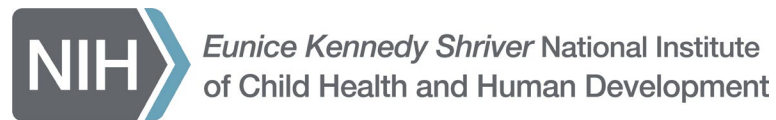


# The National Institutes of Health Overview

Diana W. Bianchi, M.D.

Director, NICHD



December 12, 1988

Diana W. Bianchi, M.D.  
Assistant in Medicine  
The Children's Hospital  
300 Longwood Avenue  
Boston, MA 02115

Dear Dr. Bianchi:

Thank you for your interest in the Joseph P. Kennedy, Jr. Foundation Biomedical Research Grants Program for 1989. We received a large number of letters of intent, and from these several were selected to complete the formal proposal process. Although your proposal has a great deal of merit, unfortunately it was not among those chosen for final consideration for funding.

The Foundation uses a number of criteria in deciding which projects to fund: the excellence of the science, the uniqueness of the proposal, its "high risk" nature, and its alignment with the objectives of the Foundation.

We hope you will be successful in finding support for your project elsewhere.

Sincerely yours,



*The Joseph P. Kennedy, Jr. Foundation*

1350 NEW YORK AVENUE, N.W., SUITE 500  
WASHINGTON, D.C. 20005-4709  
(202) 393-1250

December 12, 1988

Diana W. Bianchi, M.D.  
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We hope you will be successful in finding support for your project elsewhere.

Sincerely yours,

*Eunice Kennedy Shriver*  
Eunice Kennedy Shriver

**Moral of the story: Don't let your self-worth or career choices be influenced by failure to get grant funding!**



## Talk Outline

- Overview of the National Institutes of Health
- NICHD Investment in Training
- NICHD Overview and Strategic Plan
- Getting Started: Shared Data and Resources
- Select Programmatic Highlights

# National Institutes of Health



**November 8, 2016**



- Largest funder of biomedical research in the world
- Consists of 27 separate institutes and centers (ICs)
- Each IC has an individual budget that is appropriated by Congress
- ICs support both extramural research at universities and institutions across the country (~83% of the budget) and intramural research programs (~11% of the budget)



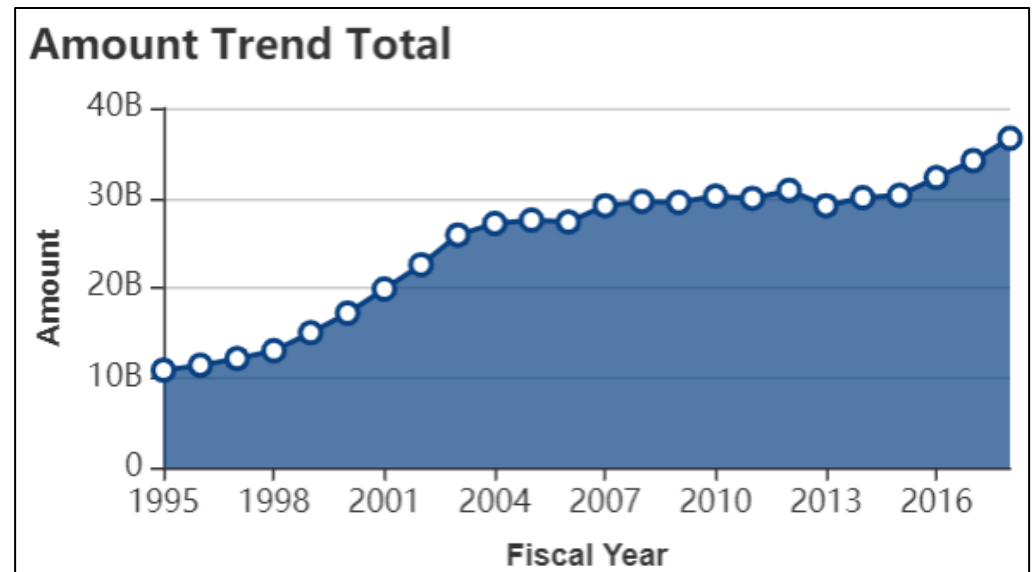
# NIH Clinical Center

- World's largest research hospital
- Admits patients only on clinical research protocols
- More than 9,100 new patients in 2019
- Currently ~ 1,600 clinical studies in progress
- Patients referred by providers or self via [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- Career and funding opportunities exist for bench to bedside research



# NIH Budget

- NIH FY 2020 budget was \$41.68 billion
- NICHD's FY 2020 budget was ~\$1.5 billion
- Additional funds come from special projects
  - HEAL (Helping to End Addiction Long-term)
  - INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome)
  - COVID-19 supplements



# Where Does the NIH Money Go?

- RCDC stands for “Research, Condition and Disease Categorization”
- NIH keeps the public informed as to how tax dollars are spent
- RCDC is a computerized process NIH has used since 2009 to categorize and report amount of funding in 265 categories
- No categories for “pregnancy” or “breastfeeding” until 2017



[report.nih.gov](https://report.nih.gov)







# All Appropriations are Personal



Rep. Herrera-Beutler



Rep. DeLauro

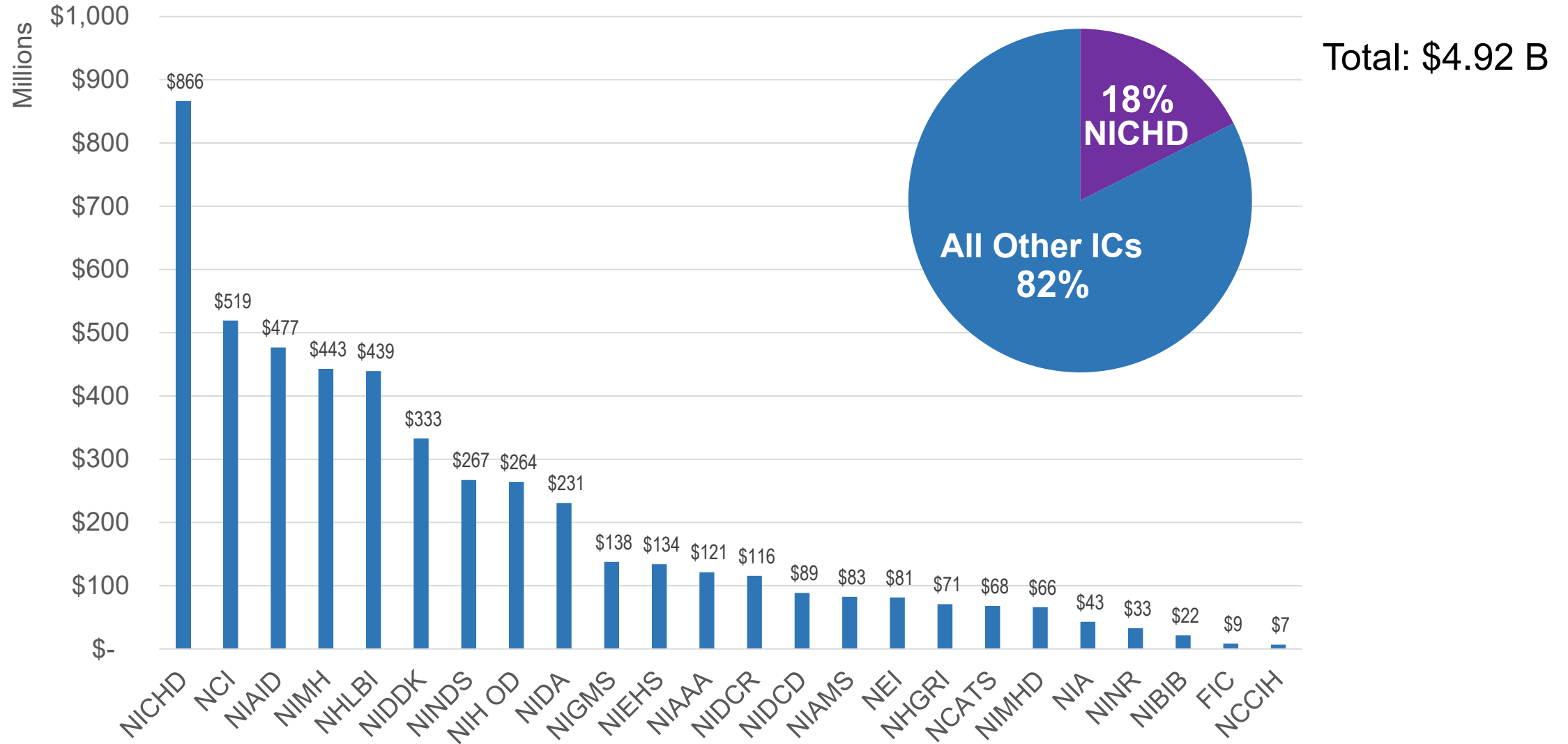


Rep. Lee

8 out of 13 Members of the House Labor-HHS Appropriations Subcommittee are women



# NIH Pediatrics Research Spending by IC, FY 2019



Note: NICHD funds over 18% of pediatrics research at NIH.



