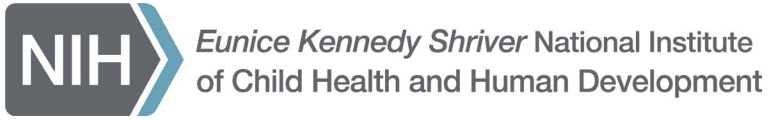
NICHD Director's Report
NACHHD Meeting

Diana W. Bianchi, M.D.

September 6, 2023



Talk Outline

- FY 2024 Budget Update
- NICHD Strategic Planning
  - Aspirational Goals Update
- NIH Clinical Center Pediatric Research Strategic Plan
- NIH IMPROVE Program
- NIH and NICHD Staff Updates

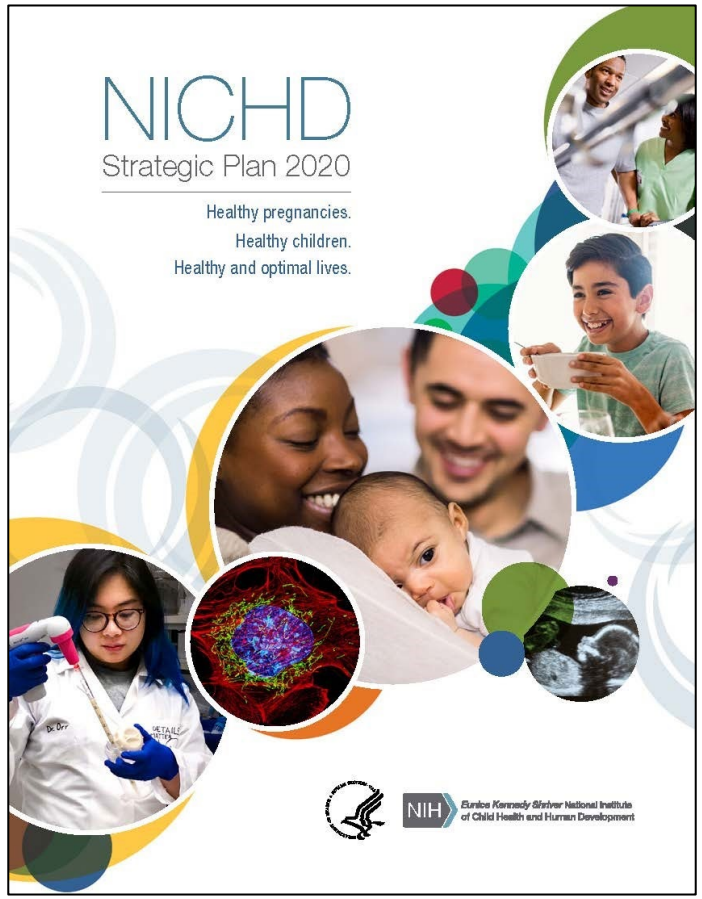
FY24 Budget Update

- **FY24 House Labor-HHS Appropriations bill**
  - NIH appropriation: $43 B (decrease of $3.8 B from FY23)
  - NICHD appropriation: $1.75 B (flat compared to FY23)
- **FY24 Senate Labor-HHS Appropriations bill**
  - NIH appropriation: $49.2 B (increase of $940 M over FY23)
  - NICHD appropriation: $1.76 B (increase of $10M over FY23)
  - Additional $10 M for IMPROVE initiative over FY23 amount
- **Next Steps**
  - House and Senate must vote on respective bills
  - Differences between House and Senate bills must be reconciled in final appropriations legislation
  - **Budget or Continuing Resolution needed by September 30**

NICHD Strategic Planning

Starting to think about 2025 Strategic Plan

- NICHD Strategic Plan 2020 spans 5 years
  - Research, Stewardship, Management and Accountability
  - NICHD has been documenting and tracking activities and achievements towards current objectives
- Refreshing the Strategic Plan over the next year
  - Informed by data analysis of achievements on current activities and accomplishments
  - Seek NICHD staff input on progress and potential new scientific opportunities
  - Solicit external feedback from the scientific and advocacy communities and the public
- Starting point: Progress toward Aspirational Goals



Aspirational Goals

- Accelerate efforts to definitively diagnose, prevent, and treat endometriosis, a disease that affects an estimated 10 percent of women in the United States and results in chronic pain, infertility, and a higher risk of some cancers.
- Advance the ability to regenerate human limbs by using emerging technologies to activate the body's own growth pathways and processes.
- Enhance the survival and healthy development of preterm infants by exploring the role of environmental factors, such as feeding methods and nutritional support, human touch, and music and lighting.
- Facilitate application of precision medicine approaches in children by capitalizing on advances in genomics and by updating normative data on the growth and development of a diverse population of children, including those with intellectual, developmental, and physical disabilities.

