

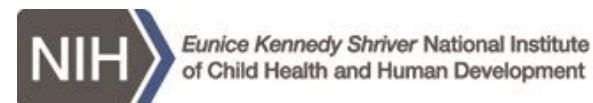
DIRECTOR'S REPORT



Alan E. Guttmacher, M.D.
Director, NICHD

**National Advisory Child Health and Human
Development Council**

June 4, 2015



What's To Come



- News from NIH
- News from NICHD
- Budget and legislative updates
- Discussion and Q&A

News from NIH



National Cancer Institute Changes



- Harold Varmus has stepped down as NCI Director



- Douglas Lowy is the Acting Director

NIMHD Director Announced



- Eliseo J. Pérez-Stable, M.D., has been named Director of the National Institute on Minority Health and Health Disparities
- Currently Professor of Medicine, Chief of the Division of General Internal Medicine and Director of the Center for Aging in Diverse Communities at UCSF
- Dr. Pérez-Stable to start in September



Precision Medicine Initiative (PMI)



THE PRECISION MEDICINE INITIATIVE



POTUS in SOTU



“I want the country that eliminated polio and mapped the human genome to lead a new era of medicine -- one that delivers the right treatment at the right time. In some patients with cystic fibrosis, this approach has reversed a disease once thought unstoppable. Tonight, **I’m** launching a new Precision Medicine Initiative to bring us closer to curing diseases like cancer and diabetes -- and to give all of us access to the personalized information we need to keep ourselves and our families healthier.”

Precision Medicine Initiative



- **Vision:** Build a broad research program to encourage creative approaches to precision medicine, test them rigorously, and, ultimately, use them to build the evidence base needed to guide clinical practice
- **Near Term:** apply the tenets of precision medicine to a major health threat – cancer
- **Longer Term:** generate the knowledge base necessary to move precision medicine into virtually all areas of health and disease

PMI ACD Working Group



- Co-chairs: Rick Lifton (Yale), Bray Patrick-Lake (Duke) and Kathy Hudson (NIH)
- Charged to articulate the vision for PMI and to detail the issues that will need to be addressed and considered as part of the study design
- Report to the ACD in September

Past Public Workshops



- Building a Precision Medicine Research Cohort (Feb 11–12)
- Unique Scientific Opportunities for the National Research Cohort (Apr 28–29)
- Cohorts and Electronic Health Records (May 28–29)
- <http://www.nih.gov/precisionmedicine/events.htm>

Upcoming Public Workshops



- Participants and Community Engagement
 - July 1–July 2 at NIH, Bethesda, MD
- mHealth
 - July 27– July 28 at Intel Corp., Santa Clara, CA
- All public workshops are video cast live

Gabriella Miller Kids First Pediatric Research Program



- Lorette Javois will give an update later in the morning about this wonderful opportunity

News from NICHD



NICHD DER Director



NICHD Associate Director for Extramural Research and Director of the Division of Extramural Research will be announced soon . . . stay tuned!

Hinnebusch Elected to NAS

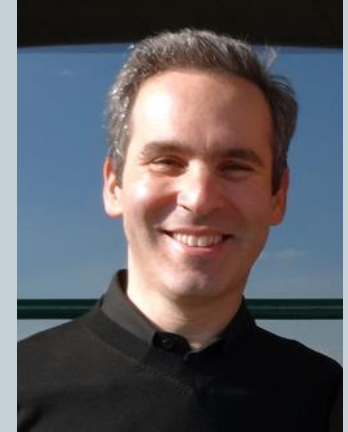


- Alan Hinnebusch, Ph.D. was elected into the National Academy of Sciences
- Alan is Section Head of the Section on Nutrient Control of Gene Expression

New Staff Member



- Stephen Gilman, ScD, Acting Chief of the Health Behavior Branch in the Division of Intramural Population Health Research in our intramural program
 - **Steve's research focuses on developmental** origins of health inequalities and aims to identify intervention targets during childhood that could reduce inequalities over the lifecourse
 - Among his primary interests are common mental disorders, including mood and substance use disorders



NICHD Extramural Training Review



- Dennis Twombly, Deputy Director of Extramural Policy at NICHD, is leading a task force to review **NICHD's extramural** training programs
- Scope of review:
 - Individual National Research Service Awards, Institutional National Research Service Awards, Individual Career Development Programs, Institutional Career Development Programs, R25 Education Programs
- Final report at September Council

NICHD Data and Specimen Hub (N-DASH)