# Trans-NIH Pediatric Research Consortium (N-PeRC)

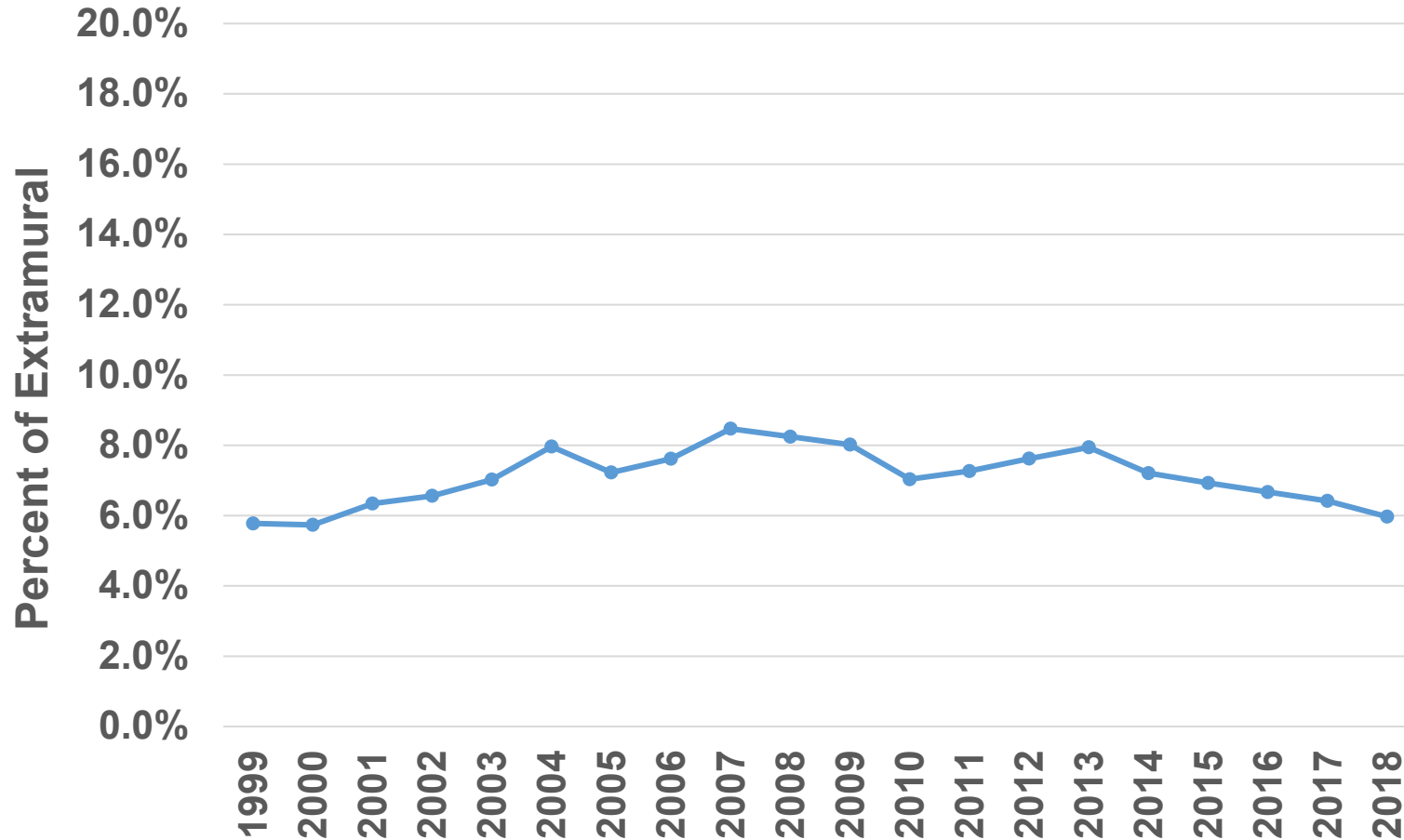
- Harmonize efforts in child health research across NIH Institutes and Centers
- Meetings held bi-monthly since June 2018
- Identify gaps and opportunities for collaboration
  - *Pediatric research workforce*
  - Transition from adolescence to adulthood
    - Workshop on transition to adult healthcare for children with chronic conditions (September 2020)
  - COVID-19
  - Pediatric drugs and devices (BPCA)



<https://www.nichd.nih.gov/research/supported/nperc>



# NICHD Training Budget History



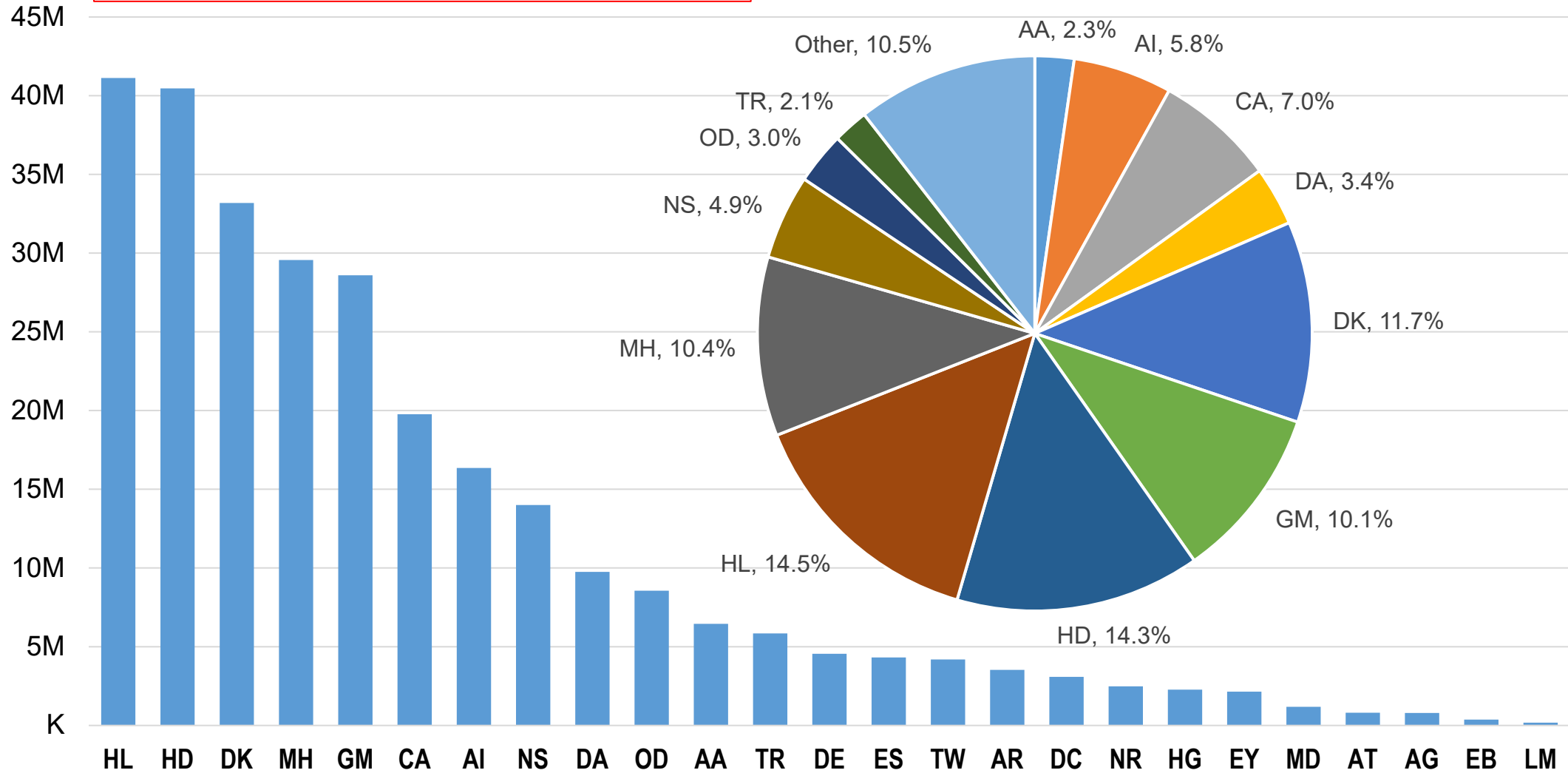
Intent to maintain overall training budget at ~6%

NICHD expenditures on training as a percentage of the annual NICHD Extramural Budget



# FY 2018 Pediatric Training/Career Development by IC

Total awarded: \$283,551,759



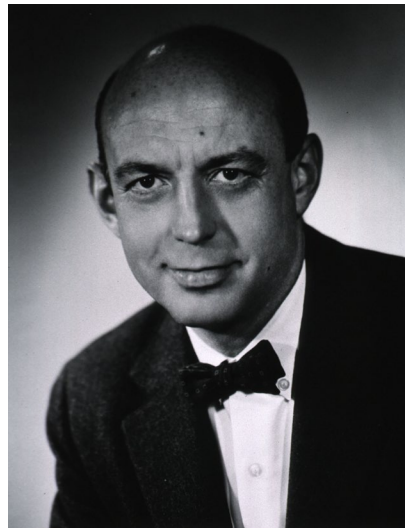


# **NICHD Overview**

# NICHD Directors 1963-Present



Robert Aldrich  
1963-1964



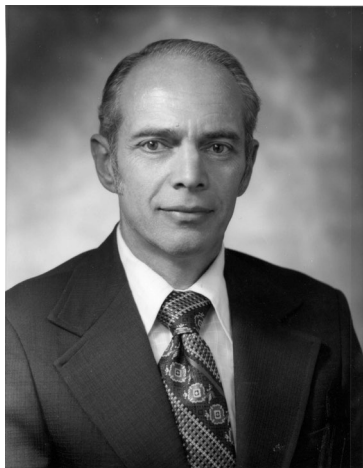
Donald Harting  
1965-1966



Gerald LaVeck  
1966-1973



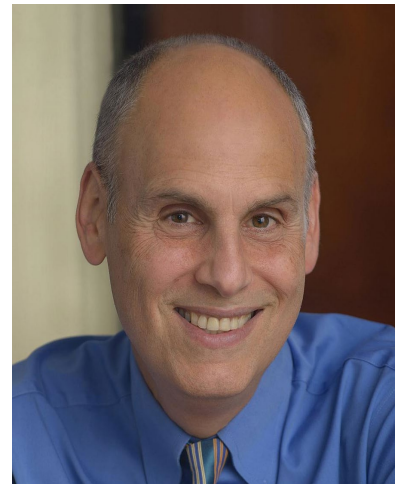
Norman Kretchmer  
1974-1981



Mortimer Lipsett  
1982-1985



Duane Alexander  
1986-2009



Alan Guttmacher  
2009-2015



Diana Bianchi  
2016-





# Our Name is Misleading

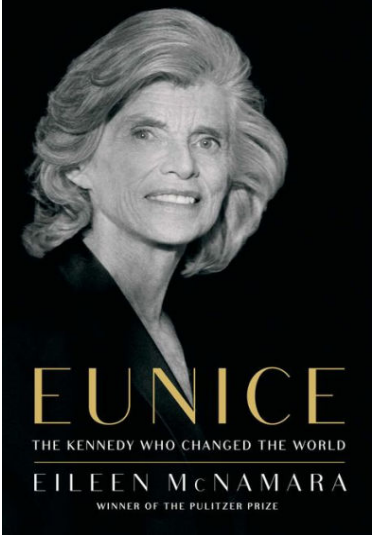
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*Eunice Kennedy Shriver*

