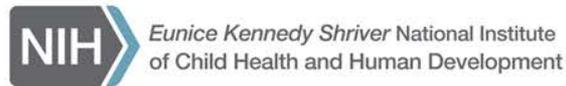


A Vision for the Future of NICHD

Diana W. Bianchi, M.D.
Director, NICHD





Humbled to be at the Helm of This Great Organization

- Passionate advocate for NICHD
- Of my 43 funded project-years in RePORT database, 41 funded by NICHD
- Participant and moderator in VISION process 2010
- Participant and moderator in HPP workshops



Advisory Council Member 2012-2016



Core Values

- **Maintain a High Standard of Excellence**
- **Promote Transparency**
- **Time to Listen, Learn and Think**
- **“Vision”=Observations, Suggested Path Forward**



A Time of Transition in the US

From the “Greatagain.gov” website:

- **Protect individual conscience in healthcare**
- **Protect innocent human life from conception to natural death, including the most defenseless and those Americans with disabilities**
- **Advance research and development in healthcare**
- **Reform the Food and Drug Administration, to put greater focus on the need of patients for new and innovative medical products**
- **Modernize Medicare, so that it will be ready for the challenges with the coming retirement of the Baby Boom generation – and beyond**
- **Maximize flexibility for States in administering Medicaid, to enable States to experiment with innovative methods to deliver healthcare to our low-income citizens**

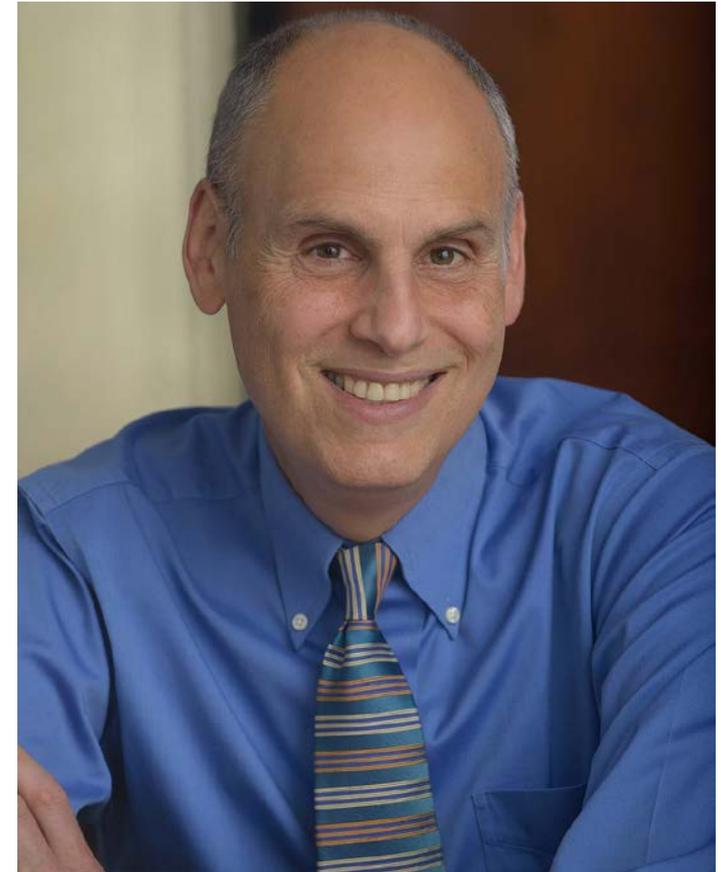




Standing on the Shoulders of Giants

The Guttmacher Era 12/2009-9/2015

- **Conceived of and Completed the NICHD Visioning Process**
- **Reorganized NICHD**
 - DER, PTCIB, GHDB,
 - OD, OSPRA, OC
- **National Children's Study**
 - Human Placenta Project
 - ECHO
 - IDeA States Pediatric Network
- **PregSource™ Data App**





A Huge Thanks to Cathy Spong!

Interim Director 10/2015-11/2016



- **Developed a coordinated effort re Zika in pregnancy**
- **Improved payline!**
- **Completed relocation to 6710B Rockledge Drive**
- **Worked with Della Hann to establish extramural branch priorities**
- **Worked with Alison Cernich to complete NIH Medical Rehabilitation Plan**
- **Finalized restructuring of the Office of the Director**
- **Review of the Office of Health Equity**



