

Policy and Advocacy

Tina Cheng and Sherin Devaskar





ACADEMIC
PEDIATRIC
ASSOCIATION

AMERICAN
PEDIATRIC
SOCIETY

ASSOCIATION OF MEDICAL
SCHOOL PEDIATRIC
DEPARTMENT CHAIRS

SOCIETY FOR
PEDIATRIC
RESEARCH

Shetal Shah, MD, chair
(10/1/2020 – 12/31/2024)

Academic Pediatric Association



- Mona Patel, MD
- Jean Raphael, MD, MPH

American Pediatric Society



- Lisa Chamberlain, MD
- David Keller, MD

Association of Medical School Pediatric Department Chairs

- Tina Cheng, MD, MPH
- Sherin Devaskar, MD



Society for Pediatric Research

- Joyce Javier, MD
- Lois Lee, MD, MPH

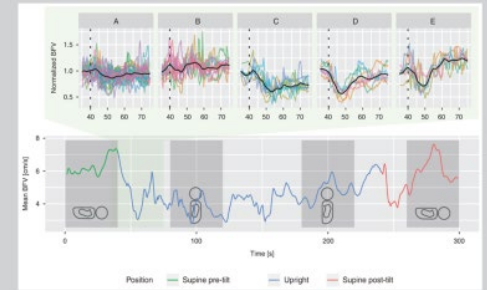


Staffed by American Academy of Pediatrics

James Baumberger & Matt Mariani



- Priorities
 - Improving Health Care Access and Coverage
 - Expanding Child Health Research
 - Advancing Health Equity
 - Strengthening the Next Generation of Diverse Researchers
- Monthly PPC call
- Liaison, AAP Committee on Federal Government Affairs
- Address policy issues with legislators and agencies through letters, visits, legislation
- Policy commentaries in *Pediatric Research*
- Sponsor sessions at PAS and beyond
- Increase advocacy training and web and social media presence





Sign On Letters and Other Advocacy

- FY 2023 appropriations request for National Center for Health Statistics, March 2022
- FY 2023 appropriations request for Agency for Healthcare Research and Quality, March 16, 2022
- *Doe v. Abbott* Medical Organization amicus brief in case challenging Texas's child abuse investigations of families seeking gender-affirming care for children, March 10, 2022
- FY 2023 appropriations request for gun violence prevention research, April 2022
- Access to Coverage and Care in Medicaid and CHIP RFI joint comments with AAP, April 18, 2022
- FY 2023 appropriations request for National Institutes of Health (Ad Hoc Group for Medical Research), May 10, 2022
- HRSA COVID-19 Uninsured Program funding renewal, May 16, 2022
- FY 2023 appropriations request for Pediatric Subspecialty Loan Repayment Program, May 17, 2022
- FY 2023 appropriations request for *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, May 23, 2022
- FY 2023 appropriations request for Census Bureau, May 2022
- FY 2023 appropriations request for Children's Hospitals Graduate Medical Education Program, May 2022
- FY 2023 appropriations request for NIH Environmental influences on Child Health Outcomes program, July 1, 2022
- HHS Primary Care Action Plan comments with AAP, August 1, 2022
- Comments in support of proposed rules to prohibit menthol cigarettes and flavored cigars, August 2, 2022
- Letter supporting strong final funding allocation for Census Bureau in FY 2023 appropriations legislation, September 2022
- Letter supporting strong final funding allocation for National Center for Health Statistics in FY 2023 appropriations legislation, September 2022
- Letter in support of passage of Accelerating Kids' Access to Care Act, October 2022
- Letter to HHS in support of expanding ACA enrollment to DACA recipients, October 2022
- Letter urging inclusion of permanent, mandatory Medicaid coverage for individuals 12-months postpartum, October 2022
- PPC comments on CMS proposed rule to streamline eligibility, enrollment, and renewal processes for Medicaid and CHIP, November 2022
- Letter urging passage of final FY 2023 spending legislation with robust funding for NIH, November 2022
- Response to CMS RFI on Affordable Care Act essential health benefits outlining proposed improvements for pediatric benefits, January 2023