National Institute of Child Health and Human  
Development

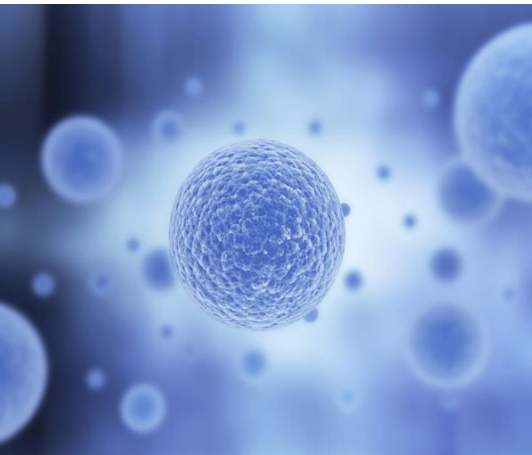
30%

18%



# Mission Statement

**The NICHD leads research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all.**



# NICHD Vision Statement



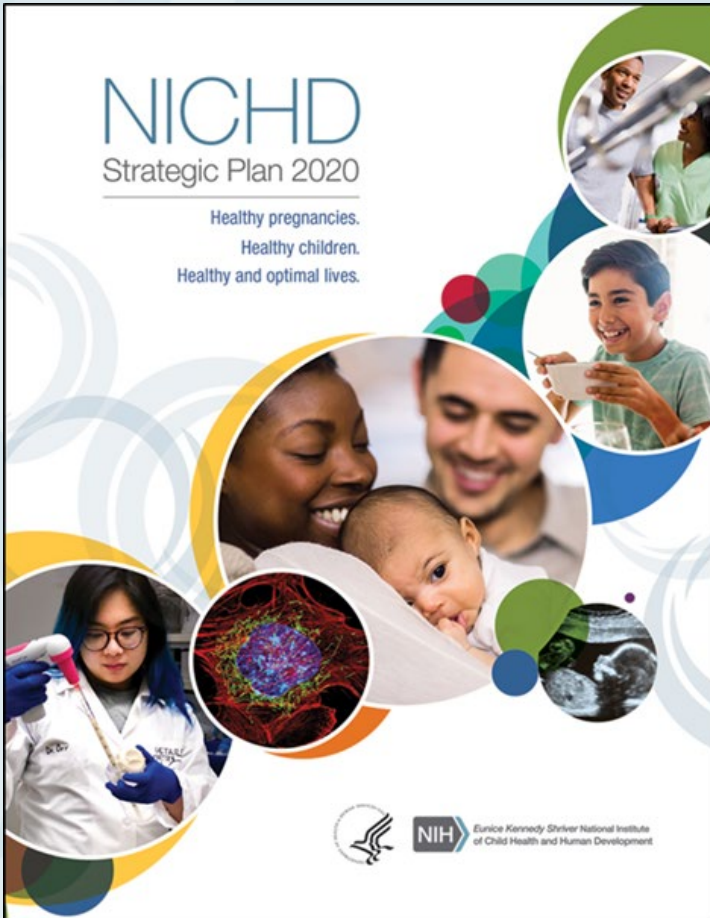
**Healthy pregnancies. Healthy children.  
Healthy and optimal lives.**



# NICHD Strategic Plan 2020

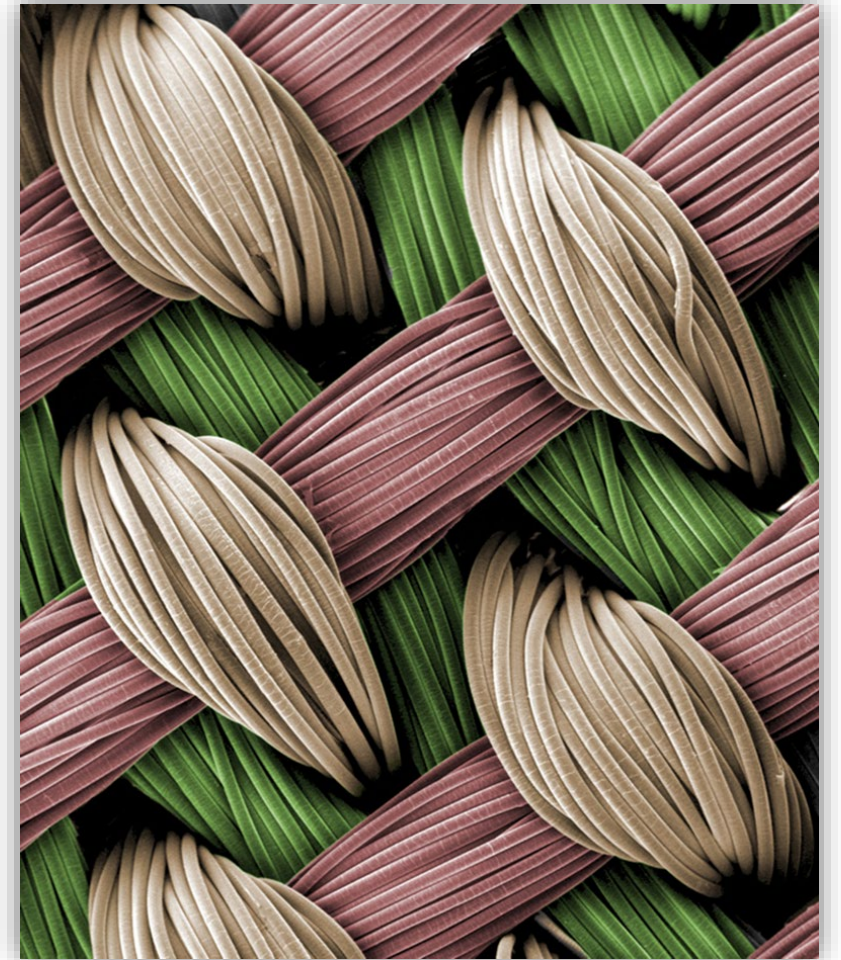
## Research Themes

- Understanding the Molecular, Cellular, and Structural Basis of Development
- Promoting Gynecologic, Andrologic, and Reproductive Health
- Setting the Foundation for Healthy Pregnancies and Lifelong Wellness
- Improving Child and Adolescent Health and the Transition to Adulthood
- Advancing Safe and Effective Therapeutics and Devices for Pregnant and Lactating Women, Children, and People with Disabilities



# Cross-Cutting Themes

- Global Health
- Health Disparities
- Prevention
- Nutrition
- Infectious Disease

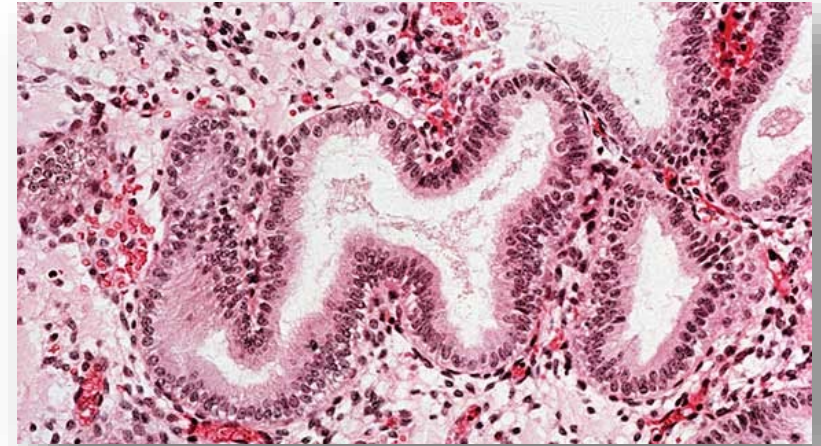


Credit: Guilak Lab, Washington University



# Aspirational Goals

- **Goal 1:** Limb Regrowth
- **Goal 2:** Personalized Medicine for Children
- **Goal 3:** Diagnose, Treat, and Cure Endometriosis
- **Goal 4:** Predict Pregnancies at Risk for Fetal Loss
- **Goal 5:** Advance and Apply Knowledge of the Fetomaternal Immune Relationship
- **Goal 6:** Improve Care of Premature Infants
- **Goal 7:** Explore Risks of Technology and Media Exposure in the Developing Brain
- **Goal 8:** Synthesize and Personalize Human Milk
- **Goal 9:** Build Connections Between Atypical Neurodevelopment and Risk of Neurodegeneration
- **Goal 10:** Train Investigators in Artificial Intelligence



# NICHD Funding Strategy

- Goal: to fund the best science and make the most of our research investments
- Each extramural research branch lists their research priorities on NICHD's website
  - Recently updated to align with NICHD's Strategic Plan
- Important to connect with a program officer to see if your project aligns with branch priorities



