



# **Pediatric Health Research Funded by NIH**

December 2024



COALITION FOR PEDIATRIC MEDICAL RESEARCH

# Outline

- Importance of Pediatric Research
- Pediatric Research at NIH
  - Research grants
  - Training grants
  - NIH Clinical Center
- Structural barriers to child health research funding
- Example: All of Us Study does not include all of us
- Recommendations



# Importance of Pediatric Research:

- Impact of addressing disease in children is much greater than in adults  
“the highest yield science”
- Emerging science emphasizes the potential and promise of risk prediction and prevention
- Pediatric diseases frequently present the strongest signals of underlying pathogenic mechanisms that can be confounded by more complex intrinsic and environmental factors in adults.
- Pediatrician and pediatrician scientist workforce is essential for a healthy community. Decline in pediatric residency applications is accelerating, notably in research-oriented areas.

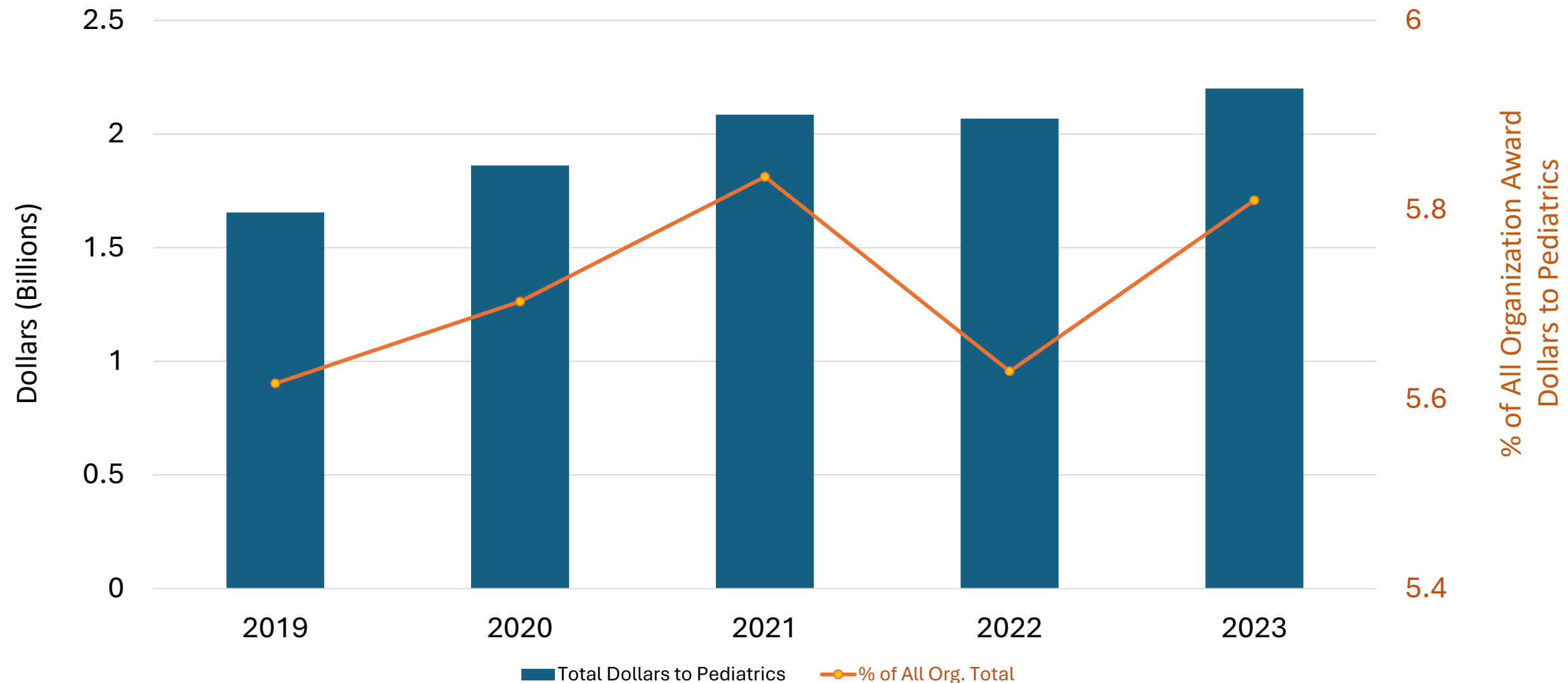


“Although children comprise over 20% of the US population, only 12-14% of NIH funding is directly or indirectly related to their health needs.”