My Vision for NICHD-I

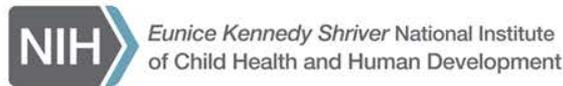
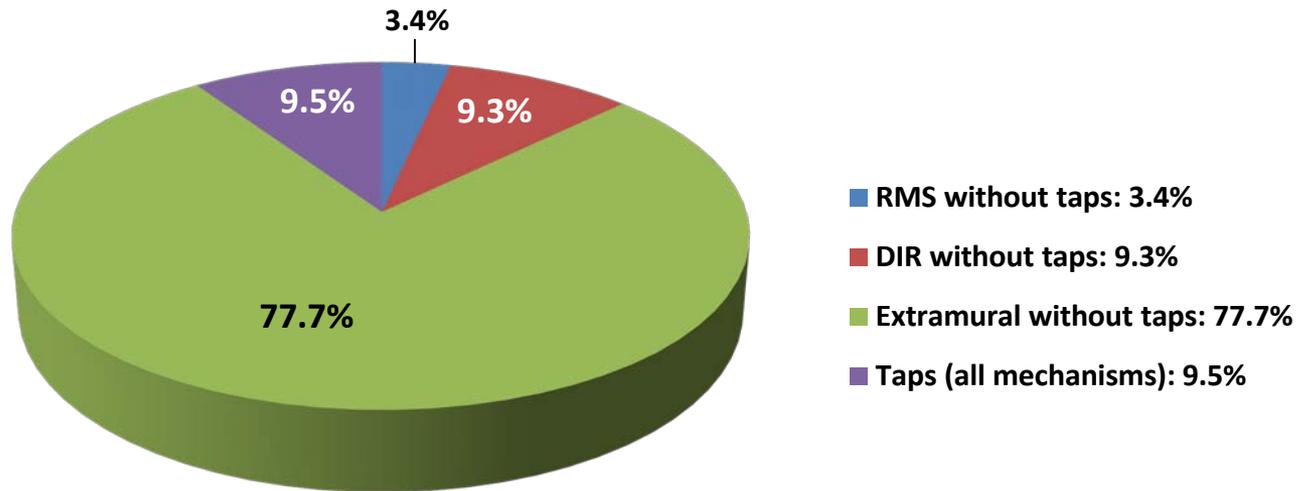
- **Define “our brand” (what is our focus?)**
 - **Communicate the message**
- **Listen to the Voice of the Patient**
- **Integrate obstetrics and pediatrics research at NICHD; take the long view (DoHaD)**
- **Advocate for personalized medicine in pediatrics, obstetrics and rehabilitative medicine**
- **Build bridges between other NIH Institutes – especially NHGRI and NICHD**



My Vision for NICHD-II

- **Stress the importance of data science and sharing to leverage our investments**
- **Analyze best way to identify trainees most likely to succeed**
- **Increase access to clinical trials for pediatric and obstetric patients, extramurally and intramurally**
- **Catalyze innovation**
- **Emphasize the “A” (for “Advice”) in the Advisory Council**

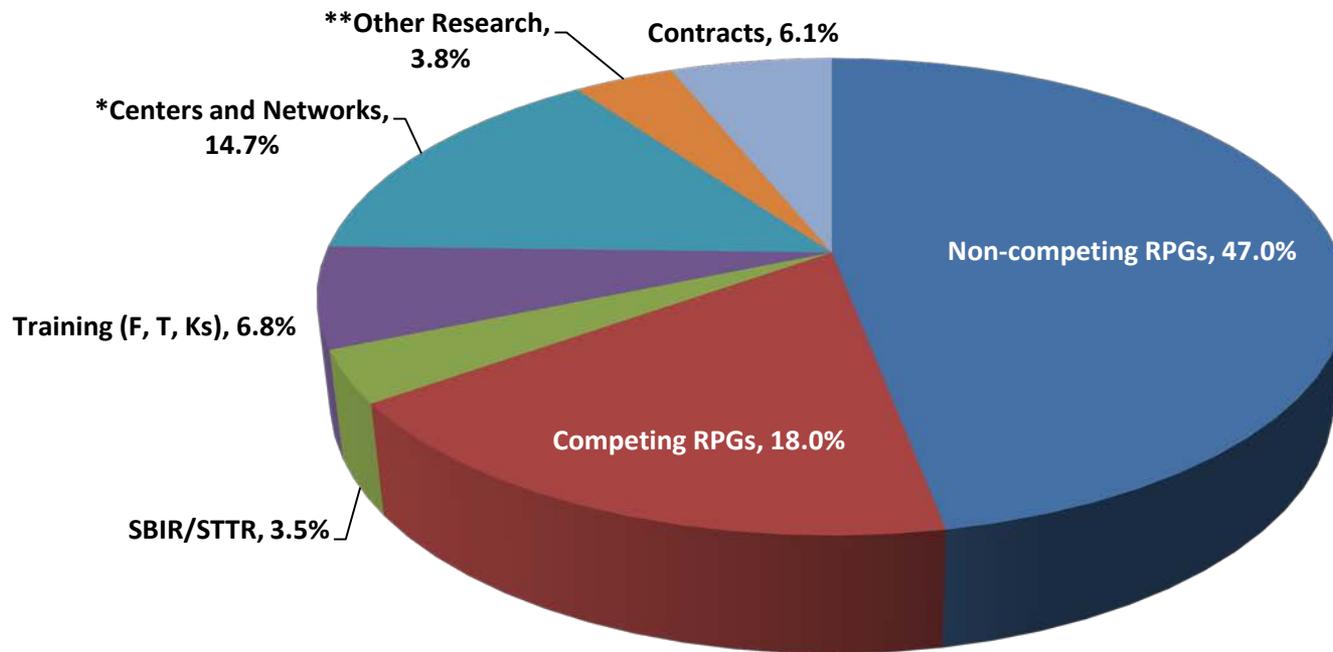
Show Us The Money: FY2016 NICHD Direct Appropriations \$1.338 Billion Total



Extramural Total= \$1.04B
Intramural Total = \$124M
RMS Total= \$45M
Taps= \$127M



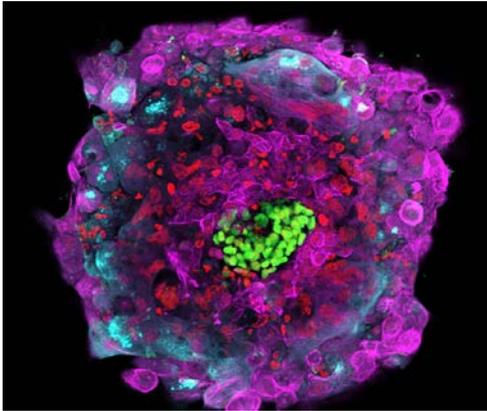
FY2016 NICHD Direct Appropriations Extramural Only



- ***Select contracts supporting networks included in Centers and Networks**
- **** Other Research – G11, U13, R13, R24, R25, P2C, U24 and T15 (+others)**



A Vision for NICHD's Future



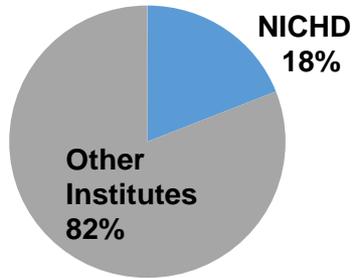


Define Our Brand

- **Refine or Redefine who we are**
- **Communicate the message**
- **Advocacy**



What's In a Name?