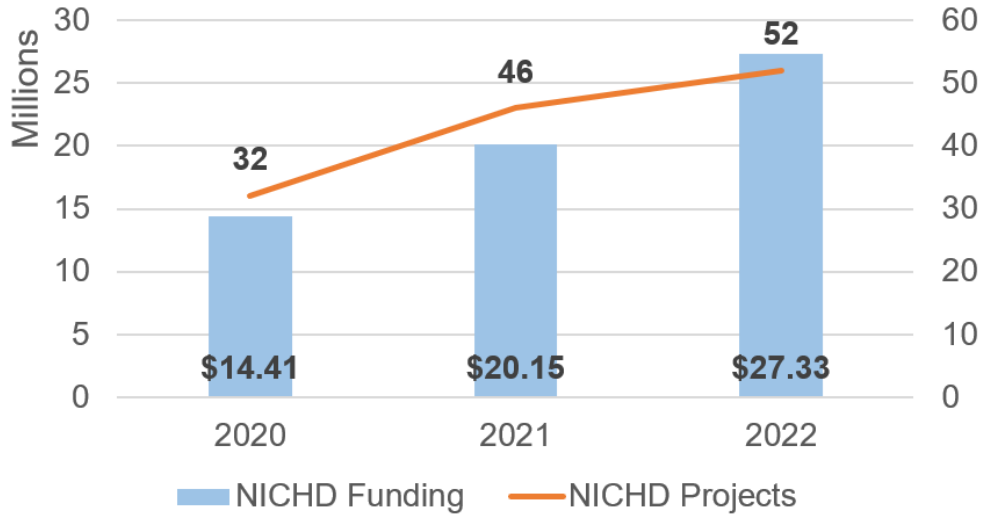
Aspirational Goals: Endometriosis

Baseline → **Actions** → **Findings**

1 in 10 women

Pain, Infertility, Cancer Risk

0 **proven, non-invasive diagnostic tests widely available**



Source: NIH RCDC Categorical Spending (official data)

Includes but not limited to:

- **Centers RFA: HD21-002;**
- **Organoids RFA: HD23-005;**
- **Diagnostics RFA: HD21-020**

- Genetic Factors Underlying Comorbidity (PMID 36914876)
- Drug reduces endometriosis progression and improves fertility in mice (PMID 36419064)
- Non-surgical treatment shows promise in mouse study (PMID 35434932)
- Broad AP-1 Inhibitors Have Potential as Treatment for Endometriosis (PMID 35616875)

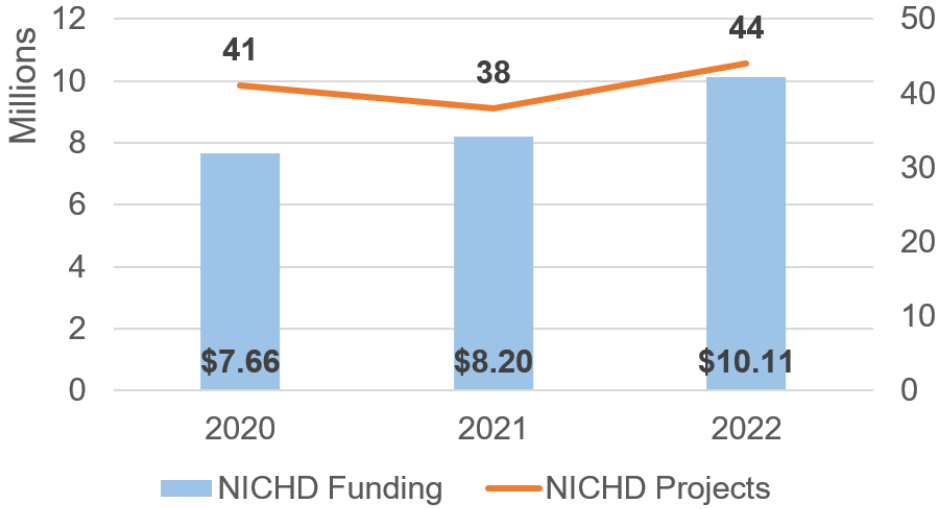
Aspirational Goals: Limb Regeneration

Baseline → **Actions** → **Findings**

2.1 M in US with limb loss

Pain, Long-term Disability

$878,926
Average lifetime direct medical cost after limb amputation
(PMID 32339483)



Source: NICHD Child Health Information Retrieval Program (unofficial data)

Includes but not limited to:

- **Limb Regeneration RFA, HD24-004**

- In salamanders, patterns of gene expression are similar between developing and regenerating limbs. (PMID 35531102)
- Building a blastema (a mass of cells capable of growth and regeneration) is a key step of salamander limb regeneration. Researchers outlined a key step that involves active inhibition of protein synthesis during blastema formation and growth. (PMID 36893754)