# NICHD Overview

## Division of Extramural Research Branches (N=12)

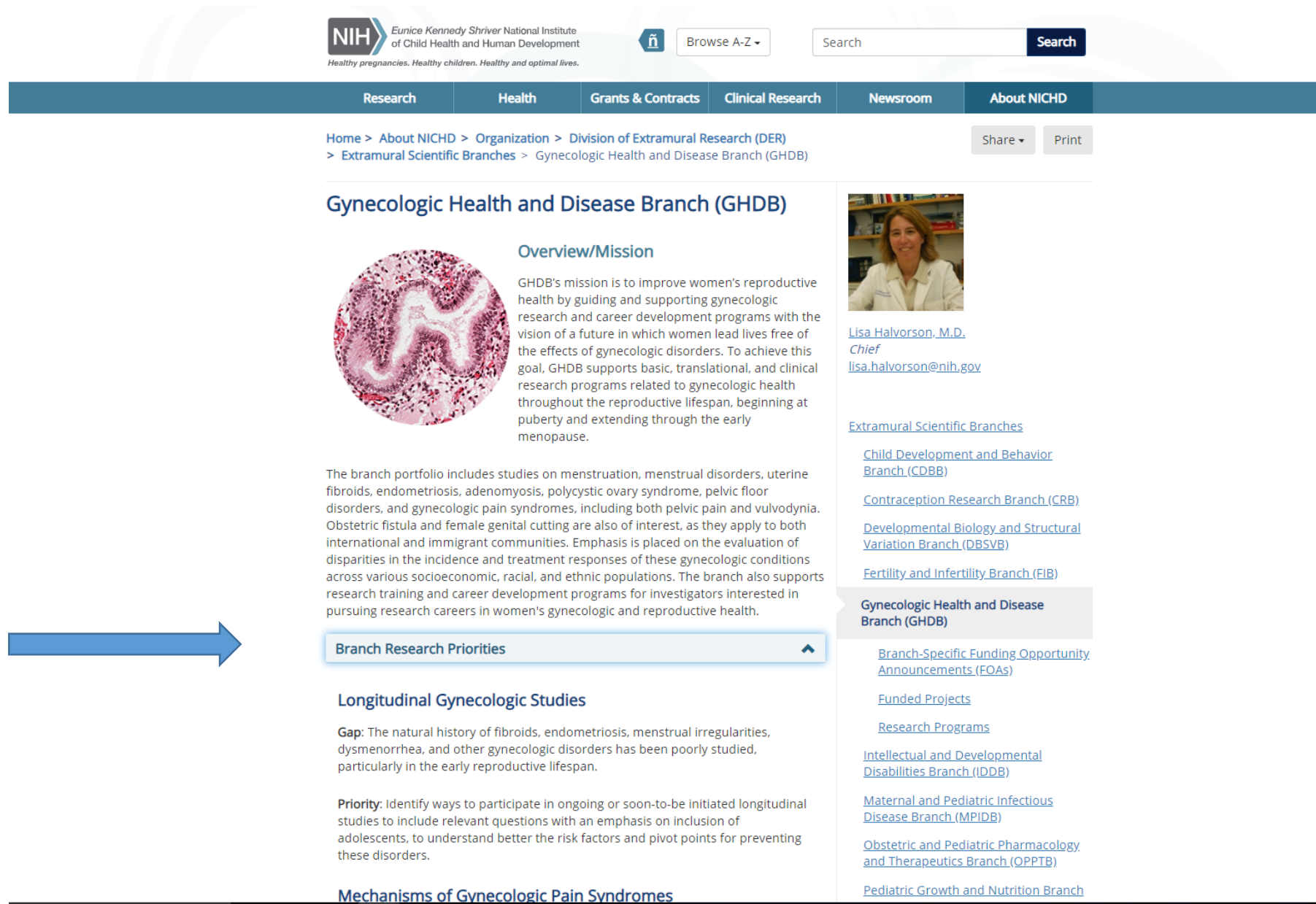
- Child Development and Behavior
- Contraception Research
- Developmental Biology and Structural Variation
- Fertility and Infertility
- Gynecologic Health and Disease
- Intellectual and Developmental Disabilities
- Maternal and Pediatric Infectious Disease
- Obstetric and Pediatric Pharmacology and Therapeutics
- Pediatric Growth and Nutrition
- Pediatric Trauma and Critical Illness
- Population Dynamics
- Pregnancy and Perinatology





# NICHD Website:

[www.nichd.nih.gov](http://www.nichd.nih.gov)



**NIH** Eunice Kennedy Shriver National Institute of Child Health and Human Development  
Healthy pregnancies. Healthy children. Healthy and optimal lives.

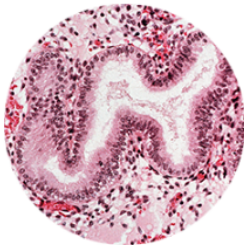
Browse A-Z Search

Research Health Grants & Contracts Clinical Research Newsroom About NICHD

Home > About NICHD > Organization > Division of Extramural Research (DER) > Extramural Scientific Branches > Gynecologic Health and Disease Branch (GHDB)

## Gynecologic Health and Disease Branch (GHDB)

**Overview/Mission**



GHDB's mission is to improve women's reproductive health by guiding and supporting gynecologic research and career development programs with the vision of a future in which women lead lives free of the effects of gynecologic disorders. To achieve this goal, GHDB supports basic, translational, and clinical research programs related to gynecologic health throughout the reproductive lifespan, beginning at puberty and extending through the early menopause.

The branch portfolio includes studies on menstruation, menstrual disorders, uterine fibroids, endometriosis, adenomyosis, polycystic ovary syndrome, pelvic floor disorders, and gynecologic pain syndromes, including both pelvic pain and vulvodynia. Obstetric fistula and female genital cutting are also of interest, as they apply to both international and immigrant communities. Emphasis is placed on the evaluation of disparities in the incidence and treatment responses of these gynecologic conditions across various socioeconomic, racial, and ethnic populations. The branch also supports research training and career development programs for investigators interested in pursuing research careers in women's gynecologic and reproductive health.


**Branch Research Priorities**

### Longitudinal Gynecologic Studies

**Gap:** The natural history of fibroids, endometriosis, menstrual irregularities, dysmenorrhea, and other gynecologic disorders has been poorly studied, particularly in the early reproductive lifespan.

**Priority:** Identify ways to participate in ongoing or soon-to-be initiated longitudinal studies to include relevant questions with an emphasis on inclusion of adolescents, to understand better the risk factors and pivot points for preventing these disorders.

### Mechanisms of Gynecologic Pain Syndromes



[Lisa Halvorson, M.D.](#)  
Chief  
[lisa.halvorson@nih.gov](mailto:lisa.halvorson@nih.gov)

**Extramural Scientific Branches**

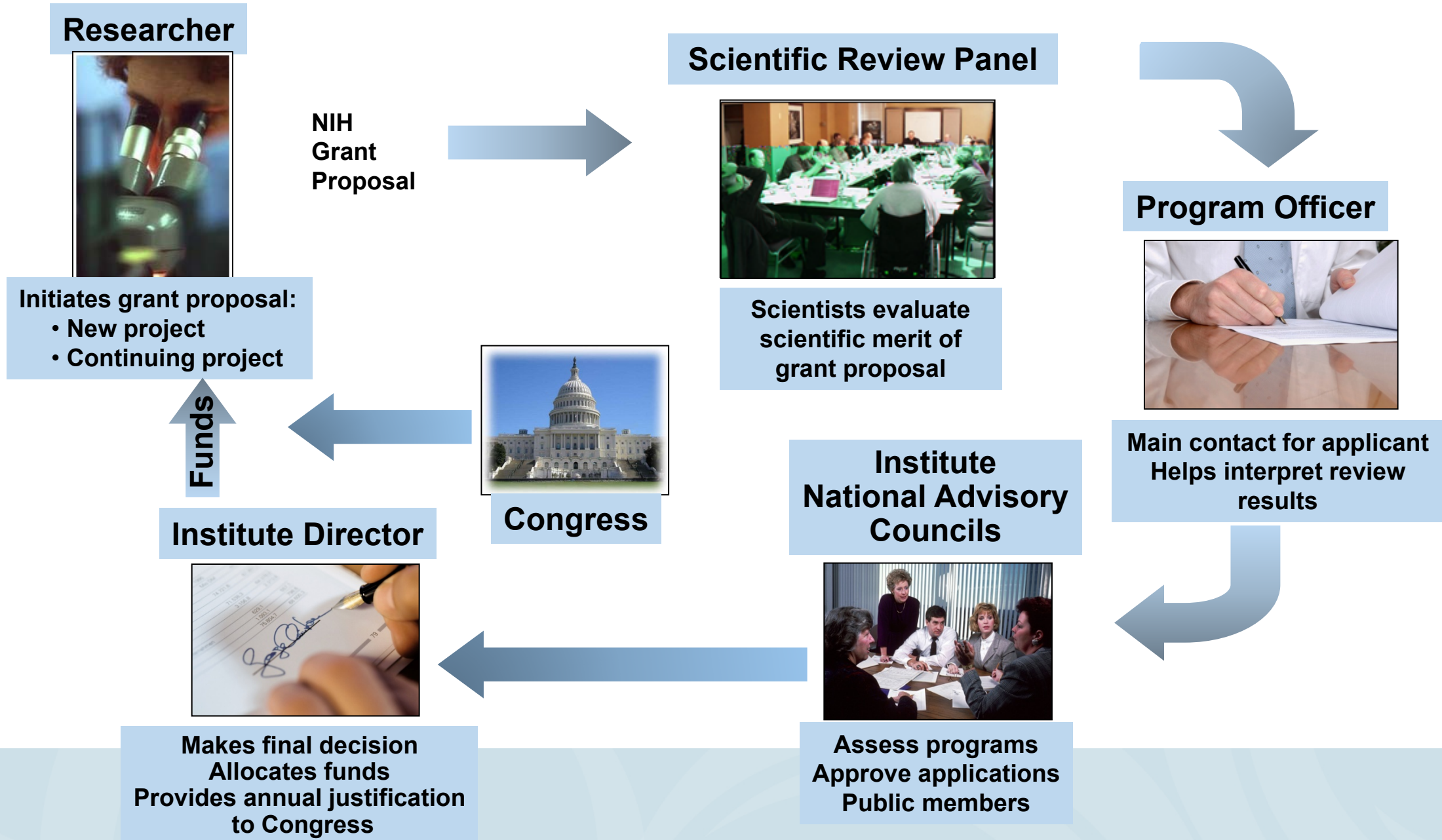
- [Child Development and Behavior Branch \(CDBB\)](#)
- [Contraception Research Branch \(CRB\)](#)
- [Developmental Biology and Structural Variation Branch \(DBSVB\)](#)
- [Fertility and Infertility Branch \(FIB\)](#)