Eunice Kennedy Shriver
**National Institute of Child Health and
Human Development**





Institute Tag Lines

- **NINR**: “Building the scientific foundation of clinical practice”
- **NHGRI**: ”Advancing human health through human genomics research”
- **NIEHS**: “Your environment. Your health”
- **NIBIB**: “Creating biomedical technologies to improve health”
- **NIMH**: “Transforming the understanding and treatment of mental illness”
- **NEI**: “Research today. Vision tomorrow”
- **NICHD**: “Health research across the lifespan”



History of Our Mission

". . . We will look to the National Institute of Child Health and Human Development for a concentrated attack on the unsolved health problems of children and of mother-infant relationships. This legislation will encourage imaginative research into the complex processes of human development from conception to old age. . . For the first time, we will have an institute to promote studies directed at the entire life process rather than toward specific diseases or illnesses."

—John F. Kennedy, October 17, 1962



Focus on Human Development?

Zika virus infection

Opportunity to understand mechanisms of birth defects



Effects on male fertility?

Long-term effects on child health

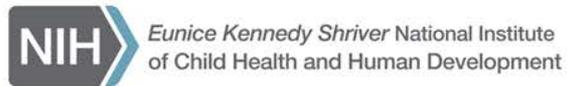
Intellectual and physical disabilities



Conclusions of the 1961 Task Force

The task force members called for the founding of a "centralized unit," whose sole purpose was to launch concentrated research into disorders of human development, including intellectual and developmental disabilities (IDDs). The plan included three parts: the development of university-affiliated facilities to train personnel to help care for people with IDDs, the construction of 12 IDD research centers on university campuses to provide facilities and a focus for research, and the establishment of a new Institute within the NIH to conduct and support research on human development and developmental disabilities.

Communicate the Message





Updating the NICHD Website

- **Of major strategic importance with regard to communicating our mission and achievements to a variety of stakeholders**
 - “Our business card to the world”
- **Pew data regarding mobile technology: no disparities**
- **Goal is to improve search functions, design/layout, navigation, management and maintenance, optimize for Google et al.**
- **Introduce new features that highlight NICHD’s scientific contributions, including clinical trial data**
- **Will ask for your help in ensuring content accuracy**

Draft Web Site Design



US Department of Health and Human Services | National Institutes of Health

Directory | Follow     

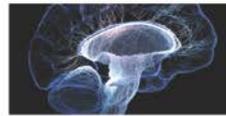


 Browse A-Z

[Research](#) [Health Topics](#) [Grants & Contracts](#) [Clinical Trials](#) [Newsroom](#) [About NICHD](#)

1 in every 33 infants born in the U.S. has a birth defect

[Learn about common types, risks, and treatments](#)



Childhood brain injury linked to adult psychiatric illness, earlier death



FACT: A Flu Shot is more important for pregnant women



Research Resource: Check Out DASH, the NICHD Data and Specimen Hub

Featured



SAFE TO SLEEP®

Learn from leading research of Sudden Infant Death Syndrome. Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.



REHABILITATION RESEARCH AT NIH

Moving the field forward. Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.

Director's Corner



GETTING TO KNOW THE NEW NICHD DIRECTOR

Diana W. Bianchi, M.D., Director

[Bookshelf](#)

Funding Opportunities

Active Funding Announcements
Small Business Programs
Lorem ipsum dolor

Grant Information

Peer Review
Sample Applications
Qui accusamus



Division of Extramural Research (DER)



Division of Intramural Research (DIR)



Division of Intramural Population Health Research (DIPHR)



National Center for Medical Rehabilitation Research (NCMRR)