Commentaries in Pediatric Research

- January 23, 2023: Drs Kelsen Kobayashi, Anna Miller-Fitzwater, Cherece Grier & Kimberly Montez, [The lapse of federal COVID-19 funding: implications for health equity](#)
- December 8, 2022: Drs Brian Varisco, Sherin U. Devaskar, Kristy Murray, and Tina Cheng, [The Advanced Research Projects Agency—Health \(ARPA-H\): a new model for research in child health](#)
- October 25, 2022: Dr Shetal Shah, [Legislative remedies to mitigate the national emergency in pediatric mental health](#)
- October 14, 2022: Drs Lindy McGee, Jean Raphael, and Mona Patel, [Every child deserves a smoke-free home](#)
- September 16, 2022: Drs Kristin Ray and David Keller, [Telehealth and pediatric care: policy to optimize access, outcomes, and equity](#)
- September 14, 2022: Drs Bonnie Zima and Sherin U. Devaskar, [Imperative to accelerate research aligning real-time clinical demand with mental health supply](#)
- June 18, 2022: Drs Kristen Shanahan, Kendall Burdick, and Lois Lee, [Reducing infant mortality: maternal health is infant health](#)
- June 10, 2022: Drs Christian Pulcini, Rachel Berman, Jean Raphael, and Mona Patel, [The politicization of children: implications for child health and public policy](#)
- April 12, 2022: Drs Susan Baker and David Keller, [Health and access to care for refugees, asylees, and unaccompanied children](#)
- February 21, 2022: Tina Cheng, MD, MPH, Carolyn Russo, MD, Conrad Cole, MD, MPH, MSc, and David A. Williams, MD, [Advocacy for research starting early in the life course](#)



Sponsored Events at PAS 2023

Pediatric Policy Council Legislative Breakfast: “Unpacking the Politicization of Child Health ”

State of the Art Plenary: “Policy Responses to Child Health Challenges in a Post-Pandemic World”

State of the Art Plenary: “NASEM Report on the Long-Term Impact of COVID-19 on Children and Families”

Hot Topic Symposia: “Child Advocacy in Action: Success Stories to Build On”



Advocacy Education

- **Advocacy Training Modules:** <https://www.aap.org/en/advocacy/advocacy-training-modules/>

Training Module 1: Overview of the Legislative Process

Training Module 2 : Working in Partnerships

Training Module 3: Working with Decision-Makers

Training Module 4: Advocacy Communication

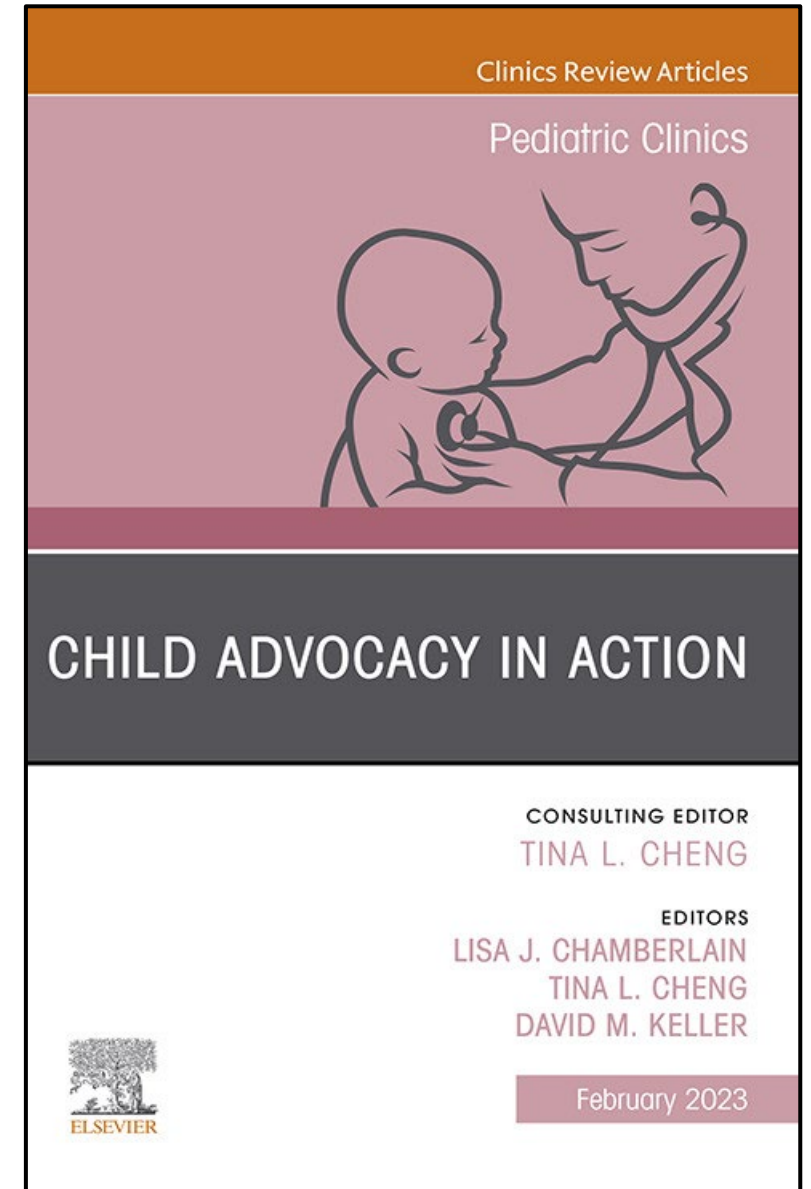
Training Module 5: Voting with Children's Health and Pediatric Resident's Schedule in Mind