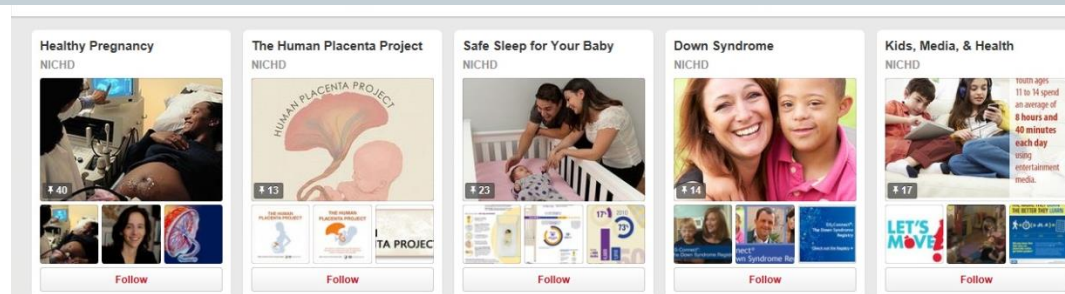


- Centralized resource for researchers to store and access de-identified data from NICHD-supported studies
- Will launch with 14 studies ranging in data complexity; more will be added
- Many benefits, including helping grantees comply **with NIH's Data Sharing Policy**
- Anticipated launch late this month, with outreach to research organizations
- Thanks to Rohan Hazra, Dave Songco, and crew!

NICHD on Pinterest



- One in four Americans use Pinterest to access and share information
- NICHD shares visually engaging content on a range of topics including healthy pregnancy, safe infant sleep, and Down syndrome
- Information is easily shared on social media, websites, or email
- www.pinterest.com/NICHD_NIH



Spanish-language Site Launched



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

Escriba aquí el término que desea buscar **Buscar**

Investigaciones sobre la salud **Noticias y multimedia** **Actividades y proyectos** **Acerca del NICHD**

Inicio

¿Cómo puede prepararse para un parto saludable?
Descubre qué dicen las investigaciones del NICHD.

[¿Cómo puede prepararse para un parto saludable?](#)

[¿Cuál es la apariencia de un ambiente seguro para dormir?](#)

[Ayude a su niño a aprender a leer.](#)

[El Embarazo: Conozca los términos](#)

Compartir:
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¿Qué es el NICHD?
El Instituto Nacional de Salud Infantil y Desarrollo Humano Eunice Kennedy Shriver (NICHD, por sus siglas en inglés) es una agencia del gobierno federal que realiza investigaciones sobre temas de salud.
Creado en 1962, el Instituto es parte de los Institutos Nacionales de Salud (NIH, por sus siglas en inglés) del Departamento de Salud y Servicios Humanos de los Estados Unidos.

Esto y más información gratuita en Inglés

Investigaciones sobre la salud

Noticias y multimedia

Actividades y proyectos

Human Placenta Project Update



Ultimate goal: To monitor human placental development and function in real time



2nd Human Placenta Project Meeting



April 27-28, 2015 with >300 participants

2nd Human Placenta Project Meeting



- Goal: to evaluate the role of omics technologies and imaging to achieve the goals of the HPP
- A combination of imaging and omics will be necessary to generate individualized fingerprint of placental well-being
- New technologies and techniques need to be developed and optimized
- Bioinformatics need to be developed and will be essential to the effort

3rd Human Placenta Project Meeting



- Save the date: April 14-15, 2016 at NIH's Natcher Conference Center
- Likely focus on imaging, bioinformatics, and technology, but still working on the agenda
- Will continue to have breakout groups and poster session(s)
- Technology demonstrations will be a new activity for 2016 meeting



A research
initiative to
better
understand
pregnancy



MyPregnancy



- A crowd-sourced, interactive, mobile app to:
 - Detail the natural history – and variations - of human pregnancy
 - Provide accurate info about pregnancy from trusted sources
 - Let pregnant women know about opportunities to participate in targeted research
- In early developmental stage with >15 partner organizations



Budget and Legislative Updates



Budget Update



- No FY2016 budget yet
- House and Senate committees working on their respective appropriations bills
- Without action from Congress, sequestration caps will return in FY2016



Photo Credit: Goulody99 via Compfight cc

21st Century Cures Act



- Most recent House version includes:
 - Authorize increase in NIH funding: \$31.811 B (FY16); \$33.331 B (FY17); \$34.851 B (FY18)
 - NIH Director must develop five-year NIH Research **Strategic Plan, to increase “efficient and effective focus of biomedical research,”** identifying “strategic focus areas” to expand knowledge about human health and include measureable objectives for each focus area
 - IC Directors (except NCI) appointed by NIH Director for five-year terms; can be removed earlier or reappointed with no limit as to number of terms

Pediatric Emphasis in 21st Century Cures



- NIH would be mandated to establish Pediatric Research Networks, and may not use existing network or center programs to do so
- NIH would be required to work with the European Medicine Agency to support a Global Pediatric Clinical Trials Network, supplementing young investigators who agree to participate
- Would require the NIH to hold a workshop on appropriate age groupings to be included in research studies, and report on the demographic information of children included in NIH-supported research

NIH Caucus on the Hill



- Sens. Lindsey Graham (R-S.C.) and Dick Durbin (D-III.) co-**chair the Senate's newest** caucus, dedicated specifically to the National Institutes of Health
- The caucus will seek bipartisan help to **restore NIH's capacity to fund research** after losing 25 percent of its purchasing power since 2003

Now it's your turn...



Comments, questions?