**Gynecologic Health and Disease Branch (GHDB)**

- [Branch-Specific Funding Opportunity Announcements \(FOAs\)](#)
- [Funded Projects](#)
- [Research Programs](#)
- [Intellectual and Developmental Disabilities Branch \(IDDB\)](#)
- [Maternal and Pediatric Infectious Disease Branch \(MPIDB\)](#)
- [Obstetric and Pediatric Pharmacology and Therapeutics Branch \(OPPTB\)](#)
- [Pediatric Growth and Nutrition Branch](#)



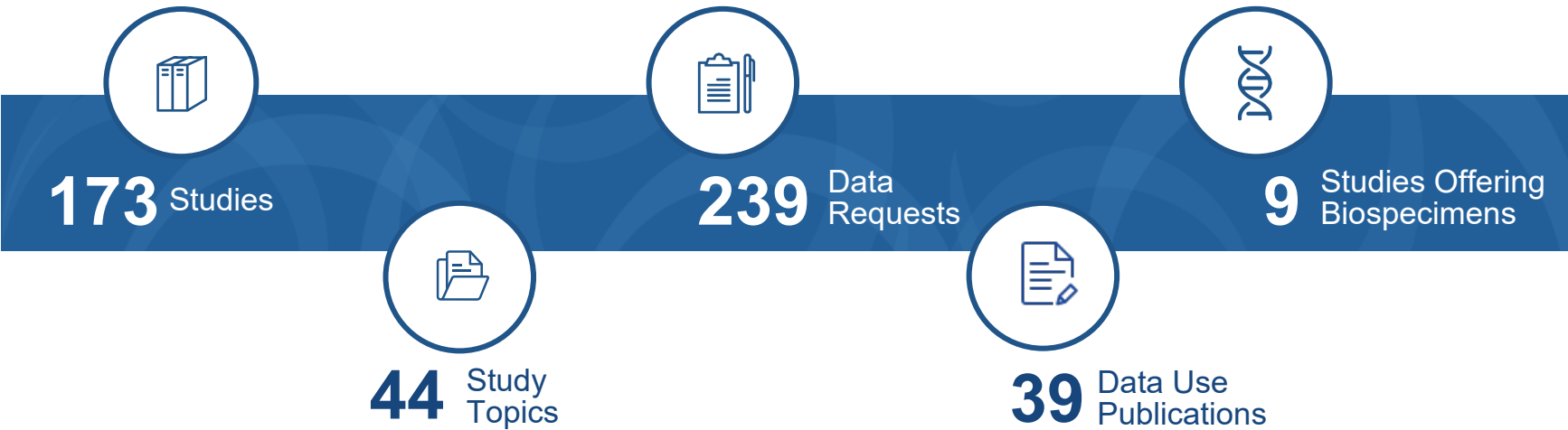
# The Process for Review and Funding



**Shared Data  
and Resources:  
Opportunities  
to Get your  
Research  
Career Started**

- NICHD Data and Specimen Hub (DASH)
- Gabriella Miller Kids First Data Resource

- Centralized resource for researchers to share de-identified data from studies funded by NICHD. DASH also serves as a portal for requesting biospecimens from selected studies in DASH.
- Data sharing launched in August 2015; biospecimen request launched in March 2019
- Aims to accelerate scientific findings to ultimately improve human health



## Study Topics in DASH

- |                                  |                               |
|----------------------------------|-------------------------------|
| Adrenal Gland Disorders          | Neuroscience                  |
| Amenorrhea                       | Obesity & Overweight          |
| Autism Spectrum Disorders        | Obstetrics                    |
| Birth Defects                    | Pediatric Injury              |
| Breastfeeding & Breast Milk*     | Pelvic Floor Disorders        |
| Cerebral Palsy                   | Pharmacology                  |
| Child Health*                    | Preconception & Prenatal Care |
| Children's Bone Health & Calcium | Preeclampsia & Eclampsia      |
| Delayed Puberty                  | Pregnancy*                    |
| Diabetes                         | Pregnancy Loss                |
| Driving Risk                     | Preterm Labor & Birth*        |
| Early Learning                   | Primary Ovarian Insufficiency |
| Fertility Problems               | Puberty & Precocious Puberty  |
| High-Risk Pregnancy              | Rehabilitation Medicine       |
| HIV/AIDS*                        | Sleep                         |
| Infant Care & Health *           | Spinal Cord Injury            |
| Infant Mortality                 | Stillbirth                    |
| Infertility & Fertility          | Stroke                        |
| Labor & Delivery                 | Sudden Infant Death Syndrome  |
| Men's Reproductive Health        | Traumatic Brain Injury        |
| Menkes Disease                   | Turner Syndrome               |
| Necrotizing Enterocolitis        | Women's Health*               |

\*biospecimens available

- While not a biorepository itself, DASH serves as a portal for access to biospecimens associated with DASH data collections.
- Investigators worldwide can request both biospecimens and data for secondary analyses; other than the costs of preparing and shipping biospecimens, these specimens are free to investigators.
- Studies with biospecimens currently available include:
  - Genomic and Proteomic Network for Preterm Birth Research (GPN) – three studies
  - NICHD International Site Development Initiative (NISDI) – four studies
  - Mothers and Infants Cohort Study (MICS)
  - National Children’s Study (NCS)

### Study Topics Areas of Current Biospecimens

Breastfeeding and Breast Milk	Pregnancy
Child Health	Preterm Labor and Birth
HIV/AIDS	Women’s Health
Infant Care and Infant Health	

### Currently Available Biospecimens

Amniotic fluid	Hair
Blood	Lymphocytes
Breast Milk	Meconium
Buffy Coat	Nail
Cord Blood (Buffy Coat, RBC, Plasma, Serum)	Saliva
DNA/RNA/Proteins	Serum/Plasma
Environmental Samples	Tissue samples
Erythrocytes (RBC)	Urine
	Vaginal Fluid

# Sample Publications from DASH Data Reuse

## Maternal and Neonatal Outcomes of Induction of Labor Compared with Planned Cesarean Delivery in Women with Gestational Diabetes Mellitus

Tetsuya Kawakita, MD<sup>1</sup> Katherine Bowers, PhD<sup>2</sup>

<sup>1</sup> Department of Obstetrics and Gynecology, Washington Hospital Center, Washington, District of Columbia  
<sup>2</sup> Division of Biostatistics and Epidemiology, Hospital Medical Center, Cincinnati, Ohio

Am J Perinatol 2018;35:95–102.

### Abstract

**Objective:** To evaluate whether the racial and socioeconomic disparities are present in adverse cervical parameters, and, if so, when such disparities develop.

**Study Design:** A prospective cohort study was conducted. 175 women with a prior preterm birth had up to four endovaginal ultrasounds between gestational weeks 16 and 24 (Cervical Ultrasound Trial of the MFMU). Each sociodemographic factor (race/ethnicity, marital status, insurance funding and education) was examined as a predictor of short cervix or U/funnel shape, using multiple logistic and linear regression. Changes in the cervical length and shape across pregnancy and after pressure were also examined.

**Results:** The strongest associations were seen between race and government-funded insurance and short cervix and U shape per funneling (race and length < 25 mm per funnel: adjusted odds ratio (OR) 5.52, 2.24 to 13.63; government-funded insurance and length < 30 mm per funnel: adjusted OR 3.10, 1.34 to 7.15). Changes in cervical length were not associated with sociodemographics.

**Conclusion:** African-American race and, to a lesser extent, insurance funder, are associated with cervical length and shapes that have been associated with preterm birth, and those properties are present largely early in pregnancy.

### Keywords

cesarean delivery  
expectant management  
induction of labor  
macrosomia  
neonatal intensive care unit

Open Access

Research

## BMJ Open Impact of gestational weight gain and prepregnancy body mass index on the prevalence of large-for-gestational age infants in two cohorts of women with type 1 insulin-dependent diabetes: a cross-sectional study

Ketrell L McWhorter,<sup>1,2,3</sup> Katherine Bowers,<sup>1,2,3</sup> Ka Chandra L Jackson,<sup>3</sup> Jane

### ABSTRACT

**Objectives:** Despite improvements in treatment modalities, large-for-gestational age (LGA) has remained between 30% and 40% among mothers with type 1 insulin-dependent diabetes (T1DM). Our objective was to estimate LGA examine the association between gestational weight gain (GWG) and prepregnancy body mass index (BMI) among mothers with T1DM.

**Design:** Cross-sectional study.

**Setting:** Regional data in Cincinnati, Ohio Diabetes in Pregnancy Program Project – a prospective cohort for the period 1978–2000 data from Consortium on Safe Labor (CSL) cross-sectional study for the period 2000–2009.

**Participants:** The study included 333 preterm pregnancies (PPG) and 358 pregnancies in the CSL delivered prior to 23 weeks' gestation with T1DM.

Women with T1DM in the PPG were identified by physician confirmation of ketoacidosis, HbA1c levels, and by International Classification of Diseases version codes within the CSL. LGA was defined as weight >90th percentile according to gestational age and sex.