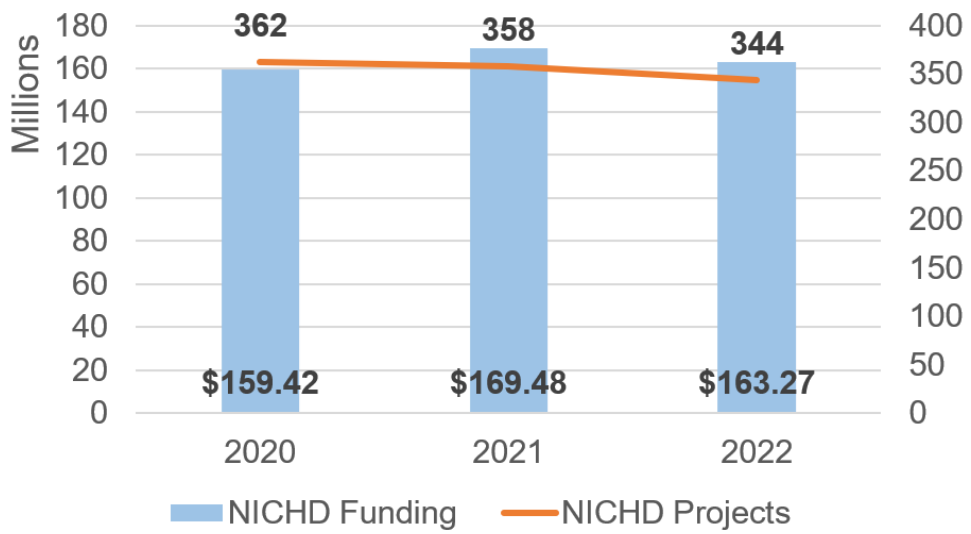
Aspirational Goals: Survival and Health of Preterm Infants

Baseline → **Actions** → **Findings**

10.5% **US Preterm birth rate, 2021 (CDC)**

Mortality risk, Long-term Disability

9.0% **Estimated US NICU admission rate, 2021 (CDC/ NCHS)**



Source: NIH RCDC Categorical Spending (official data)

Includes but not limited to:

- **Neonatal Research Network, HD23-001, HD23-002, PAR23-130;**
- **MFMU Network, HD23-016, HD23-017, PAR23-130**

- Extremely preterm infants fed fortified human milk grew longer and more rapidly than infants fed unfortified human milk (PMID 37551512)
- Preterm infants who were exposed to more speech in the NICU gained significantly more weight (PMID 36720260)
- Steroid treatment before birth appears to improve survival and reduce complications among extremely preterm infants (PMID 36156145)

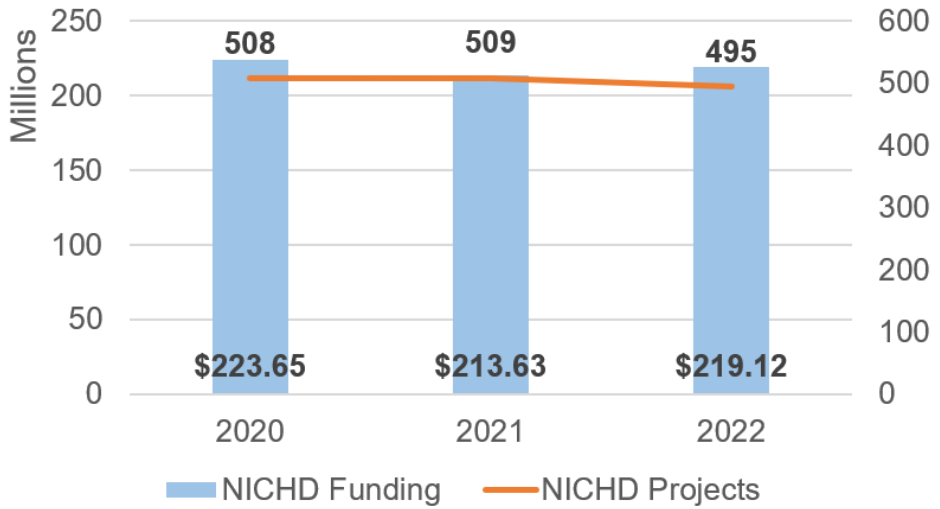
Aspirational Goals: Precision Pediatrics

Baseline → **Actions** → **Findings**

44-50%

of ID, hearing, vision disorders with a diagnosis was achieved through DNA sequencing (UK 100,000 genomes project, PMID 34758253)

Mortality risk, Long-term Disability



Sources: NICHD Child Health Information Retrieval Program (unofficial data) and NIH RCDC Categorical Spending Data

Includes but not limited to:

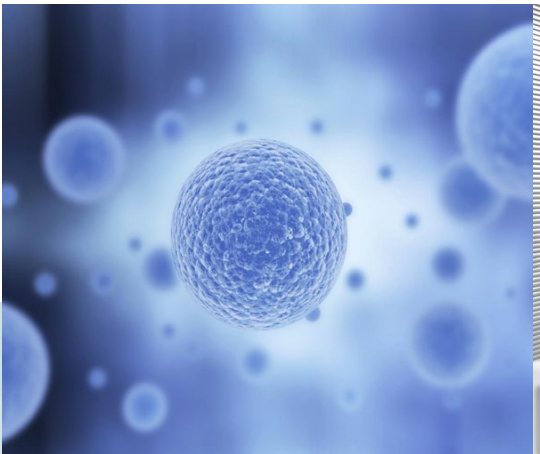
- **Genomic Curation, PAR23-199, PAR20-101;**
- **dGTEx: HD21-008;**
- **Also: PAR23-199, PAR21-248**

- Computer algorithm based on electronic health record data identifies children to be tested for rare genetic condition (PMID 35321655)
- Genetic testing of siblings of newborns with cancer genes could reduce rare pediatric cancer deaths (PMID 34661666)
- GWAS studies identified genetic variants contributing to variation in dexmedetomidine and fentanyl clearance in children (PMID 37353859)

NIH Clinical Center Pediatric Research Strategic Plan

Clinical Center Pediatric Research Strategic Plan Working Group Charge

To identify the most impactful scientific areas of pediatric research in which the NIH can play a major role to substantially improve child health. Using this horizon scanning, to perform long-term, strategic planning for intramural trans-NIH clinical pediatric research to occur over the next decade and beyond.