- **AAP Advocacy Guide**, 2009: same website as above



Advocacy Education

- PPC Capitol Connection, emailed monthly
- Child Advocacy in Action
Pediatric Clinics of North America
February 2023, Vol 70



Developing the Next Generation of Diverse Pediatric Researchers

- Led two conference convenings focusing on legislative action
 - Virtual, Feb 9, >240 participants
 - In person May 2022 with federal funders, policymakers, >80 participants
- Legislative advocacy around the Pediatricians Accelerate Childhood Therapies (PACT) Act, subspecialty loan repayment and NIH Inclusion of Children

BURROUGHS
WELLCOME
FUND 



COALITION FOR PEDIATRIC MEDICAL RESEARCH



PEDIATRIC POLICY COUNCIL
Advancing child health through public policy

ACADEMIC
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ASSOCIATION OF MEDICAL
SCHOOL PEDIATRIC
DEPARTMENT CHAIRS

SOCIETY FOR
PEDIATRIC
RESEARCH

POLICY BRIEF

MAY 2022

SUPPORTED BY: Academic Pediatric Association • American Academy of Pediatrics • American Board of Pediatrics
American College of Allergy, Asthma and Immunology • American Pediatric Society
American Society of Pediatric Nephrology • Association of Medical School Pediatric Department Chairs
Association of Pediatric Program Directors • Burroughs Wellcome Fund • Child Neurology Society
Coalition for Pediatric Medical Research • Federation of Pediatric Organizations
North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
Organization of Neonatal Program Directors • Pediatric Endocrine Society • Pediatric Infectious Diseases Society
Society for Developmental and Behavioral Pediatrics • Society for Pediatric Dermatology • Society for Pediatric Research

Legislative Priorities for Developing the Next Generation of Diverse Child Health Researchers

Executive Summary

Investing in child health research, conducted by diverse researchers, benefits

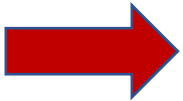
Why focus on child health research?

- Health early in the life course profoundly influences health across the lifespan. Most adult chronic physical and behavioral



Research FY23 Appropriations, 12-22

Federal Agency	FY 2023 Funding	Change from FY 2022 Funding (% change)
National Institutes of Health (NIH)	\$47.5 billion	+\$2.5 billion (5.3%)
Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)	\$1.749 billion	+\$66 million (3.8%)
NIH Environmental influences on Child Health Outcomes (ECHO) Program	\$180 million	\$0 (0)
Advanced Research Projects Agency for Health (ARPA-H)	\$1.5 billion	+\$500 million (33%)
Gun Violence Prevention Research	\$25 million (\$12.5 million at NIH and \$12.5 million at CDC)	\$0 (0)
Agency for Healthcare Research and Quality (AHRQ)	\$373.5 million	+\$23.5 million (6.3%)
Children's Hospitals Graduate Medical Education (CHGME)	\$385 million	+\$10 million (2.6%)
Centers for Disease Control and Prevention (CDC)	\$9.2 billion	+\$700 million (7.6%)



Advanced Research Projects Agency for Health

ARPA-H would be primarily for a “mix of start-ups, small businesses and academics”

Frances Collins

 **National Institutes of Health**
Turning Discovery Into Health

Search NIH

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COVID-19 | [Public health information from CDC](#) | [Research information from NIH | Español](#) | [NIH staff guidance on coronavirus \(NIH Only\)](#)

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PROPOSED ADVANCED RESEARCH PROJECTS AGENCY FOR HEALTH (ARPA-H)