CONTACT US

NEWSROOM

News Releases
NICHD in the News
Videos

PUBLICATIONS

OUTREACH

Safe to Sleep®
The National Child & Maternal Health Education Program

SITEMAP

RELATED WEBSITES

NIH.gov
HHS.gov
USA.gov
ClinicalTrials.gov



WEBSITE POLICIES

Disclaimer
FOIA
Privacy Policy
Accessibility

The Importance of Advocacy



Friends of NICHD

Supporting the Eunice Kennedy Shriver

National Institute of Child Health and Human Development



Listen to the Voice of the Patient



Patient Advocacy Groups at NIPT Stakeholder Meeting July 2015

NIH
ORDRINCATS, NCI, NHLBI,
NIAID, NIAMS, NICHD, NIDCR,
NIDDK, NIMH, NINDS, ODS

Dystonia Coalition

Coalition of Patient Advocacy Groups

Porphyria Rare Disease Clinical Research Consortium

North America Mitochondrial Diseases Consortium

Primary Immune Deficiency Treatment Consortium

Brittle Bone Disorders Consortium

Chronic Graft Versus Host Disease

The Data Management and Coordinating Center

Urea Cycle Disorders Consortium

Brain Vascular Malformation Consortium

Genetic Disorders of Mucociliary Clearance

Consortium of Eosinophilic Gastrointestinal Disease Researchers

Rett, MECP2 Duplications and Rett-Related Disorders Consortium

Sterol and Isoprenoid Diseases Consortium

Autonomic Disorders Consortium

Developmental Synaptopathies Associated with TSC, PTEN And SHANK3 Mutations

The Frontotemporal Lobar Degeneration Clinical Research Consortium

Inherited Neuropathies Consortium

Nephrotic Syndrome Study Network

Rare Lung Diseases Consortium

Lysosomal Disease Network

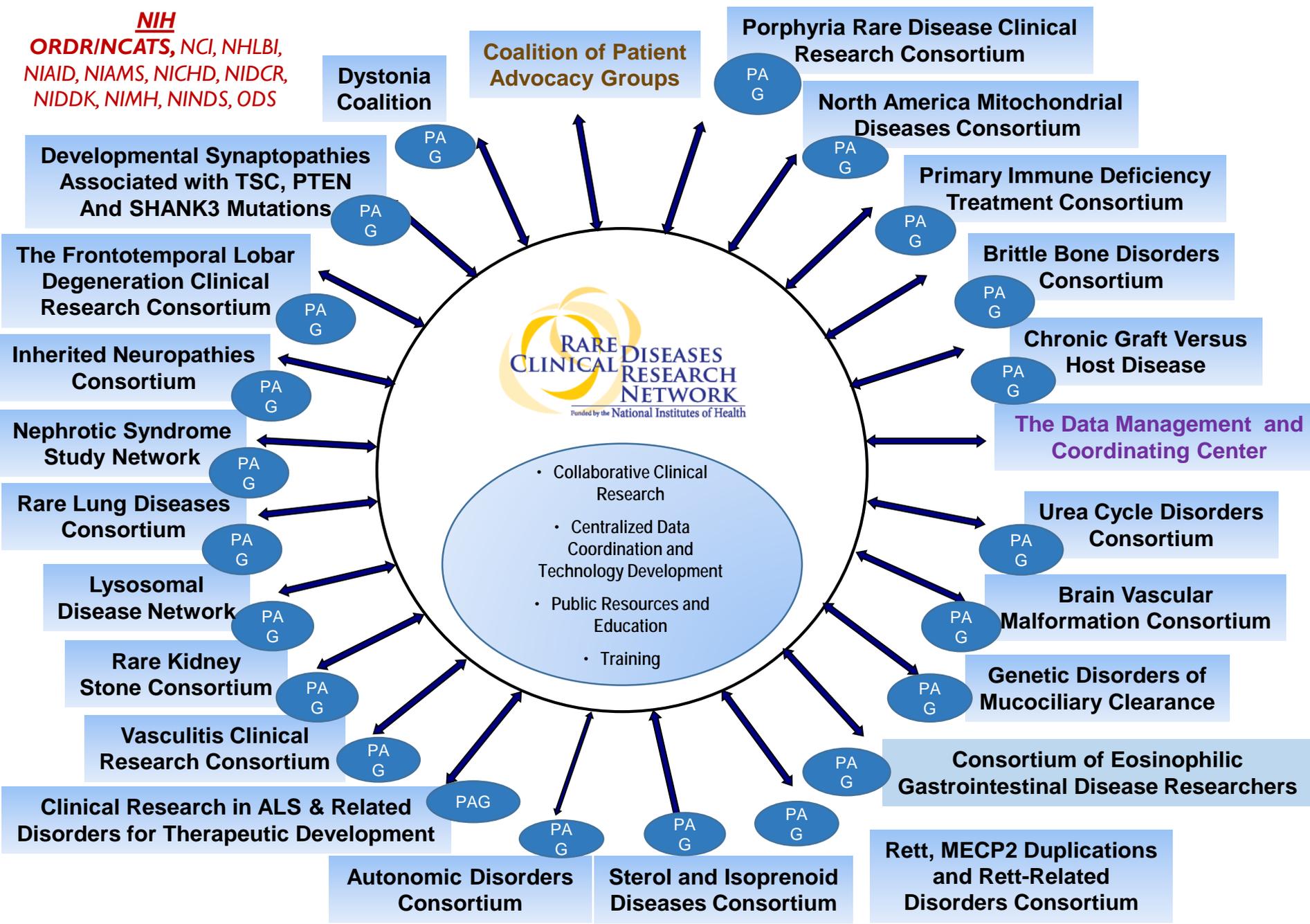
Rare Kidney Stone Consortium

Vasculitis Clinical Research Consortium

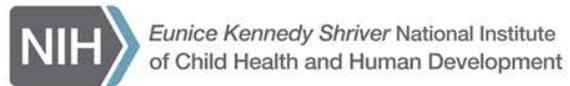
Clinical Research in ALS & Related Disorders for Therapeutic Development



- Collaborative Clinical Research
- Centralized Data Coordination and Technology Development
- Public Resources and Education
- Training



Building Bridges





Integrate Obstetrics and Pediatrics Research at NICHD



Eunice Kennedy Shriver
National Institute of Child Health and Human Development
Maternal-Fetal Medicine Units Network

Home History Network Centers Research Projects Datasets Members Only VBAC Calculator

mfmunetwork / Home

The National Institute of Child Health and Human Development (NICHD) created the Maternal-Fetal Medicine Units (MFMU) Network in 1986 to focus on clinical questions in maternal-fetal medicine and obstetrics, particularly with respect to the continuing problem of preterm birth.

