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
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

- Non-competing RPGs, 47.0%
- Competing RPGs, 18.0%
- SBIR/STTR, 3.5%
- Training (F, T, Ks), 6.8%
- *Centers and Networks, 14.7%
- **Other Research, 3.8%
- Contracts, 6.1%

*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”
"... 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

1 in every 33 infants born in the U.S. has a birth defect
Learn about common types, risks, and treatments.
The Importance of Advocacy
Listen to the Voice of the Patient

Patient Advocacy Groups at NIPT Stakeholder Meeting July 2015
Building Bridges
Integrate Obstetrics and Pediatrics Research at NICHD

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

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

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 Sequencing In Genomic medicine and public Health (NSIGHT) program
Importance of Data Science and Shared Resources

Welcome to the NICHD Data and Specimen Hub, a publicly accessible online archive

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.

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

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

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

National Library of Medicine Task Force
Fetal Growth Calculator as a Shared Resource

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)

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

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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
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