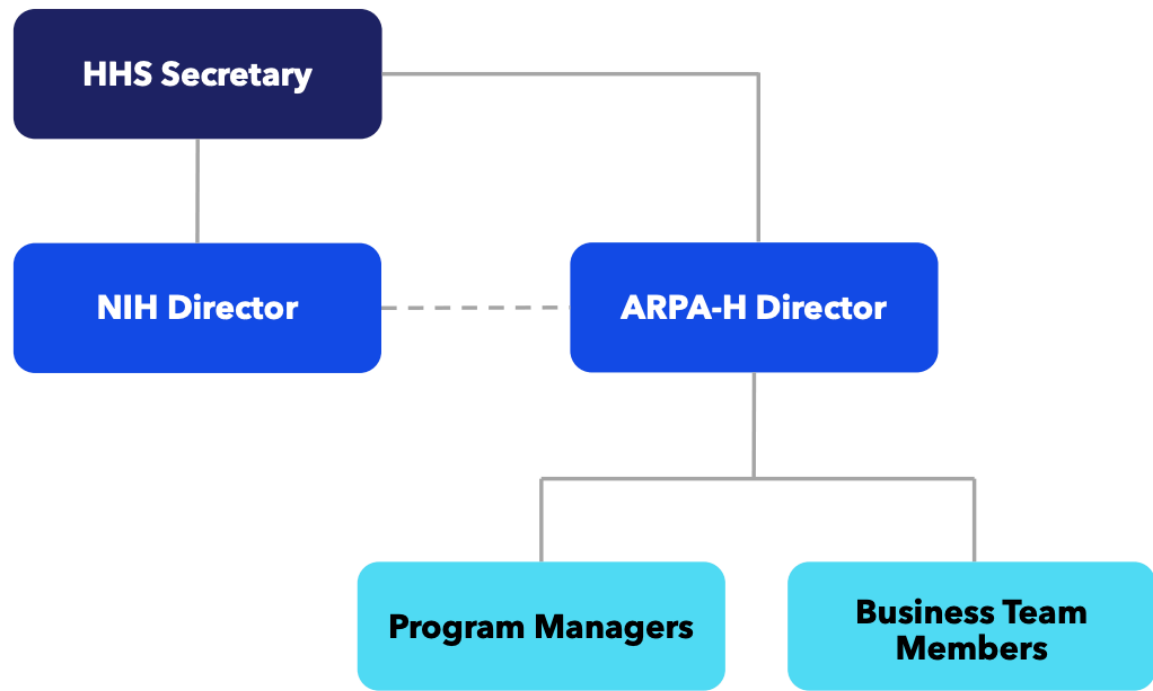
ARPA-H

- [Mission and Concept](#)
- [News and Publications](#)
- [Events](#)
- [Resources](#)
- [Contact](#)

Recent advances in biomedical and health sciences—from immunotherapy to treat cancer, to the highly effective COVID-19 vaccines—demonstrate the strengths and successes of the U.S. biomedical enterprise. Such advances present an opportunity to revolutionize how to prevent, treat, and even cure a range of diseases including cancer, infectious diseases, Alzheimer’s disease, and many others that together affect a significant number of Americans.

To improve the U.S. government’s capabilities to speed research that can improve the health of all Americans, President Biden is proposing the establishment of the Advanced Research Projects Agency for Health (ARPA-H). Included in the President’s FY2022 budget as a component of the National Institutes of Health (NIH) with a requested funding level of \$6.5B available for three years, ARPA-H will be tasked with building high-risk, high-reward capabilities (or platforms) to drive biomedical breakthroughs—ranging from molecular to societal—that would provide transformative solutions for all patients.





- Independent component of HHS within NIH, reporting directly to HHS Secretary
- No internal research labs; disease agnostic
- Program Manager driven ideas and decision-making

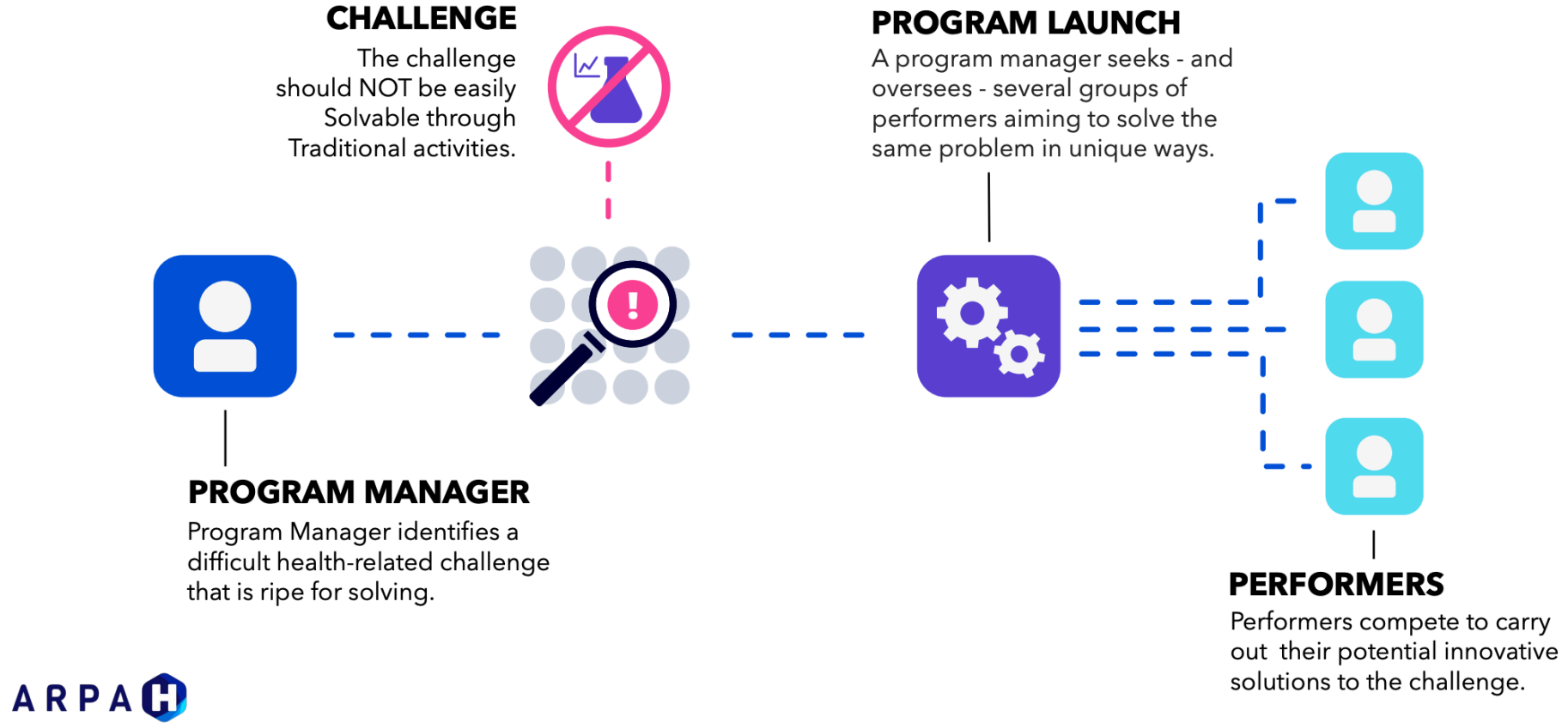
ARPA-H MISSION:

“to benefit the health of all Americans by catalyzing health breakthroughs that **cannot readily be accomplished through traditional research or commercial activity**”.

What is the gap ARPA-H is looking to fill? Gap between NIH-type fundamental research and commercial entities (biotech, pharma)

- the risk is too high
- the cost is too large
- the time frame is too long
- the focus is too applied for academia
- there is a need for complex coordination among multiple parties
- the near-term market opportunity is too small to justify commercial investment
- the scope is so broad that no one company can realize the full economic benefit

ARPA Model: Program Formation



- Solutions are not research grants
- Program Managers use flexible contracting vehicles: Cooperative Agreements, Contracts, Other Transactional Authorities
- NIH ARPA-H-like programs: Rapid Acceleration of Diagnostics (RADx), Accelerating COVID-19 Therapeutic Interventions and Vaccines (ACTIV)

Program Lifecycle

From ideas to solutions in the real world



DESIGN PROGRAMS

- ARPA-Hard and well-defined problems in health
- Heilmeier Framework
- High risk/High consequence
- Stakeholder Insights



BUILD A PERFORMER TEAM

- Solicit Solutions from the community
- Find the best non-traditionals, industry, and academics to solve
- Build new coalitions



EXECUTE & MEASURE

- Active program management against metrics; PM = CEO
- Stakeholder engagement throughout to ensure transition
- Pivot resources when needed



LEARN & GROW

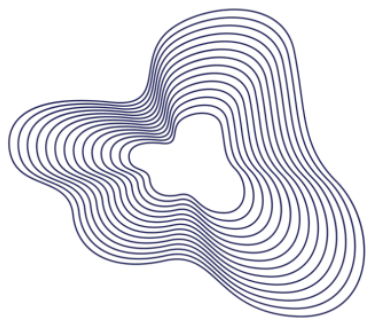
- Capture and share insights
- Technical honesty
- Advance the state of the art; 10x+ improvement, no incremental change



COMMERCIALIZE & TRANSITION

- Assist company formation or licencing
- Provide mentorship, connections to customers, investors
- De-risk investments

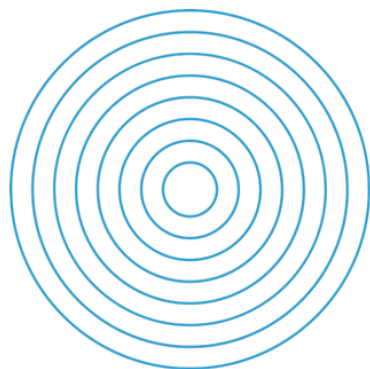
Initial Mission Focus Areas



Health Science Futures

Expanding what's technically possible

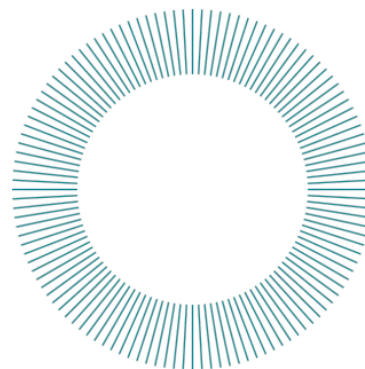
Accelerate advances across research areas and remove limitations that stymie progress towards solutions. These tools and platforms apply to a broad range of diseases.



Scalable Solutions

Reaching everyone quickly

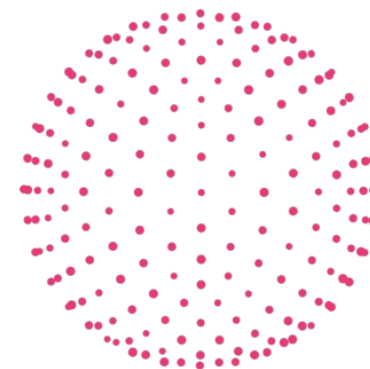
Address health challenges that include geography, distribution, manufacturing, data and information, and economies of scale to create programs that result in impactful, timely, and equitable solutions.