Operating under cooperative agreements, the current Network is comprised of fourteen university-based clinical centers and a data coordinating center. More than 45 randomized clinical trials, cohort studies and registries have been completed or are in progress.



Vision Statement

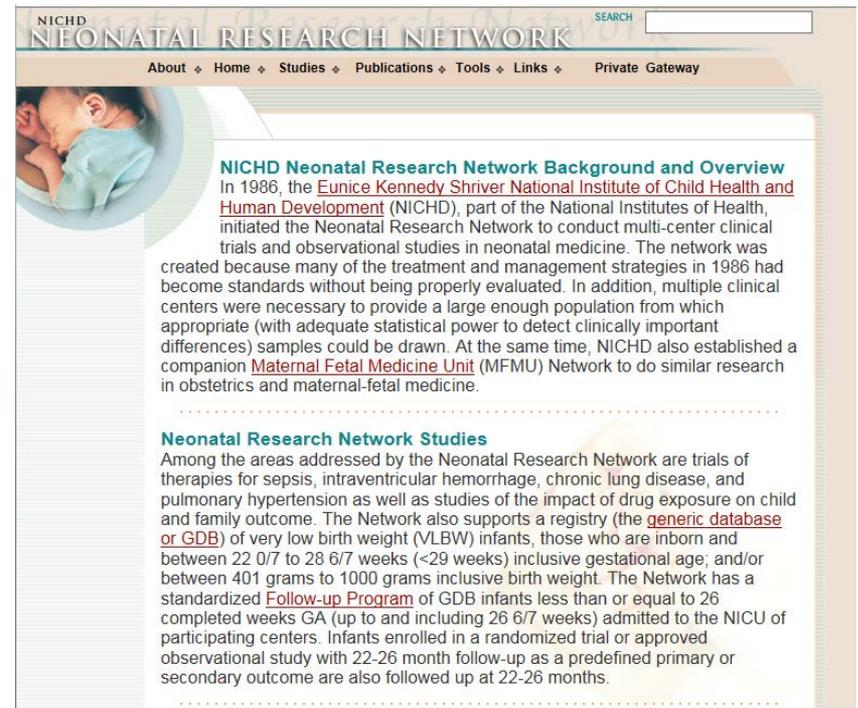
The MFMU Network is designed to conduct perinatal studies to improve maternal and fetal outcomes. Greatest emphasis and priority are given to randomized-controlled trials, followed by observational studies.

The major aims of the Network are to:

- Reduce the rates of preterm birth, fetal growth abnormalities, neurologic sequelae of the newborn, and maternal complications of pregnancy
- Evaluate maternal and fetal interventions for efficacy, safety, and cost-effectiveness

Included in these aims are:

- Translational research
- The use of genetics
- The evaluation of new technologies in the promotion of maternal-child health/prevention of disease



NICHD NEONATAL RESEARCH NETWORK

About Home Studies Publications Tools Links Private Gateway



NICHD Neonatal Research Network Background and Overview

In 1986, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), part of the National Institutes of Health, initiated the Neonatal Research Network to conduct multi-center clinical trials and observational studies in neonatal medicine. The network was created because many of the treatment and management strategies in 1986 had become standards without being properly evaluated. In addition, multiple clinical centers were necessary to provide a large enough population from which appropriate (with adequate statistical power to detect clinically important differences) samples could be drawn. At the same time, NICHD also established a companion [Maternal Fetal Medicine Unit \(MFMU\)](#) Network to do similar research in obstetrics and maternal-fetal medicine.

Neonatal Research Network Studies

Among the areas addressed by the Neonatal Research Network are trials of therapies for sepsis, intraventricular hemorrhage, chronic lung disease, and pulmonary hypertension as well as studies of the impact of drug exposure on child and family outcome. The Network also supports a registry (the [generic database or GDB](#)) of very low birth weight (VLBW) infants, those who are inborn and between 22 0/7 to 28 6/7 weeks (<29 weeks) inclusive gestational age; and/or between 401 grams to 1000 grams inclusive birth weight. The Network has a standardized [Follow-up Program](#) of GDB infants less than or equal to 26 completed weeks GA (up to and including 26 6/7 weeks) admitted to the NICU of participating centers. Infants enrolled in a randomized trial or approved observational study with 22-26 month follow-up as a predefined primary or secondary outcome are also followed up at 22-26 months.

12 Sites Enrolling Participants

15 Sites Enrolling Participants

8 Sites Have Both Networks

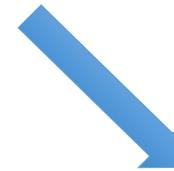
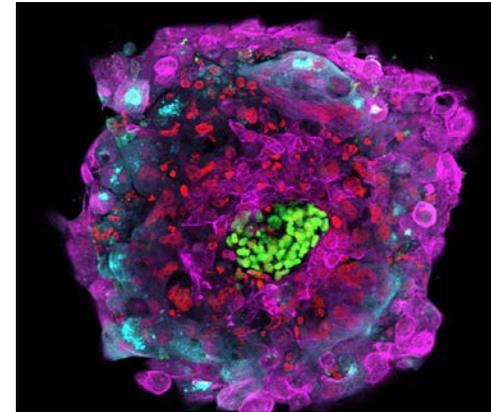
(UAB, Brown, Case, UT Houston, U Penn, U Utah, UNC and Ohio State)