**Main outcome measures:** LGA at birth.

**Results:** Mean±SD maternal age at delivery years for PPG women and 27.5±6.0 years (p=0.008). LGA prevalence did not differ between cohorts (PPG: 40.2% vs CSL: 38.1%). More women began pregnancy as overweight (PPG (16.8%) vs CSL (27.1%), p<0.001).

## Nonmedically Indicated Induction of Labor Compared with Expectant Management in Nulliparous Women Aged 35 Years or Older

Tetsuya Kawakita, MD<sup>1</sup> Katherine Bowers, PhD<sup>2</sup>

<sup>1</sup> Department of Obstetrics and Gynecology, MedStar Washington Hospital Center, Washington, District of Columbia  
<sup>2</sup> Division of Biostatistics and Epidemiology, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio  
<sup>3</sup> Division of Endocrinology, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio

Am J Perinatol 2019;36:45–52.

### Abstract

**Objective:** This article compares the prevalence of cesarean delivery, expectant management, induction of labor, macrosomia, and neonatal intensive care unit admission among nulliparous women aged 35 years or older who experience nonmedically indicated induction of labor compared with expectant management.

**Study Design:** This was a retrospective cohort study comparing women aged 35 years or older who experienced nonmedically indicated induction of labor (n=1,038) with those who experienced expectant management (n=1,038).

**Results:** Of 3,819 nulliparous women aged 35 years or older, 1,038 (27.2%) experienced nonmedically indicated induction of labor, and 1,038 (27.2%) experienced expectant management. The prevalence of cesarean delivery was 38% among women with nonmedically indicated induction of labor and 38% among women with expectant management. The prevalence of macrosomia was 16.8% among women with nonmedically indicated induction of labor and 16.8% among women with expectant management. The prevalence of neonatal intensive care unit admission was 16.8% among women with nonmedically indicated induction of labor and 16.8% among women with expectant management.

### Keywords

cesarean delivery  
expectant management  
induction of labor  
macrosomia  
neonatal intensive care unit

SMFM Fellowship Series Article 45



Journal of Perinatology (2017) 37, 335–339  
© 2017 Nature America, Inc., part of Springer Nature. All rights reserved 0743-8346/17  
www.nature.com/jp

### ORIGINAL ARTICLE

## Racial and social predictors of longitudinal cervical measures: the Cervical Ultrasound Study

EW Harville<sup>1</sup>, KS Miller<sup>2</sup> and LR Knoepp<sup>3</sup>

**OBJECTIVE:** To evaluate whether the racial and socioeconomic disparities are present in adverse cervical parameters, and, if so, when such disparities develop.

**STUDY DESIGN:** A prospective cohort study was conducted. 175 women with a prior preterm birth had up to four endovaginal ultrasounds between gestational weeks 16 and 24 (Cervical Ultrasound Trial of the MFMU). Each sociodemographic factor (race/ethnicity, marital status, insurance funding and education) was examined as a predictor of short cervix or U/funnel shape, using multiple logistic and linear regression. Changes in the cervical length and shape across pregnancy and after pressure were also examined.

**RESULTS:** The strongest associations were seen between race and government-funded insurance and short cervix and U shape per funneling (race and length < 25 mm per funnel: adjusted odds ratio (OR) 5.52, 2.24 to 13.63; government-funded insurance and length < 30 mm per funnel: adjusted OR 3.10, 1.34 to 7.15). Changes in cervical length were not associated with sociodemographics.

**CONCLUSION:** African-American race and, to a lesser extent, insurance funder, are associated with cervical length and shapes that have been associated with preterm birth, and those properties are present largely early in pregnancy.

Journal of Perinatology (2017) 37, 335–339; doi:10.1038/jp.2016.240; published online 12 January 2017

### INTRODUCTION

Even in the absence of clinical cervical insufficiency, shorter cervix is associated with preterm birth (PTB).<sup>1</sup> In the United States, the most striking epidemiologic feature of PTB is the disparity between African-American women and other racial/ethnic groups;<sup>2</sup> gradient relationships, with those at highest social risk also having the highest medical risk, are also seen between other socioeconomic indicators, such as poverty and education, and PTB.<sup>3</sup> A study of 5092 Dutch women found that white ethnicity was associated with longer cervical length, while women of African origin had the shortest mean cervical length.<sup>4</sup> There are also racial disparities in cervical insufficiency: an analysis of the US Natality file found that African Americans are more prone to cervical insufficiency than European Americans,<sup>5</sup> although other socioeconomic risk factors for preterm birth, such as marital status and education, were not related. While genetics have a role in cervical structure and function,<sup>6</sup> immigrant studies do not suggest genetic differences as a major cause for between-population disparities.<sup>7,8</sup>

The key role of the cervix in parturition has led to examination of cervical measures (length, shape, length after pressure, changes in length or shape, funneling) especially when repeated, as possible predictors of PTB. The Cervical Ultrasound Study (CRVUS)

associated with increased risk of early preterm birth in CRVUS, results were impressive.

We are not aware of studies that have more extensively examined the relationship between social factors and cervical length and changes in length or shape early in pregnancy. Although cervical length is the major cervical property known to be clinically predictive of preterm birth,<sup>10</sup> cervical shape and changes in length and shape are also associated with, if not diagnostic for, PTB. A major goal of this research field is to determine the pathophysiologic mechanisms that create health disparities and the times during which interventions are most likely to be useful. In this analysis, we consider social influences on cervical length, shape, and changes.

### MATERIALS AND METHODS

This study is a secondary analysis of the 'Mid-trimester endovaginal sonography in women at high risk for spontaneous preterm delivery' study (Cervical Ultrasound Study) (CRVUS) of the Maternal-Fetal Medicine Units (MFMU) Network. The goal of the study was to determine the predictive value of longitudinal cervical sonographic data collected prior to 24 weeks in predicting spontaneous preterm birth at <35 weeks' gestation, including for cervical characteristics other than length. The study has been described in detail previously.<sup>1</sup> 187 participants were recruited between 1997 and 1999 from nine sites (University of Alabama, Wayne



- Scientific Vision
  - Alleviate suffering from childhood cancer and structural birth defects by fostering **collaborative research** to uncover the etiology of these diseases and supporting **data sharing** within the pediatric research community.
  - Tens of thousands of whole genome sequences
- Kids First Data Resource
  - A platform for empowering collaborative pediatric research
  - Query, search, discover, build & visualize synthetic cohorts
  - Model clinical data in FHIR-based data services for semantic interoperability and coordination
  - Data visualization tools
  - Pull data from multiple sources into one workspace.



# Impact: Kids First Sequencing Cohorts 2015-2019

39 projects | 37,000 WGS | 15,000 cases | 13 released datasets | >150 Data Access Requests



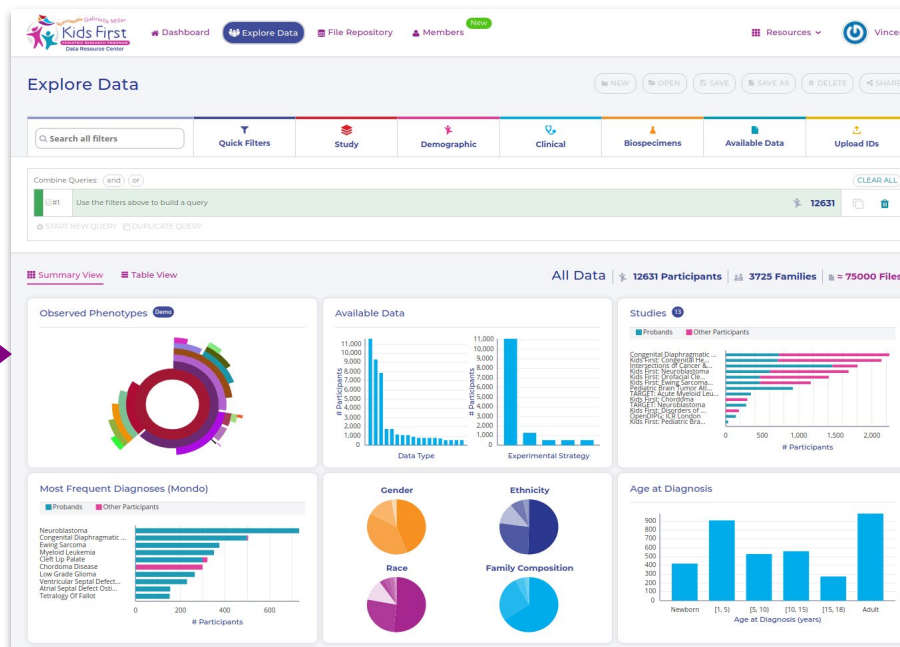
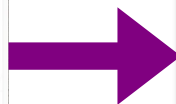
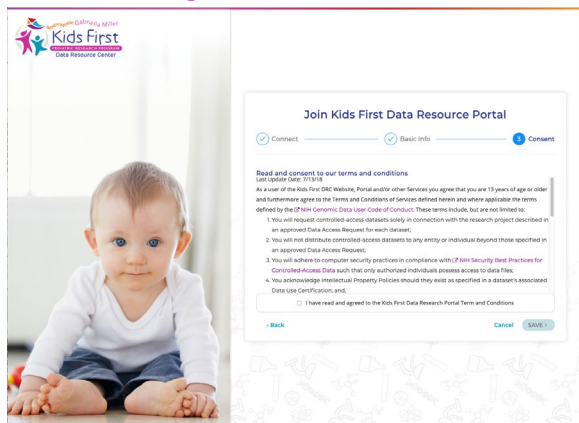
- Congenital Diaphragmatic Hernia
- Disorders of Sex Development
- Ewing Sarcoma
- Structural Heart & Other Defects
- Syndromic Cranial Dysinnervation Disorders
- Cancer Susceptibility
- Adolescent Idiopathic Scoliosis
- Neuroblastomas
- Enchondromatoses
- Orofacial Clefts in Caucasian, Latin American, Asian & African, Filipino populations
- Osteosarcoma
- Familial Leukemia
- Craniofacial Microsomia
- Hemangiomas, Vascular Anomalies & Overgrowth
- Nonsyndromic Craniosynostosis
- Patients with both childhood cancer and birth defects
- Kidney and Urinary Tract Defects
- Microtia
- Hearing Loss
- Bladder Exstrophy
- Cornelia de Lange Syndrome
- Intracranial & Extracranial Germ Cell Tumors
- Esophageal Atresia and Tracheoesophageal Fistulas
- Fetal Alcohol Spectrum Disorders
- Myeloid Malignancies + overlap with Down syndrome
- Congenital Heart Defects and Acute Lymphoblastic Leukemia in Children with Down Syndrome
- Structural Brain Defects
- Structural Defects of the Neural Tube (Spina Bifida: Myelomeningocele)
- CHARGE Syndrome
- Laterality Birth Defects
- T-cell Acute Lymphoblastic Leukemia
- Pediatric Rhabdomyosarcoma





# Data Resource Use Case: Compare genetic variants of congenital heart defects & neuroblastoma

Anyone can register & login to the portal (via ORCID, Google). User agrees to [terms](#)



In *Explore Data*, user searches the terms "heart" and "neuroblastoma". Discovers data from children with congenital heart disease (KF & BDC data) & neuroblastoma (KF & NCI TARGET)



User builds a synthetic cohort based on these criteria and can view summary & deidentified individual-level clinical, demographic, and phenotypic information.