Proactive Health

Keeping people from being patients

Preventative programs will create new capabilities to detect and characterize disease risk and promote treatments and behaviors to anticipate threats to Americans' health, whether those are viral, bacterial, chemical, physical, or psychological.



Resilient Systems

Building integrated healthcare systems

Create capabilities, business models, and integrations to weather crises such as pandemics, social disruption, climate change, and economic instability. Systems are sustained between crises—from the molecular to the societal—to achieve better health outcomes.

CORRESPONDENCE



The Advanced Research Projects Agency—Health (ARPA-H): a new model for research in child health

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Pediatric Research; <https://doi.org/10.1038/s41390-022-02405-0>

research indicates that without strong advocacy, it is likely that pediatric-focused research will again be left behind. When the Clinical and Science Translation Awards (CTSA) Program was

Brian M. Varisco^{1,2}, Sherin U. Devaskar³, Kristy O. Murray^{4*}, Tina L. Cheng^{1,2*}

- History indicates that without strong advocacy, it is likely that pediatric-focused research will again be left behind.
- Growing research demonstrates that many conditions have their origins early in the life course with the opportunity for ARPA-H to prevent or change the trajectory of disease.
- ARPA-H should focus on health equity starting early in the life course and examine the multiple ways that health disparities negatively impact children's development and predisposition to acute and chronic diseases.

White Paper on ARPA-H and Pediatrics

Nov. 2022

Ensuring ARPA-H Enables a Focus on Child and Adolescent Health & Lifespan Research

SUPPORTED BY: Academic Pediatric Association, American Academy of Allergy, Asthma, and Immunology; American Academy of Pediatrics, American College of Allergy, Asthma and Immunology; American Pediatric Society, Association of Medical School Department Chairs, Coalition for Pediatric Medical Research; Council of Pediatrics Subspecialties; North American Society for Pediatric Gastroenterology, Hepatology & Nutrition; Pediatric Endocrine Society; Pediatric Policy Council, Society for Adolescent Health and Medicine; Society for Developmental and Behavioral Pediatrics; Society for Pediatric Dermatology, Society for Pediatric Research

Overview

As Congress and the Biden Administration work to establish the Advanced Research Projects Agency – Health (ARPA-H), this agency must ensure that its structure supports research focused on child and adolescent health and health across the lifespan. Legislators have been crafting ARPA-H so it will not be focused on or limited to specific diseases or conditions and will be undeterred by the possibility of failure. ARPA-H could prevent or change the trajectory of multiple diseases if it focuses on research early in the lifespan, as research demonstrates that many conditions have their origins early in the life course. Understanding the trajectories of diseases in childhood requires intentional focus across the life course.

Limited Inclusion of Children and Adolescents in Large Research Programs

Previous federal research programs have excluded or severely limited inclusion of children and adolescents, and they have neglected to explore developmental origins of health and disease. Examples of past challenges include:

- **Clinical and Science Translation Awards (CTSA) Program:** The CTSA program originally did not allow for a pediatric-focused co-principal investigator (PI) or for a children's hospital application. Subsequent legislation changed this; however, funding and resources have historically been oriented toward adult-focused research activities even when awards have a pediatric Co-PI.
- **All of Us Precision Medicine Initiative:** More than four 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.