NIH CC Pediatric Research Strategic Plan Draft Priorities

- Need for cross-cutting infrastructure enhancements to increase efficiency
- Scientific priorities include:
  - Natural history studies to support research on the continuum from diagnosis to treatment
  - Conducting gene therapy, CAR-T, and other cell therapy studies
  - Precision medicine pharmacological interventions in rare, non-malignant diseases
  - Pharmacokinetic and pharmacodynamic studies to improve use and dosing

NIH CC Pediatric Research Strategic Plan Draft Priorities and Next Steps

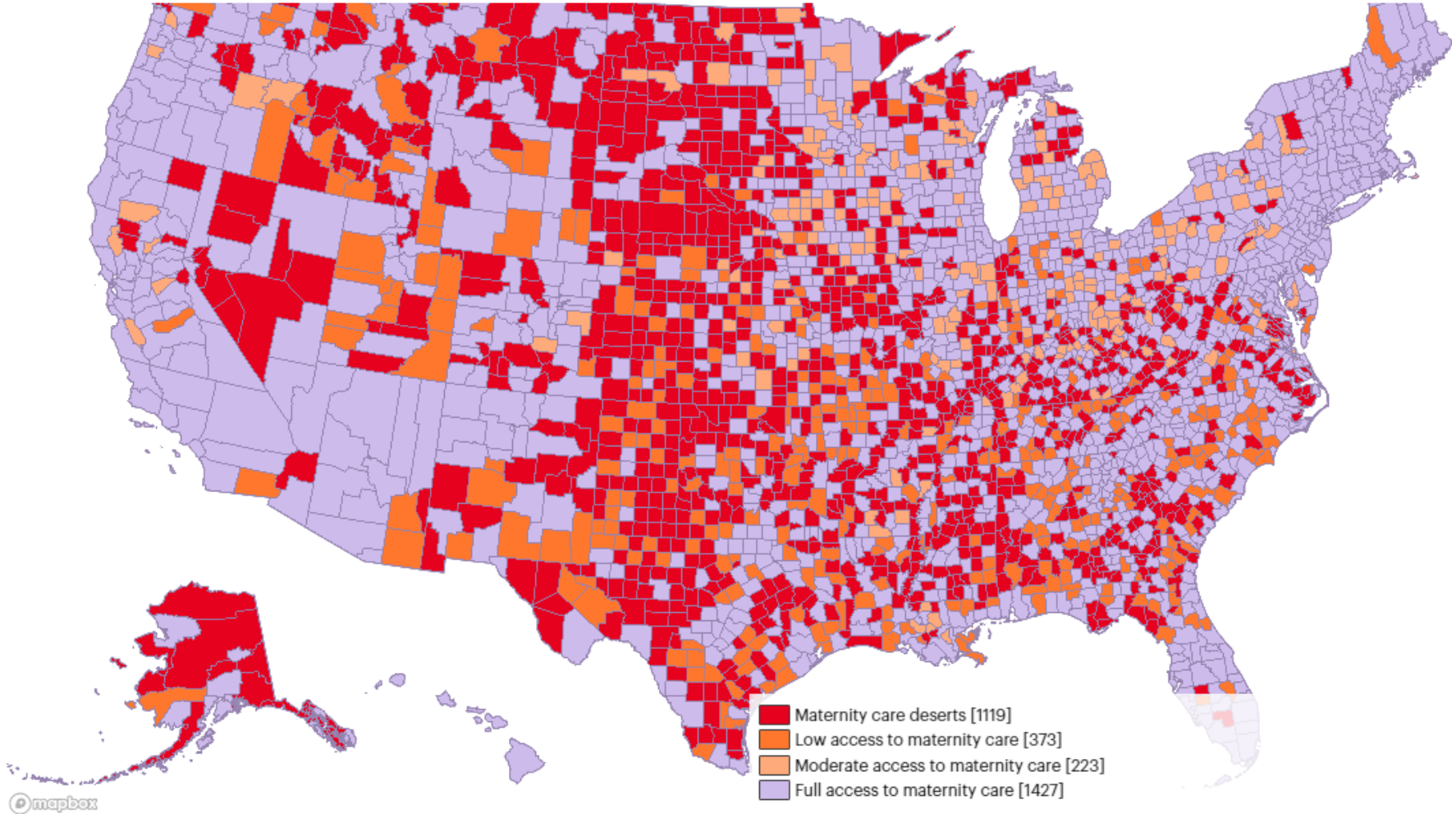
- Scientific Priorities include:
  - Performing metabolic phenotyping across a variety of pediatric conditions
  - Developing a cohort of all pediatric patients at the CC to measure physical and mental health and disease across disorders
  - Deeply phenotyped pediatric cohort to establish a standard set of control samples
  - Increasing support for research studies in pregnant and lactating people
- Next Steps
  - Approval from Clinical Center Governing Board and Clinical Center Hospital Board
  - Implementation Planning

NIH Implementing a Maternal health PRegnancy Outcomes Vision for Everyone (IMPROVE) Program

Maternal Health Crisis in the U.S.