Synthetic cohort is ported to the *File Repository* where user selects which **genomic** and **histology image** files they want to analyze.

File ID	Participants ID	Study Name	Proband	Family ID	Data Type	File Format	File Size
GF_W08BKSH	PT_8E1A9K7	Congenital Diaphra...	No	FM_Q085FM8	Aligned Reads	cram	15.53 GB
GF_B733C7YV	PT_9F7516RP	Congenital Diaphra...	No	FM_LAD0N9S3	gVCF	gVCF	4.3 GB
GF_P7YBTQZ3	PT_2P185ZYW	Congenital Diaphra...	No	FM_TCD4HEP	gVCF	gVCF	5.94 GB
GF_R0AQ4C45	PT_SVX08RA	Congenital Diaphra...	No	FM_B8TD4XF	gVCF	gVCF	4.91 GB
GF_T0P0IQ71	PT_V0C44N7	Congenital Diaphra...	Yes	FM_33M1YDM	Aligned Reads	bam	63.33 GB
GF_V0031CSX	PT_RV006ACA	Congenital Diaphra...	Yes	FM_TTQ2YWR1	gVCF	gVCF	5.37 GB
GF_88EMPER	PT_SV93767	Congenital Diaphra...	No	FM_S8PGRV3	Aligned Reads	cram	16.87 GB
GF_GV813YN	PT_4Z8VQDM	Congenital Diaphra...	Yes	FM_HFQCRV6	Aligned Reads	bam	63.74 GB
GF_S4VXAGW	PT_PV92628	Congenital Diaphra...	No	FM_DCC2C065	Aligned Reads	cram	20.77 GB
GF_RV3W522X	PT_Q0Q3MBPM	Congenital Diaphra...	Yes	FM_G52D0HE	Aligned Reads	bam	63.31 GB
GF_Q0QNXK5H	PT_2BHM8D7	Congenital Diaphra...	No	FM_TVCDVDR	Aligned Reads	cram	26.62 GB
GF_F8B15QRD	PT_Q031MEW3	Congenital Diaphra...	No	FM_PYQV8Q2	Aligned Reads	bam	44.63 GB
GF_FNM00566	PT_D7867KQ2	Congenital Diaphra...	Yes	FM_4K00D4FW	Aligned Reads	cram	20.26 GB

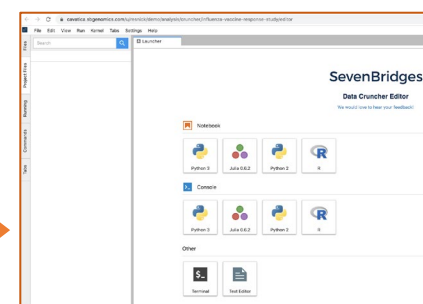
User has or applies for dbGaP access for genomic data



User pushes genomic, clinical data, and image data into Cavatica for analysis &

Name	Case ID	Sample ID
TARGET-00e47068-3d0c-4b3d-ba10-8371a1d33bc.bam	TARGET-30-PAPVEB	TARGET-30-PAPVEB-04A
KIDS-FIRST-01102766-e26e-4396-850f-3c70d89a8dbb.cram	PT_T4BK7XD1	BS_7TWWV1Y9
KIDS-FIRST-01850ccc-0993-4936-8ba6-d8751b04afe9.cram	PT_J8K6ETOG	BS_D8F885M2
KIDS-FIRST-018e6dfc-1a7e-475b-a451-9c3b2bdf11c3.cram	PT_PSYSYSZ4	BS_CCGFJW3A
TARGET-01cd7d9d-4d5d-4c0d-844d-748394d6da96.bam	TARGET-30-PASWJU	TARGET-30-PASWJU-01A
TARGET-02a86e96-346e-4ffe-bada-23b1823416b6.bam	TARGET-30-PASWYR	TARGET-30-PASWYR-01A
KIDS-FIRST-02d2de68-a5db-4c7e-a196-58d302d14d95.cram	PT_8B4J3FRQ	BS_SVJPNAF2

User runs statistical analysis in notebooks



User iterates through genomic workflows



**COVID-19**

## Milestone highlights

*Rapid Standup & Execution*

### EARLY APRIL

FNIH (Foundation for the NIH) collaborates with NIH to launch the Accelerating COVID-19 Therapeutic Interventions & Vaccines (ACTIV) Public-Private Partnership

### EARLY JUNE

Ramp-up of additional Rapid Acceleration of Diagnostics (RADx<sup>SM</sup>) programs

### EARLY JULY

RADx Data Hub effort and RADx<sup>SM</sup>-ATP program kick off

### LATE JULY

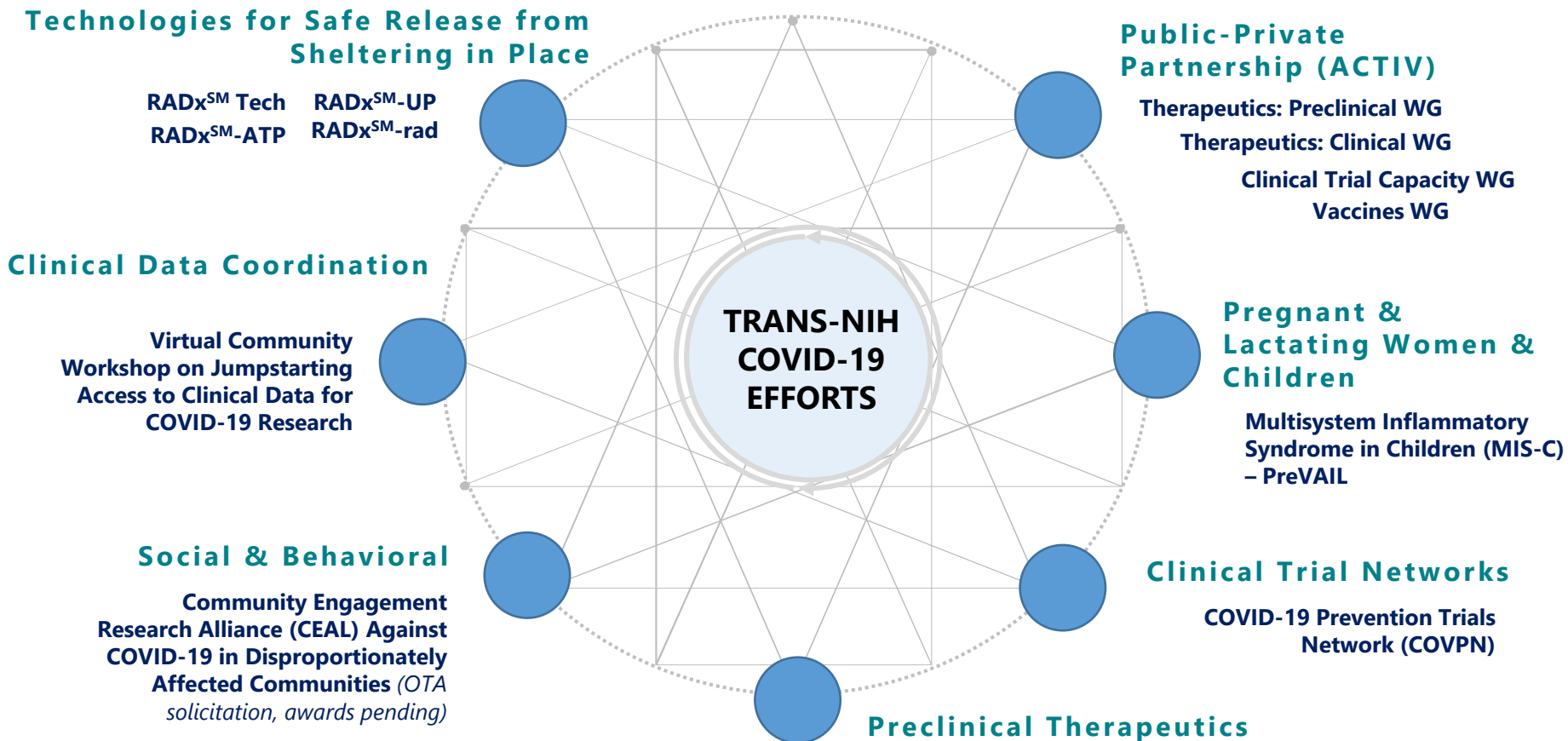
Jumpstarting Access to Clinical Data for COVID-19 Research Virtual Workshop