Increase Synergies Within NICHD



Trans-Disciplinary



**Translational
Intramural-Extramural**

**Amini et al. Orthodont
Craniofacial Res 2007**



Ensure Representation of NICHD Populations in Trans-NIH Initiatives



- One-on-one meeting with Eric Dishman, Director and former VP at Intel
- Stephanie Devaney, PhD, Deputy Director, speaking today
 - Pregnant women can be enrolled in Phase I
- Adults with intellectual disabilities can be enrolled once consent issues have been clarified



Build Bridges With Other Institutes



- **New Lab at NHGRI**
- **New Section Called “Prenatal Genomics and Therapy”**
- **Speaking at NHGRI Council**





Examples of NHGRI-NICHD Collaborations

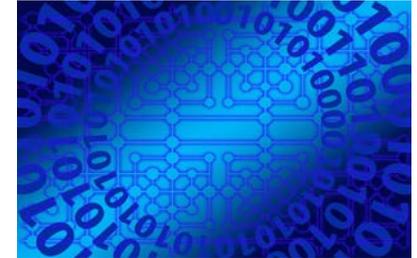


Newborn **S**equencing
In **G**enomic
medicine and public
Hea**l**th (**NSIGHT**)
program





Importance of Data Science and Shared Resources



Study Catalog Study Data Feedback Submissions Resources

Create an Account User Login



New to DASH?

First time users are encouraged to review the DASH Tutorial, which provides an overview of DASH and the instructions for using it.

[Find Out More](#)



Explore DASH Study Catalog

Explore DASH studies and access individual study overview pages from the Catalog.

[Find Out More](#)



Share your Data

Learn about the requirements and review instructions for submitting data to DASH.

[Find Out More](#)



Have Questions?

Browse through the Frequently Asked Questions (FAQs) to get answers to questions about accessing DASH, user accounts, submitting, searching and requesting data.

[Find Out More](#)

National Library of Medicine Task Force



Fetal Growth Calculator as a Shared Resource

US Department of Health and Human Services | National Institutes of Health

NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development
Health research throughout the lifespan

Enter Search Text Here SEARCH

Connect with us: [f](#) [t](#) [p](#) [i](#) [r](#)

Health & Research | Grants & Funding | Training, Education & Career Development | News & Media | About NICHD

Home > About NICHD > Organization [Email Page](#) [Print Page](#)

About NICHD

Institute Overview

Organization

- [Organization Charts](#)
- [Office of the Director \(OD\)](#)
- [Division of Extramural Research \(DER\)](#)
- [Division of Intramural Research \(DIR\)](#)
 - [Division of Intramural Population Health Research \(DIPHR\)](#)
 - [Office of the Director \(OD\)](#)
 - [Biostatistics and Bioinformatics Branch \(BBB\)](#)
 - [Epidemiology Branch \(EB\)](#)
 - [Health Behavior Branch \(HBB\)](#)
- [National Center for Medical Rehabilitation Research \(NCMRB\)](#)

Budget & Appropriations

Advisory Groups

FOIA

Jobs at NICHD

Meetings, Conferences & Events

Partnering & Donating to the NICHD

Staff Directory

Estimated Fetal Weight (EFW) Calculator

Share this: [f](#) [t](#) [p](#) [i](#)

Normal fetal growth is important not only for a healthy pregnancy, but also for ensuring health and well-being throughout childhood and adolescence. The [NICHD Fetal Growth Study](#), started in 2009, aims to set evidence-based standards for normal fetal growth and size for each stage of pregnancy. [Learn more about the study's findings.](#)

This calculator uses data from the NICHD Fetal Growth Study to estimate the weight of a single fetus between 15 weeks and 42 weeks of pregnancy. Unlike other estimation methods, the NICHD EFW calculator results take the mother's self-reported race/ethnicity into account.

Keep in mind that factors beyond those used to calculate EFW may affect an infant's birth weight. To use the calculator, enter information below, and select the CALCULATE button. Note that the more information you provide, the more accurate the results will be.

Estimated Fetal Weight Calculator

- Gestational Age**
Age of the pregnancy, in completed weeks and days
(Note: This tool is unable to estimate fetal weight for pregnancies younger than 15 weeks)
Weeks (15-41) Days (0-6)
- Mother's Race/Ethnicity**
- Biparietal Diameter (BPD)**
Distance between the two parietal bones of the fetal skull, in millimeters
 Millimeters
- Head Circumference (HC)**
Measurement of the fetal head at its widest, in millimeters
 Millimeters
- Abdominal Circumference (AC)**
Measurement of the fetal abdomen, in millimeters
 Millimeters
- Femur Length (FL)**
Length of the fetal thigh bone, in millimeters
 Millimeters



Last Reviewed: 04/22/2016

Home | Contact | Accessibility | Web Policies and Notices | EOIA

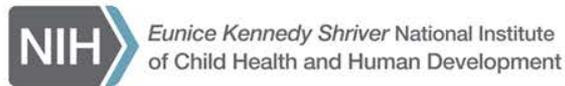
Facebook | Twitter | Pinterest | YouTube | RSS