More than 2.2 million women live in maternity care deserts (1119 counties)

- 5% increase in counties that have less maternity access since 2020



Map Source: U.S. Health Resources and Services Administration (HRSA), Area Health Resources Files, 2021

Timing of pregnancy-related deaths

22% While pregnant

13% Day of delivery

12% 1-6 days after end of pregnancy

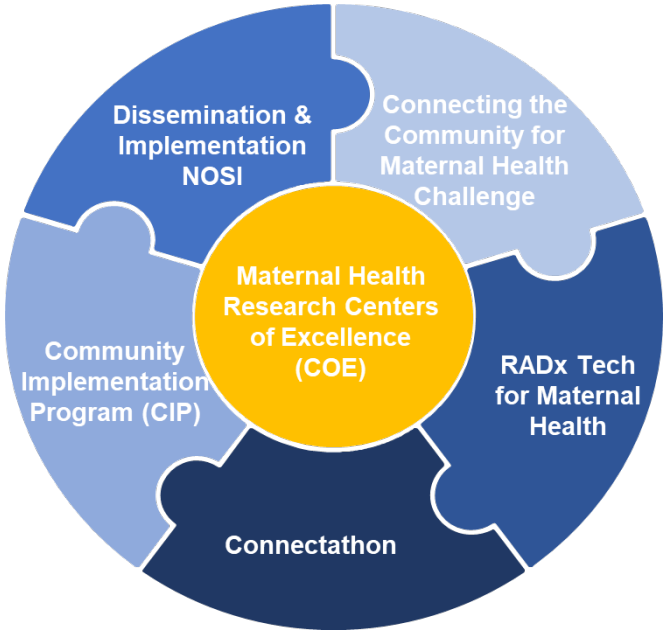
23% 7-42 days after end of pregnancy

30% 43 days to 1 year after end of pregnancy

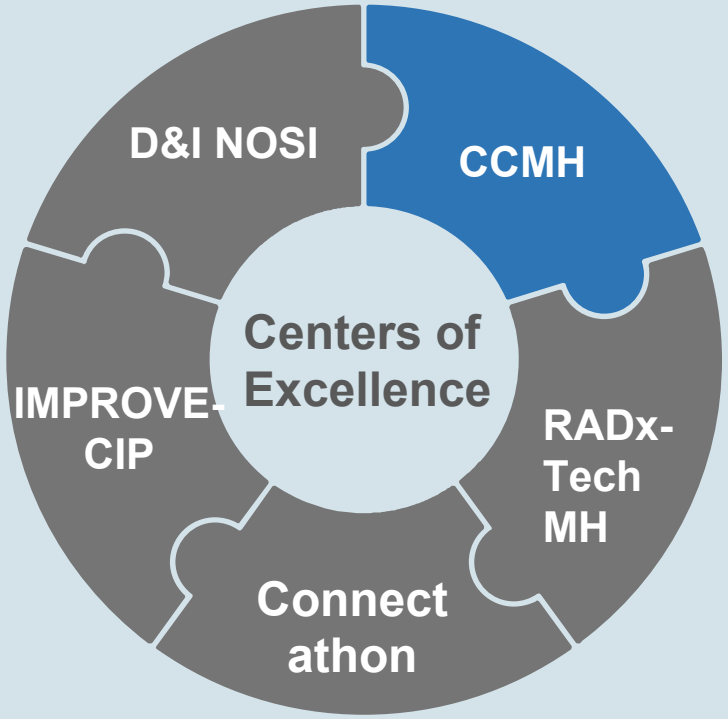
Timing was missing (n=2) or unknown (n=14) for 16 (1.6%) pregnancy-related deaths

NIH IMPROVE Initiative

- NIH-wide effort, co-led by NICHD, NINR, and ORWH
- Goals
  - Reduce preventable causes of maternal morbidity and mortality
  - Address disparities in maternal health outcomes
  - Expand implementation of evidence-based maternal health care practices before, during, and after pregnancy
  - Build research capacity in community-based organizations
  - Promote access to maternal health care with innovative technology
  - Enable real-world research with electronic health record standards
- https://www.nichd.nih.gov/IMPROVE



Connecting the Community for Maternal Health Challenge



Connecting the Community for Maternal Health Challenge

Capacity Building

- Encourages community-based organizations to develop research infrastructure and capabilities
- Total prize of ~$3M across multiple phases
- Non-monetary incentives such as mentoring and proposal writing assistance also provided
- Proposal Phase winners announced in June
- Final Research Phase: Organizations have one year to implement project plans, conduct proposed research, and report results
- Final winners announced September 2024