NIH Research Portfolio Online Reporting Tools.

- Estimates of funding for various Research, Condition, and Disease Categories (RCDC).  
<https://report.nih.gov/funding/categorical-spending#/> (2022).
- NIH awards by location and organization - NIH Research Portfolio Online Reporting Tools (RePORT).  
[https://report.nih.gov/award/index.cfm?ot=&fy=2020&state=&ic=&fm=&orgid=&distr=&rfa=&om=n&p\\_id=#tabic](https://report.nih.gov/award/index.cfm?ot=&fy=2020&state=&ic=&fm=&orgid=&distr=&rfa=&om=n&p_id=#tabic) (2022).

# NIH Award Dollars to Children's Hospitals/Pediatric Departments



# Reduction in Pediatrician Scientist Research Training Grants (funded solely by NICHD):

## Child Health Research Career Development Award Program (K12)

Decade	Number of Scholars	% Female	% MD + PhD
FY 1990-2000	394	37%	28%
FY 2001-2011	386	46%	36%
FY 2012-2023	248	54%	41%

## Pediatric Scientist Development Program (K12)

- 40 year, highly successful national pediatrician scientist training program
- In 2012, slots decreased from 15 to 10 annually

# NIH Clinical Center Focuses on Adults

**Table 1. Clinical Center Admissions for Children and Adults**

	Unique Patients			Inpatient Days			Outpatient Visits			ICU Admissions		
Age (y)	FY18	FY19	FY20	FY18	FY19	FY20	FY18	FY19	FY20	FY18	FY19	FY20
0-3	162	138	65	12	37	41	445	859	153	0	0	0
3-18	3169	3005	1529	4528	4584	3267	12094	11380	5769	47	52	49
Total	3331	3143	1594	4540	4621	3308	12539	12239	5922	47	52	49
All ages	22992	22915	15483	41579	42541	31728	95222	96860	62499	674	679	495

# Structural Barriers to Pediatric Research Funding



- Children comprise only a small proportion of the population
  - Pediatric markets small & therefore high-risk
  - Few advocates (vs AARP as an example), not a voting block
  - Low margins (Medicaid/CHIP vs Medicare) -> constrain investment in researchers and in research
- More complex than research in adults
  - Unique logistical & ethical issues (e.g., parental consent, phlebotomy)
  - Outcomes and ROI may be long term
    - Requires patience from grant agencies, politicians, donors
    - ROI in many sectors -> hard to quantify with precision



# Structural Barriers to Pediatric Research Funding

- Children's hospitals and Pediatric departments are disadvantaged
  - Sometimes ineligible for NIH awards because Children's Hospitals are not degree-conferring higher education institutions (CTSA 2006, pediatric focused co-PIs not permitted)
  - Of the 71 designated national cancer centers, only 1 is at a children's hospital. Children are not required for inclusion in NCI Cancer Centers.
  - When eligible, children's hospitals often competing against large medical centers/universities (eg. FIRST awards)
  - For competitions limiting number of applications per institution, pediatrics is often outnumbered or left out

# Example: All of Us Research Program

Lyles et al. *J Transl Med* (2018) 16:211  
<https://doi.org/10.1186/s12967-018-1585-5>


Journal of  
Translational Medicine

COMMENTARY

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## The new era of precision population health: insights for the *All of Us* Research Program and beyond