NIH **USA.gov**

NIH... Turning Discovery Into Health®

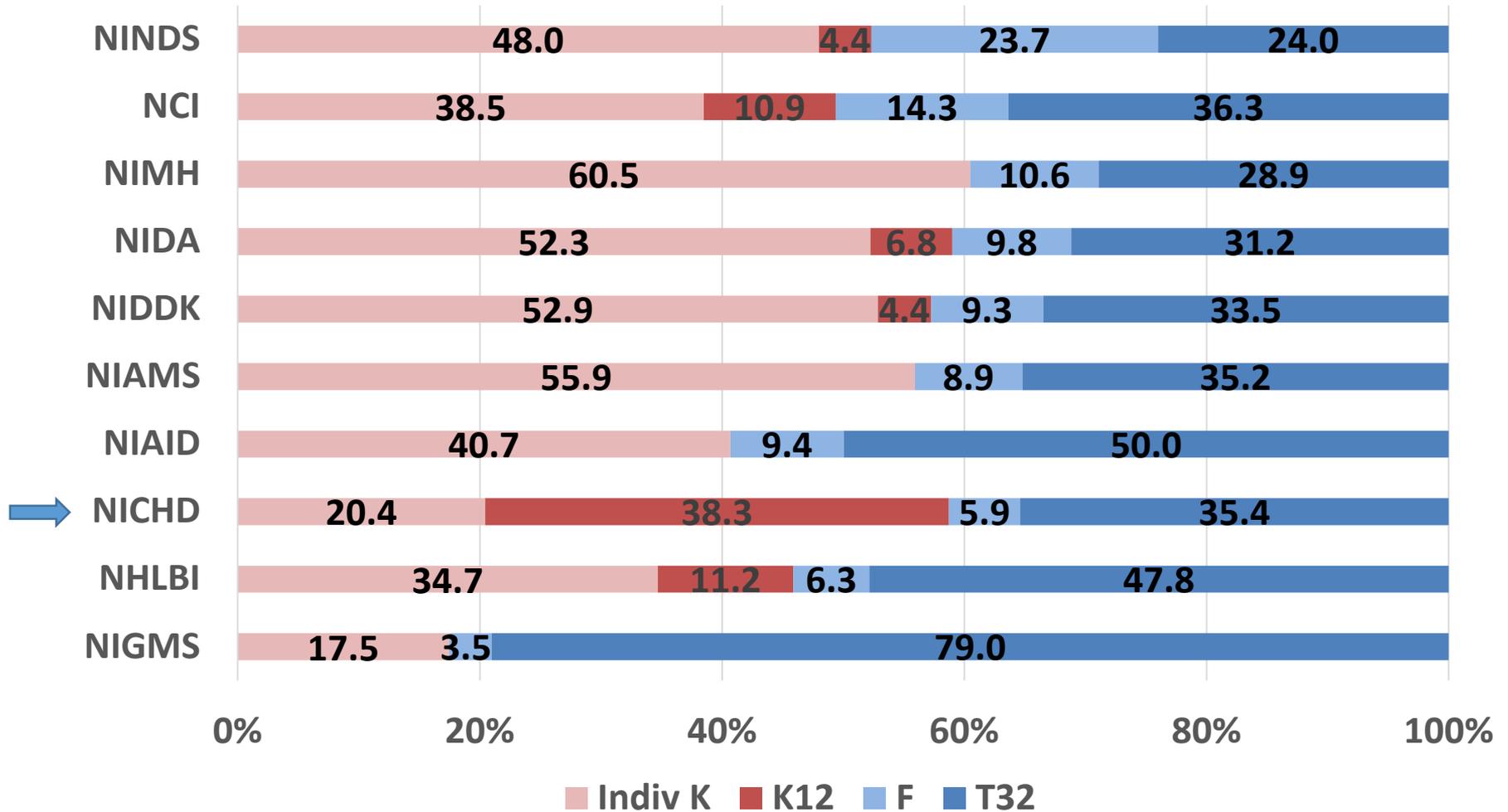
Courtesy of Division of Intramural Population Health Research