Listening Session with Maternal Health Community Organizations

Connecting the Community for Maternal Health Challenge

Proposal Phase Winners

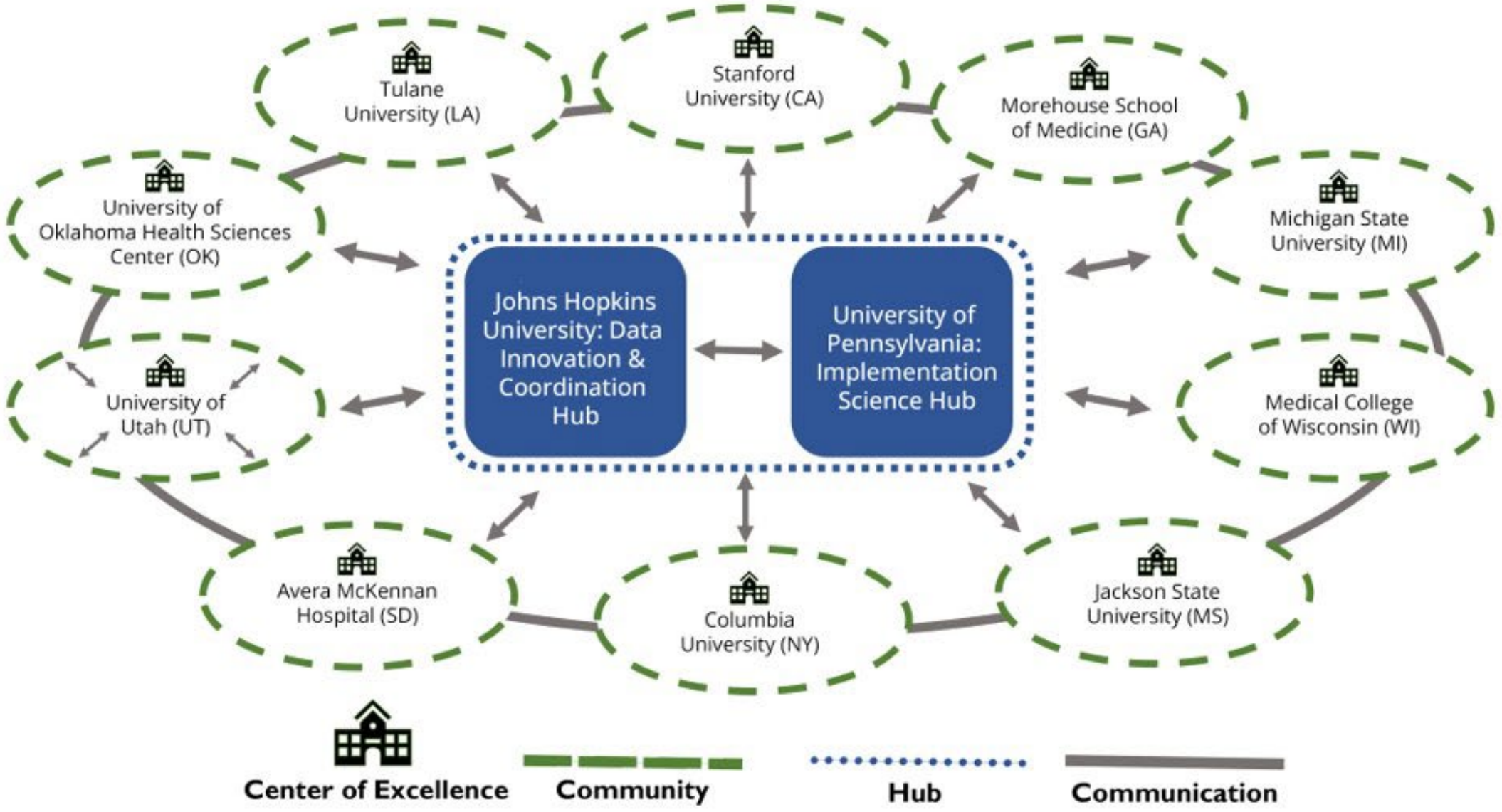
Submission Proposal Title	Organization/Institution	State
Carrying for the Culture: An Infant Carrying Intervention for Health Equity	Nurturely	Oregon
Can it Happen to Me? Developing a Maternal Morbidity Risk Prediction Tool	Central Jersey Family Health Consortium	New Jersey
Increasing Resiliency in the Perinatal Period	Atlanta Birth Center	Georgia
Leveraging Community-Rooted Peer Support to Improve Maternal Mental Health	HealthConnect One	Illinois
Maternal Health Literacy for Nutrition Care Equity	AHIMA Foundation	Illinois
Postpartum Doula Care Reduces BIPOC Mothers' Hypertension, Depression & Anxiety	The Abundance Project	Colorado
Culturally Congruent Doula Care; The Missing Lens Into Maternal Mental Health	Doula CO-OP	Nevada
Survivor Moms' Companion: A Perinatal PTSD Program	Buffalo Prenatal Perinatal Network, Inc	New York
The IMAGINE Project (Iowa MAternal Group INitiativE): Optimizing Mental Health	Postpartum Support International	Iowa