### EARLY AUGUST

Kickoff of increased focus on community engagement efforts & PreVAIl announced

# TRANS-NIH COVID-19 EFFORTS

In response to COVID-19, NIH has **multi-IC collaborative** efforts to address interdisciplinary challenges associated with the pandemic



These efforts directly support the NIH's **Strategic Priorities** outlined in its **Strategic Plan for COVID-19 Research**:

Improve Fundamental Knowledge	•	Advance Research to Improve Detection	•	Support Research to Advance Treatment	•	Accelerate Research to Improve Prevention	•	Prevent and Redress Poor COVID-19 Outcomes
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## **COVID-19: Research Goals for Pediatric Population**

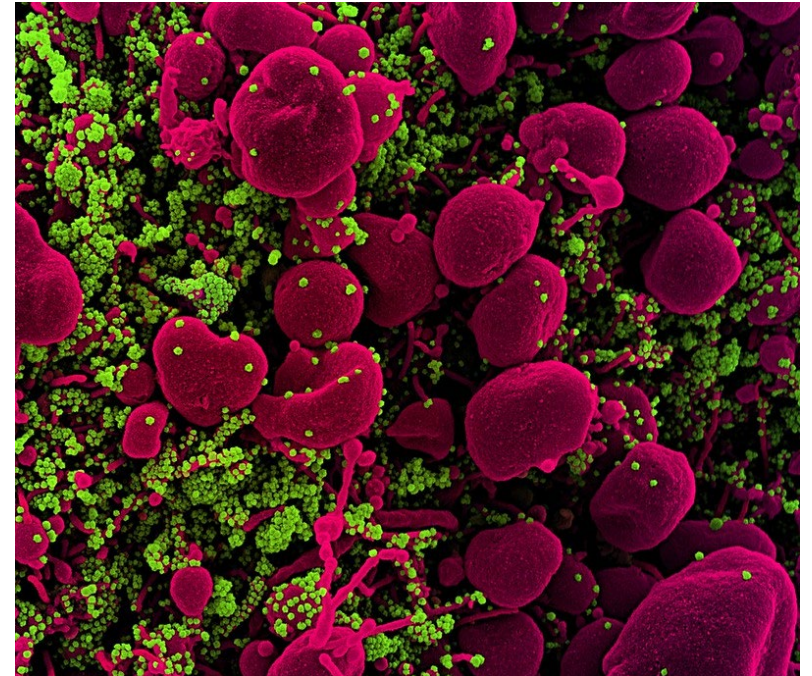
- **Understand the range of clinical manifestations of SARS-CoV-2/COVID-19**
- **Understand the etiology and clinical manifestations of MIS-C**
- **Determine the risk profile for patients that develop**
  - **MIS-C**
  - **Severe COVID-19**
- **Understand the variations in immune response underlying the wide range of clinical manifestations in children infected with SARS-CoV-2, and identify predictive and prognostic immune biomarkers**
- **Understand long-term consequences of SARS-CoV-2, COVID-19, and MIS-C**



# COVID-19: NICHD's Goals and Objectives

We are working to accelerate research and better understand the impact of COVID-19 infection on pregnant and lactating women, children, and people with intellectual, developmental, and physical disabilities.

- Engaged across NICHD to advance scientific understanding of SARS-CoV-2 and COVID-19:
  - **Identifying existing opportunities in our networks and intramural laboratories**
  - **Participating in trans-NIH funding opportunities and notices of special interest**
  - **Working with the Department of HHS and our federal colleagues to address emerging concerns**





# **Maternal Morbidity and Mortality**

# Increased Congressional Interest in Maternal Health



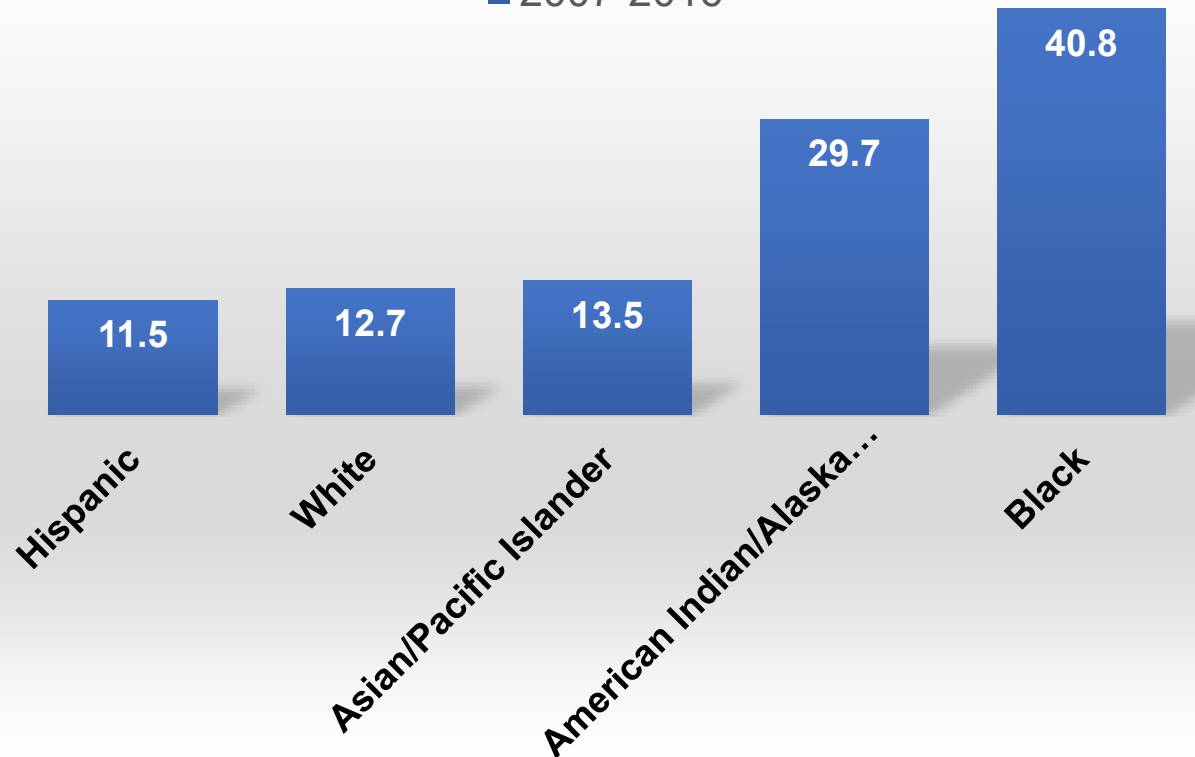
December 11, 2019



# Significant Health Disparities Exist in Maternal Mortality

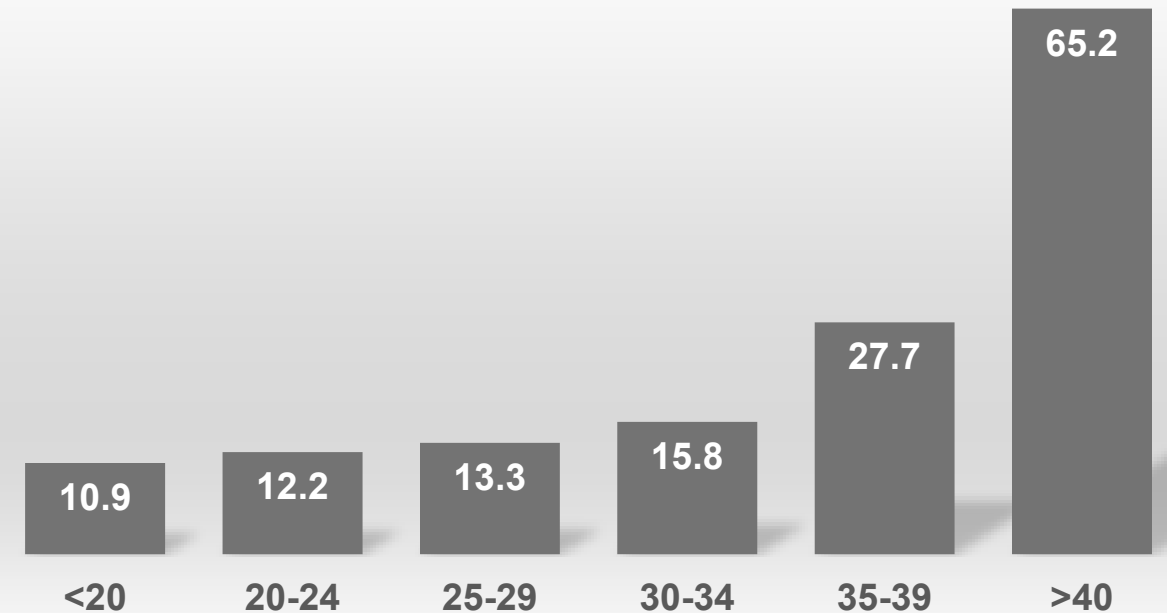
Deaths per 100,000 live births

■ 2007-2016



Deaths per 100,000 live births

■ Age





# Maternal Mortality

700-900 maternal deaths: **60% are preventable**

~50,000 near misses

~400,000 women with  
co-occurring conditions



~6.3 million  
pregnancies  
per year  
in the U.S.



# Implementing a Maternal health and PRegnancy Outcomes Vision for Everyone (IMPROVE) Initiative

- Trans-NIH initiative that is in development
- Encompasses both foundational biology as well as social and biobehavioral research
- Community partners will be key voices to assess needs and to implement interventions



# Summary

- Many reasons for optimism
  - Bipartisan support for NIH and medical research
  - Recent increases in NIH budget over past three years
  - Better paylines for Early Stage Investigators
- Many opportunities to immediately start your research career using publicly available data and specimens
- Information on NICHD extramural branch priorities is available on our web site. Make use of it!
- Opportunities for research careers outside of traditional academic PI exist
  - NIH intramural research (basic and clinical)
  - NIH extramural program administration



**Thank You!**