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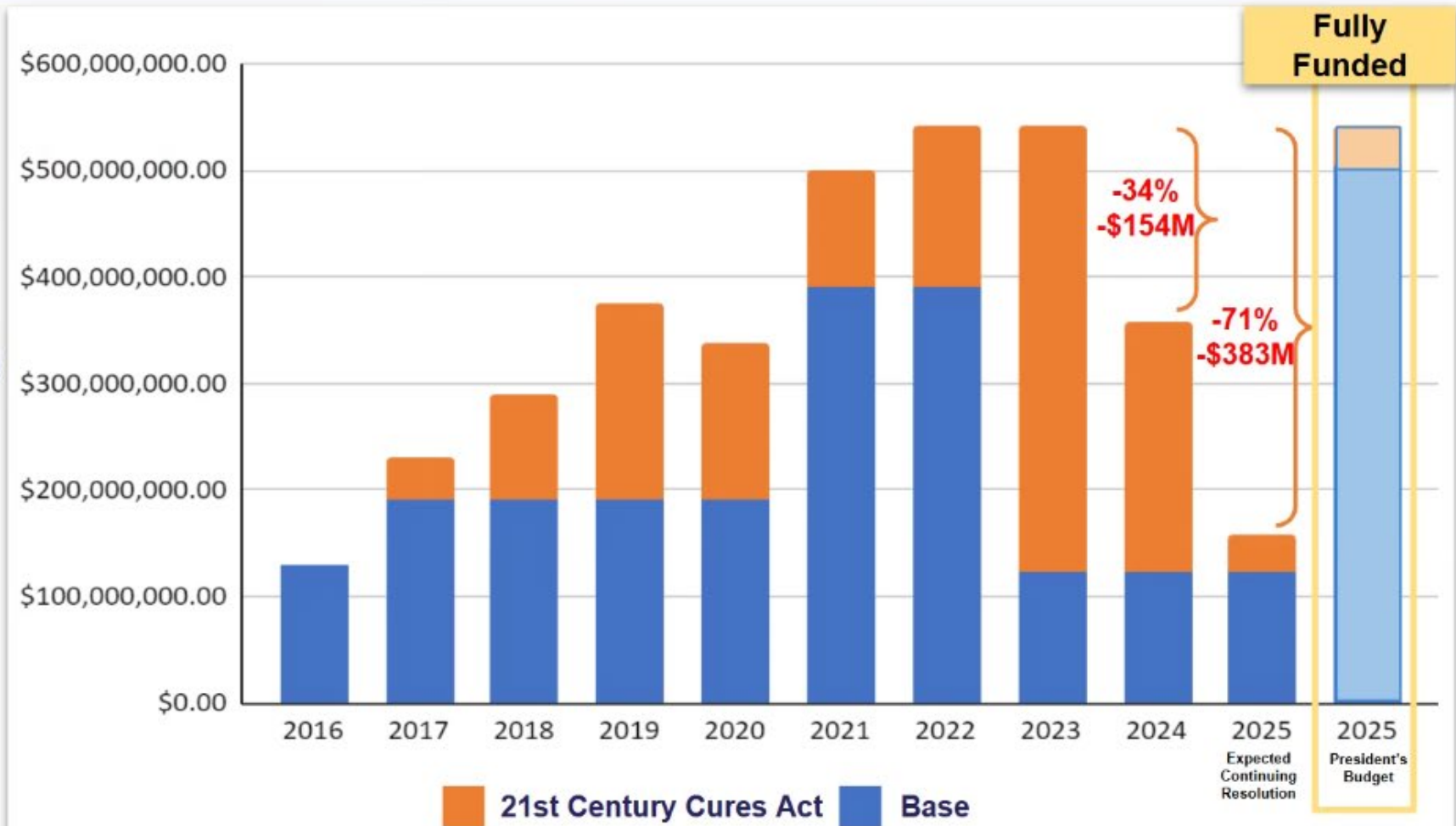


# The Program's budget

## FY25 President's Budget Request: \$541M

Senate FY25 Labor-HHS bill **restored funding** for the program to the FY23 enacted level of \$541M.

If the base allocation stays flat, when the Cures Act funding drops, **the program's budget will be cut an additional 56%.**



\*During the Aug. 1st FY25 L-HHS markup, Subcommittee Chair Tammy Baldwin (D-WI) and Ranking Member Shelley Moore Capito (R-WV) strongly supported advancing precision medicine by restoring full funding to *All of Us*.

# Ideas to Increase Inclusion of Children in NIH-funded Research

1. Increase funding and report child health research across ICs: proportion of all NIH funding should at least reflect population demographics (20+%)
2. Report data on child health research participants by age group
3. Incorporate child health research representation on all NIH Institutes and Centers (IC) councils
4. Assess and codify the goals of the NIH-Pediatric Research Consortium (N-PeRC) and develop a child health agenda in all IC councils
5. Conduct child recruitment first prior to adult recruitment for cohort studies, remove language on children as a “vulnerable” population
6. Require child health equity inclusion/impact statements for all grants
7. Increase child health research in the NIH Clinical Center

# Ideas to Increase Inclusion of Children in NIH Research, cont.

8. Ensure training grant equity for children's health researchers  
(ex; multiple institutes contribute to long-standing pediatric training grants)
9. Co-design research initiatives with youth and families, youth and family advisory councils for each IC
10. Redesign the Office of Women's Health to include Children's Health

**Issue in the “Era of the Child”  
prioritizing children in our  
national investments**







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