Maternal Health Research Centers of Excellence

IMPROVE Maternal Health Research Centers of Excellence

- **Goal:** Reduce maternal morbidity and decrease preventable mortality by partnering with communities affected and incorporating their needs and perspectives in the research performed by the Centers of Excellence
- **Key benefits:**
  - Community partnership from inception of research projects
  - Robust training component to grow future workforce
- Awarded in August 2023

Maternal Health Research Centers of Excellence: Sites and Structure



CoE Research Centers: Breadth of Science

Conditions

- Anemia
- Preeclampsia
- Hypertensive Disorders of Pregnancy
- Gestational Diabetes
- Postpartum Hemorrhage
- Substance Use Disorder
- Perinatal Mood and Anxiety Disorders

Gestational Time points

- Prenatal/ Perinatal
- Labor/ Delivery
- Postpartum

Populations

- American Indian/ Alaska Native
- Asian
- Black
- Hispanic
- Low Socioeconomic Status
- Rural

Novel Approaches

- Community health workers- including doulas
- Home visiting programs
- Applying artificial intelligence and machine learning to electronic medical records
- Integrated care models

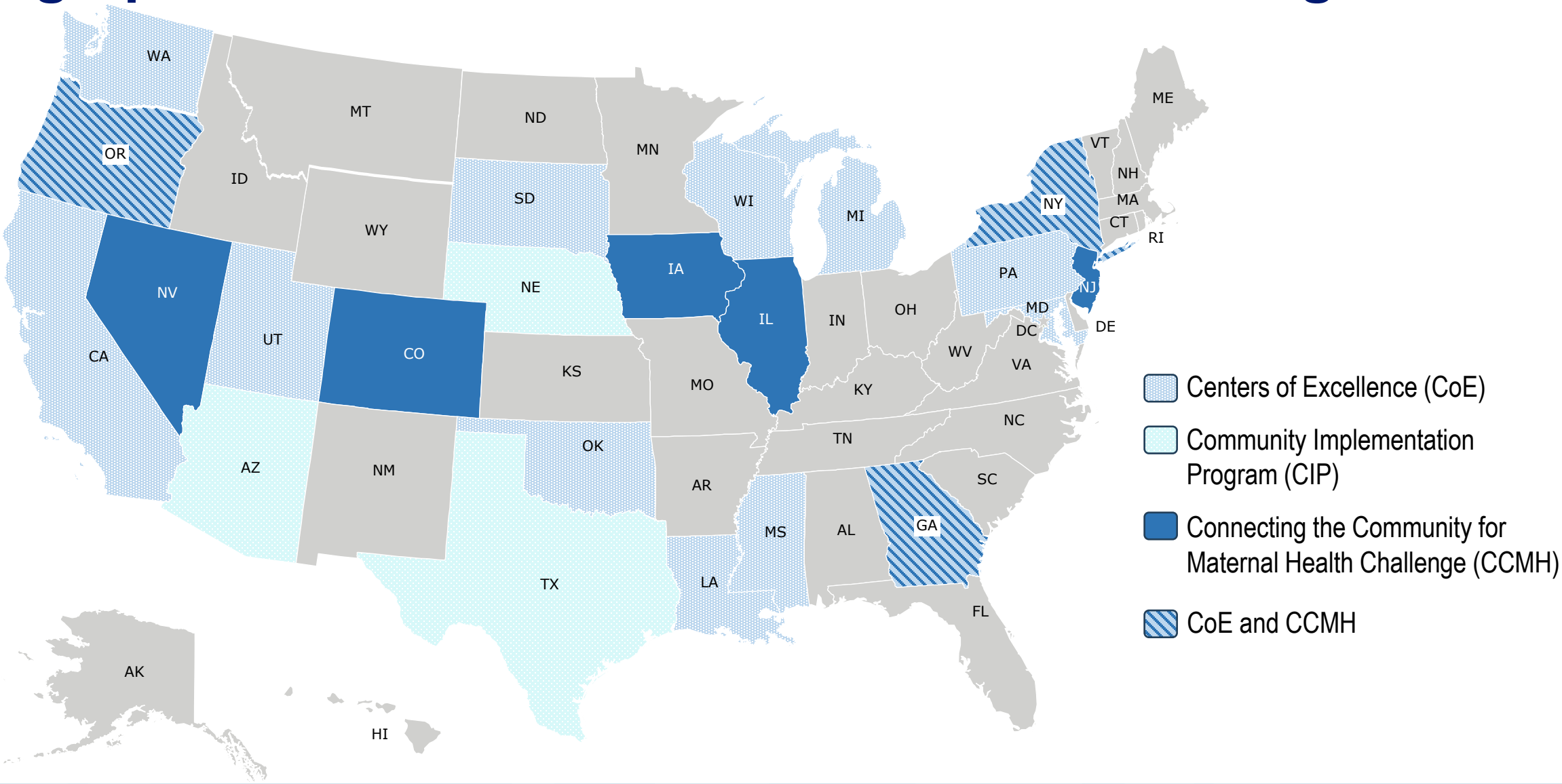
Healthcare

- Implicit provider biases
- Creation of predictive models
- Clinical interventions

Social Determinants of Health

- Housing instability
- Interpersonal violence
- Access to care
- Nutrition disparities
- Food insecurity
- Resource access

Geographic Distribution of IMPROVE Initiative Programs



NIH and NICHD Staff Updates

Director, National Institute of Allergy and Infectious Diseases (NIAID)
Jeanne Marrazzo, M.D.

