH's level of support for pediatric-focused research activities. This includes how NIH calculates spending on child health research and concerns about processes that result in an underinvestment. In November 2022, the Coalition released a white paper that details longstanding challenges this field has faced to inform policies at the newly established Advanced Research Project Agency Health (ARPA-H). Among its many findings, the white paper detailed examples of challenges child health stakeholders have navigated including:

- *National Cancer Institute (NCI) Designated Centers*: Of the 71 NCI designated cancer centers, there is only one free-standing pediatric facility, and most centers focus on adults. There are currently no incentives or requirements that direct NCI Designated Centers to invest or engage with pediatric cancers and related investigators.

- *Underinvestment*: The overall percentage of NIH funding that goes to children is not proportionate to the population. In 2021, only 12-14% of NIH dollars were allocated towards projects that were wholly or in part focused on developmental or pediatric conditions. Underscoring this misalignment of funding priorities, children comprise 20% of the U.S. population and 50% of the world-wide population.
- *NIH Award Challenges*: Only institutions of higher education are eligible for some NIH awards, creating challenges for freestanding children’s hospitals in applying. Conversely, some NIH awards are limited to one application per institution resulting in limited opportunity for pediatrics since most institutions are adult-oriented.
- *All of Us Precision Medicine Initiative*: More than five years after the start of nationwide enrollment, the program has yet to move forward in recruiting children into the program. This is a significant limitation to the overall program and its ability to advance precision medicine for our youngest citizens.

The Coalition recommends that NIH modernization activity include a review of the following:

- How NIH tags, catalogs, and reports a research grant as being “pediatric,” including if there should be a threshold to ensure NIH reporting reflects actual spending.
- How NIH establishes child health research priorities and how pediatric components are appropriately represented in signature NIH initiatives such as the *All of Us* Program, Cancer Moonshot – NCI, pandemic preparedness programs, and others.
- Other activities that could strengthen the NIH’s overall focus on child health research, including coordinating and prioritizing activities across Institutes and Centers.

Administrative Opportunities and Challenges

Q1. Regarding NIH’s interagency collaborations, what currently works well and what could be improved? How can NIH better leverage capabilities that exist within the interagency, particularly for technologies and disciplines outside NIH’s traditional scope?

Building on the points offered above, the Coalition believes that any NIH modernization effort should identify and address systemic challenges to child health research. Following are two specific actions to do so.

In addition to establishing the career development award, the *Pediatricians Accelerate Childhood Therapies Act of 2023* would also codify the NIH Pediatric Research Consortium (N-PeRC), which was established to help better coordinate and manage NIH’s pediatric research portfolio across all NIH Institutes and Centers, into statute. A strong and permanent N-PeRC that can consult with external child health stakeholders and report on results would help ensure effective coordination across NIH Institutes and Centers and yield effective utilization of taxpayer dollars invested toward pediatric research.

Beyond codifying N-PeRC and ensuring that it has external inputs and retains focus on outcomes, the Coalition also believes Congress should consider the merits of establishing an NIH-wide office of child health research. While the *Eunice Kennedy Shriver* National Institute for Child Health and Human Development has historically had a focus on kids, less than 20 percent of NICHD's budget is focused on child health. We believe Congress should establish a single office within the Office of the Director tasked with coordinating the NIH-wide child health research agenda in a manner similar to how NIH has addressed other important cross-cutting research populations or themes such as women's health, tribal health, nutrition research and autoimmune diseases. Such an Office of Child Health Research would build upon N-PeRC and fill a gap.

Conclusion

The Coalition is grateful for the opportunity to provide this feedback to Ranking Member Cassidy's request for information. We look forward to working with the Committee on its efforts to modernize the NIH and ensuring that the perspectives and expertise of pediatric researchers are incorporated into the Committee's proposals and actions. Please feel free to reach out for any additional feedback, along with any questions or concerns.

To contact the Coalition, please reach out to:

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