Meeting with ARPA-H Director this week

ARPA-H is Hiring Program Managers

THE POSITION

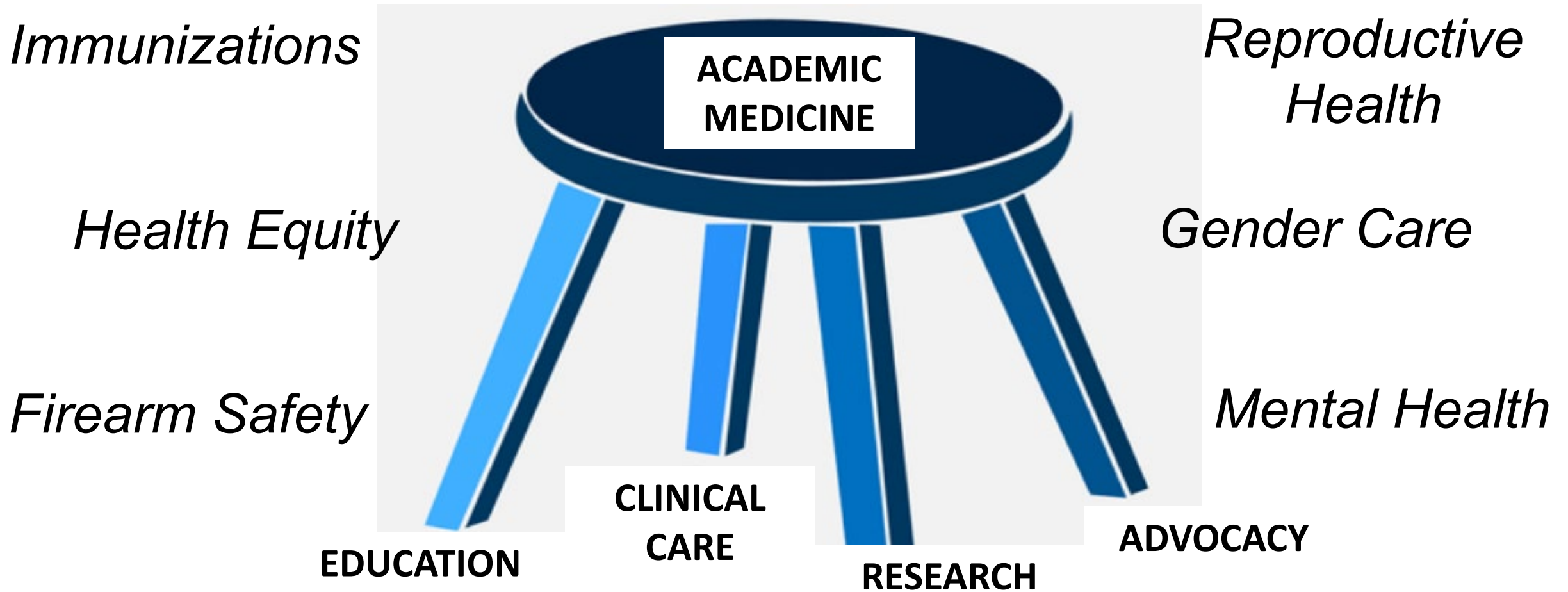
- Timebound (3 – 6 years)
 - Competitive salary
 - PMs diverse in geography, demographics, experience, and topic
 - **Full business and technical team support** for day-to-day program management, market assessments, transition, budget, human-centered design, etc.
 - **Resources and opportunity to change the future of health**
 - **Responsibility to identify well-defined problems in health**, and assemble teams from industry, academics, and government to solve.
- Hiring 20+ Program Managers each with \$50-150M for research in a proposed area
 - <https://arpa-h.gov/careers/program-managers/>



National Academy of Medicine Studies focusing on children

- Addressing the Long-Term Impact of the COVID-19 Pandemic on Children and Families (Chair: Coker), report out in 3/23
- The Pediatric Subspecialty Workforce and Its Impact on Child Health & Wellbeing (Chair: Rivara), in progress
- Assessment of the Impact of Social Media on the Health & Wellbeing of Adolescents and Children (Chair: Galea), in progress
- Improving the Health & Wellbeing of Children and Youth through Health Care System Transformation (Chairs: Cheng & Perrin): start 2/23

Advocacy: Critical for Child Health



Question

In a review of success stories in health (e.g lead poisoning, smoking, fluoride), which was NOT one of the key ingredients to success?

- A. Leadership of medical institutions
- B. Highly credible scientific evidence
- C. Health advocates
- D. Partnership with media for public awareness
- E. Law and regulation

Question

In a review of success stories in health (e.g lead poisoning, smoking, fluoride), which was NOT one of the key ingredients to success?

- ~~A. Leadership of medical institutions~~
- B. Highly credible scientific evidence
- C. Health advocates
- D. Partnership with media for public awareness
- E. Law and regulation

Where the Public Good Prevailed: Lessons From Success Stories in Health

- Highly credible scientific evidence
- Public health advocates
- Partnership with media for public awareness and discussion
- Law and regulation

Issacs & Schroeder, **The New Prospect**. June 4, 2001:26-30

How can we be stronger advocates?

- Raise awareness, counter mis-information
- Advocate for the fourth leg of the stool at your institution
- Build partnerships with legislators and coalitions
- Support research
- Provide education and training opportunities in advocacy
- Keep up-to-date
 - Be an AAP Key Contact: email kids1st@aap.org and request to be a Key Contact in the body of the email.