Investing Our Training Dollars in the People Most Likely to Succeed



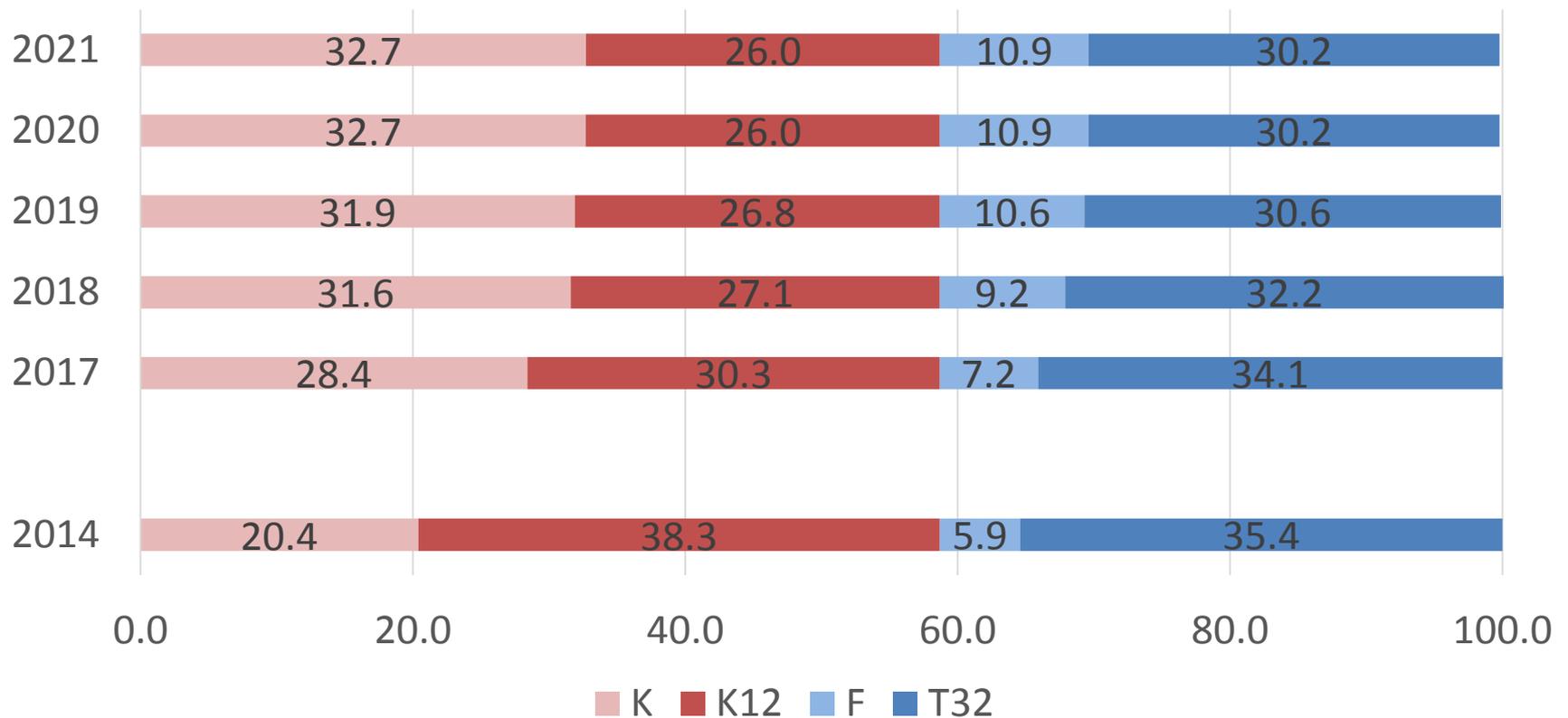


Relative % of Funds Committed to Individual vs. Institutional Training by NIH Institute (FY2014)





Anticipated Changes in Training and Career Development Spending by Group 2014-2021





Training, v.2

- **If we are going to emphasize individual training, how do we identify those individuals who are most likely to succeed?**
- **We need a scientific version of Moneyball**
- **Data from ABIM** (Marsh and Todd, Am J Med 2015)
 - **Predictors of long-term scientific engagement for clinician-scientists include prior graduate-level research training, any first author publications arising from pathway training, and receipt of an individual career development award.**
 - **Learners who become interested in research at the conclusions of a clinical fellowship are at a disadvantage**

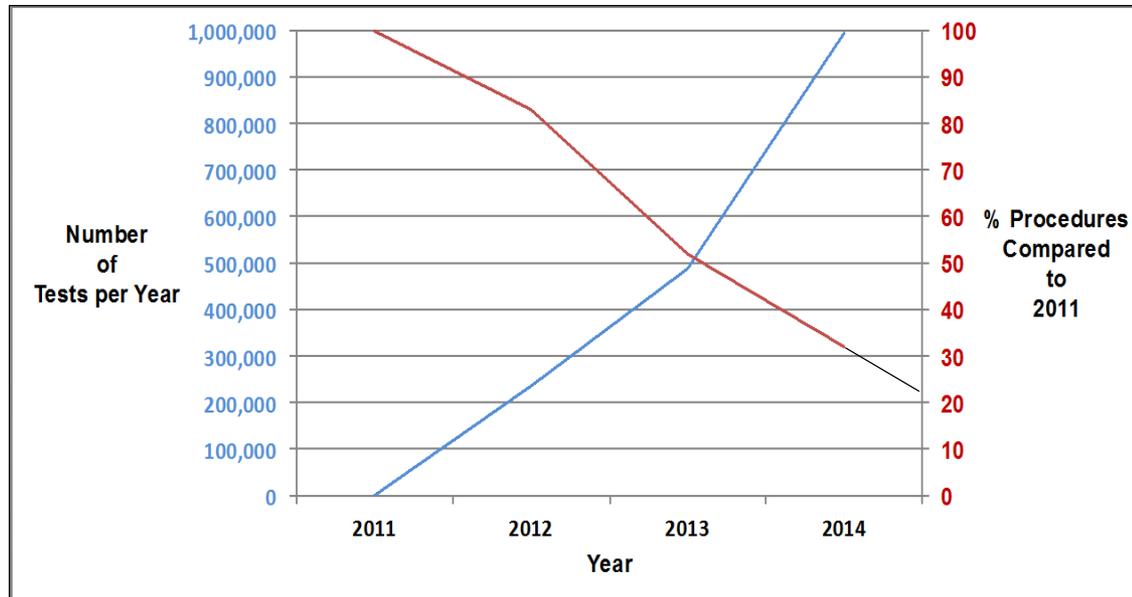


Clinical Trials and Clinical Research

- **IDeA States Pediatric Clinical Trials Network--
interventional**
- **Review of Clinical Trials Infrastructure**
- **Clinical Center**
 - **Determine what core pediatric services/consultants are necessary for the safe care**
 - **Currently no obstetric trials, no trials for children under age 3...should we change this?**
 - **What resources are needed?**



Catalyze Innovation



verifi™
prenatal test

Harmony™
PRENATAL TEST

natera™
Conceive. Deliver.

THE SCIENCE OF DELIVERING RESULTS CONFIDENTLY

0.9%
Lowest published non-reportable rate to date

MaterniT21 PLUS

NIFT®



Emphasize the “A” for Advice in the Advisory Council

- **Need to leverage the collective expertise and wisdom of this group**
- **Should we undergo a strategic planning process?**
 - **Analyze potential impact, probability of success, gaps in portfolio?**
- **What should be our funding priorities?**
 - **Difficult choices...the pie may not get bigger**
 - **How should we train physician-scientists?**
- **Are there strategic partnerships?**



Thank You and Questions?



Endocrinology and Metabolism Rotation at Clinical Center,
circa 1979