- Currently Director of the Division of Infectious Diseases at the University of Alabama at Birmingham
- Research focuses include the human microbiome, specifically related to female reproductive tract infections and hormonal contraception; prevention of HIV infection using biomedical interventions; and the pathogenesis and management of bacterial vaginosis
- B.S. in biology from Harvard University
- M.D. from Thomas Jefferson University
- MPH in Epidemiology, University of Washington

NIH Associate Director for Behavioral and Social Sciences Research

Jane Simoni, Ph.D.

- Former Professor and Director of Clinical Training, Department of Psychology, University of Washington
- Founding director, UW Behavioral Research Center for HIV and co-director, UW/Fred Hutch Center for AIDS Research
- B.A. from Princeton and Ph.D. from UCLA

Director, NIH Tribal Health Research Office

Karina Walters, Ph.D., M.S.W.

- Former tenured full professor and Katherine Hall Chambers Scholar at the University of Washington (UW) School of Social Work
- Former Associate Dean for Research at the UW School of Social Work
- B.S., M.S.W., and Ph.D. in sociology/social welfare from UCLA

Retirement
Director, National Library of Medicine (NLM)
Patricia Flatley Brennan, R.N., Ph.D.

- Director of NLM for seven years
- First nurse, industrial engineer, and woman to lead NLM
- Directed modernization and expansion of mission-critical biomedical and information systems such as PubMed, PubMed Central, ClinicalTrials.gov, GenBank, and the Sequence Read Archive (SRA)—making SRA the world's largest publicly available repository for high-throughput sequencing data
- **Acting Director**: Stephen Sherry, Ph.D., currently Director of NLM's National Center for Biotechnology Information and NLM Associate Director for Scientific Data Resources

Welcome!

NICHD Clinical Director

Catherine Gordon, M.D.

Thank You!

Former Acting NICHD Clinical Director

Deputy Clinical Director

Laverne Mensah, M.D.

Deputy Director of the Division of Extramural Activities
Director, Office of Extramural Policy
Joseph Gindhart, Ph.D.

- Formerly the Chief of the Cell Biology Branch in the Division of Genetics and Molecular, Cellular, and Developmental Biology at NIGMS
- Prior to NIH, taught genetics, cell biology, and bioinformatics at the University of Massachusetts Boston and the University of Richmond
- B.A. in biology from the University of Pennsylvania
- Ph.D. in genetics from Indiana University

Chief, Scientific Review Branch
Joanna Kubler-Kielb, Ph.D.

- Joined NICHD as Scientific Review Officer in 2013
- Formerly a staff scientist in NICHD's DIR Program in Developmental and Molecular Immunity, where her research focused on structural design and immunological properties of pediatric antimicrobial subunit vaccines
- M.Sc. In engineering and biotechnology from Wrocław University of Science and Technology in Poland
- Ph.D. in glycobiology and D.Sc. degree for independent research in vaccine development from the Ludwik Hirszfeld Institute of Immunology and Experimental Therapy of the Polish Academy of Science

Congratulations!
Juanita Chinn, Ph.D.

- Elected by her peers to the Board of Directors of the Population Association of America
- Program Director in NICHD's Population Dynamics Branch
- Manages the branch's demography of health, mortality, and population composition programs, as well as its small business-related programs
- Invaluable member of teams supporting many NIH-wide initiatives, including maternal health

In Memoriam
Koji Yoshinaga, Ph.D.

- Retired in 2018 after a 40-year career at NICHD in the Fertility and Infertility Branch (and its predecessor branches)
- Program director for a portfolio of grants in reproductive endocrinology and immunology.
- Conceived the idea for and managed an interdisciplinary collaborative team of researchers to advance the science of blastocyst implantation.
- Received the Jansen Distinguished Service Award from the Society for the Study of Reproduction in 1999 for his many contributions to the field and the society

We're Hiring!

- Extramural
  - Branch Chiefs
    - Fertility and Infertility
    - Gynecologic Health and Disease
  - Program Officers
    - Child Development and Behavior
    - Fertility and Infertility
    - Intellectual and Developmental Disabilities
    - Maternal and Pediatric Infectious Disease
- Intramural
  - Pediatric endocrinologist staff clinician
  - Chief and Senior Investigator, Epidemiology
  - Tenure-Track investigator, Social and Behavioral Sciences
  - Clinical Tenure-Track Translational Investigator
  - Fellows and Trainees

https://www.nichd.nih.gov/about/jobs

Thank You!
Questions?