Advocacy Leadership

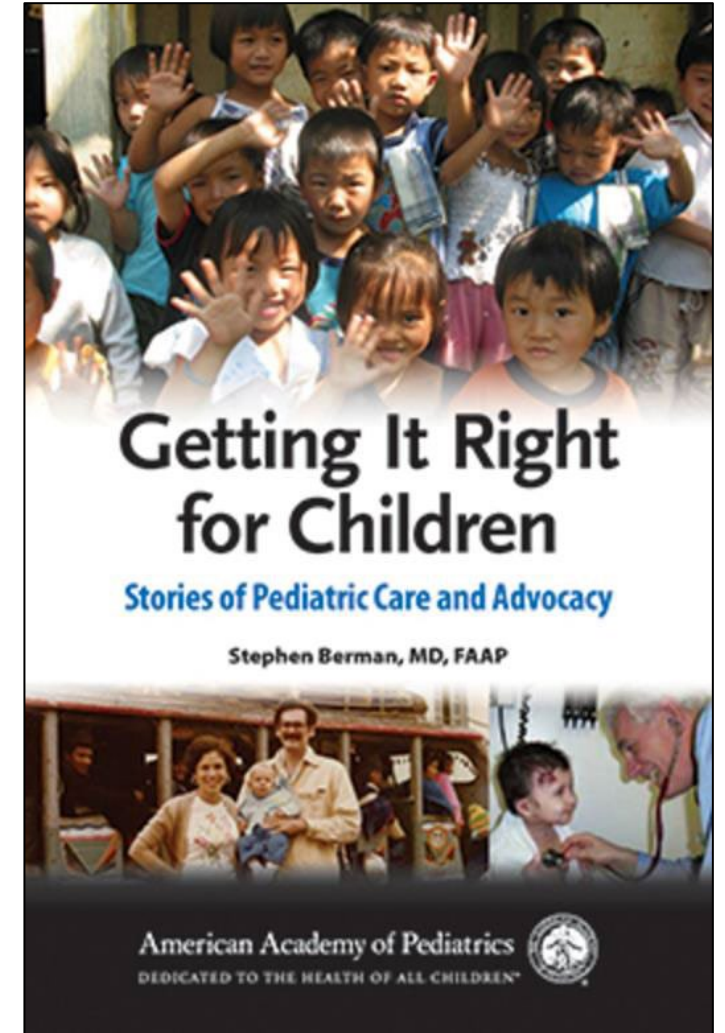
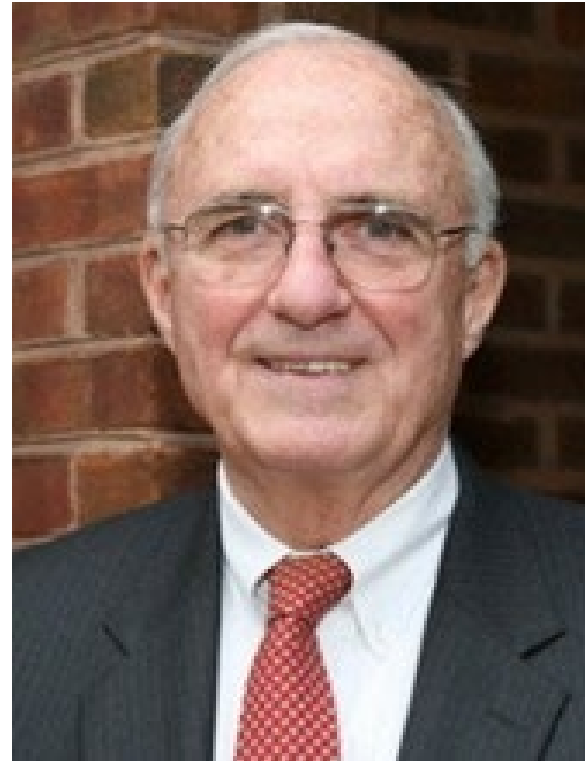
- **Development opportunities:** AAP Legislative Conference, AAP State Chapters, APA Advocacy Scholars, community leadership programs
- **Advocacy work in your community, city, county, state, federal**
 - Work with your Government Affairs Office
 - Work with your legislators
 - Work with your leaders in the community, health department, schools, Medicaid, business, funders, federal agencies
 - Build coalitions
- **Advocacy work with professional organizations**
 - Pediatric Policy Council
 - AAP Districts, Chapters, Sections, Councils, Committees, COFGA, State Government Affairs
 - ABP, CHA, Coalition for Pediatric Medical Research, specialty societies



Dr. Haegarty enlisted Princess Diana, center, who visited the hospital in 1989, to help bring attention to the struggles it faced. John Sotomayor/The New York Times

Margaret Haegarty
1934-2023

George K. Degnon
1940-2023



Steven Berman
1947-2023

Berman's “P’s” of Effective Advocacy

- Personal experience, patients
- Passion
- Persistence, perseverance, patience
- Principled
 - Integrity: commitment to gain complete understanding
 - Credibility: serve in best interest of patients
 - Fairness: ensure uniform standards of care
 - Responsibility: own the intended and unintended effects of advocacy



Berman S. 95 Global Child Advocacy
Archives of Disease in Childhood 2012;**97**:A27.





José Luis Bayer, Chile

Jose' Luis Bayer, Chile

Children are the message
we send to the future.

**“We must be the
change we wish to see
in the world.”**

Mahatma Gandhi

How can we be stronger child advocates?

- What should AMSPDC do to strengthen child advocacy?
- How can our departments strengthen our child advocacy voice in our institution, region, state?
- How can we support our faculty and trainees in advocacy efforts?