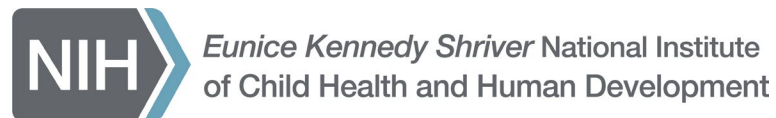


# National Advisory Child Health and Human Development Council

Overview

*September 18-19, 2019*



# Introduction

The NACHHD Council is charged with advising, consulting with, and making recommendations to the NICHD Director on matters relating to NICHD research and research support activities and functions.

## **Council Roster**

- Chair – Diana Bianchi, M.D.
- Exec Secretary – Della Hann, Ph.D.
- Council Members (12) (Michael Boninger, M.D.)
- Ex Officio Members (3) VA, MCHB, Army Medical Research Commands
- NABMRR Council Liaison – K. Ottenbacher, Ph.D., OTR



# National Institute for Child Health and Human Development (NICHD) Branches and Center

- Child Development and Behavior Branch
- Contraception Research Branch
- Developmental Biology and Structural Variation Branch
- Fertility and Infertility Branch
- Gynecologic Health and Disease Branch
- Intellectual and Developmental Disabilities Branch
- Maternal and Pediatric Infectious Diseases Branch
- National Center for Medical Rehabilitation Research (NCMRR)
- Obstetric and Pediatric Pharmacology and Pregnancy and Perinatology Branch
- Pediatric Growth and Nutrition Branch
- Pediatric Trauma and Critical Illness Branch
- Population Dynamics Branch
- Pregnancy and Perinatology Branch



# Agenda (Day 1)

- NICHD DIRECTOR'S REPORT AND DISCUSSION Dr. Bianchi
- UPDATE/OVERVIEW DIR REPORT Dr. Stratakis
- HOW WE SHUFFLE OUR GENES IN THE GERM-LINE  
AND WHY IT MIGHT MATTER FOR HUMAN FERTILITY Dr. Macfarlan
- TOUR ZEBRAFISH FACILITY
- NEW NICHD STRATEGIC PLAN Dr. Bianchi
- CONCEPT CLEARANCE REVIEW Dr. Hann



# Highlights Director's Report - Dr. Bianchi

- *Science* article on the 10-year impact of Dr. Collins decade as NIH Director
  - The Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, initiated in 2013
  - The Precision Medicine Initiative - now the All of Us Research Program
  - The Cancer Moonshot<sup>SM</sup>, launched in 2016
  - The Helping to End Addiction Long-term (HEAL) Initiative in 2018
- ACTNOW evidence base for standard of care for neonatal opioid withdrawal
- INCLUDE conditions across the lifespan to understand Down syndrome
- ECHO Environmental influences on Child Health Outcomes
- PRGLAC Research program specific to pregnant and lactating women
- Dr. Allison Cernich named as the Institute's Deputy Director
- Dr. Theresa Cruz named as acting director of the NCMRR



# NCMRR Director Search

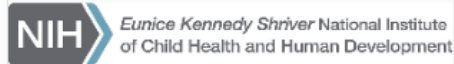
## Director NCMRR

<https://jobs.sciencecareers.org/job/505076/director-ncmrr/>

Send

Save

Apply



|                   |                                                                                      |
|-------------------|--------------------------------------------------------------------------------------|
| Employer          | National Institute of Child Health and Human Development                             |
| Location          | Bethesda, Maryland (US)                                                              |
| Salary            | Salary is competitive and will be commensurate with the experience of the candidate. |
| Posted            | October 20 2019                                                                      |
| Discipline        | Health Sciences, Clinical Research                                                   |
| Position Type     | Full Time                                                                            |
| Organization Type | Govt.                                                                                |

### VACANCY ANNOUNCEMENT

#### Director, National Center for Medical Rehabilitation Research

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

National Institutes of Health

Department of Health and Human Services

**OPENING DATE:** November 1, 2019

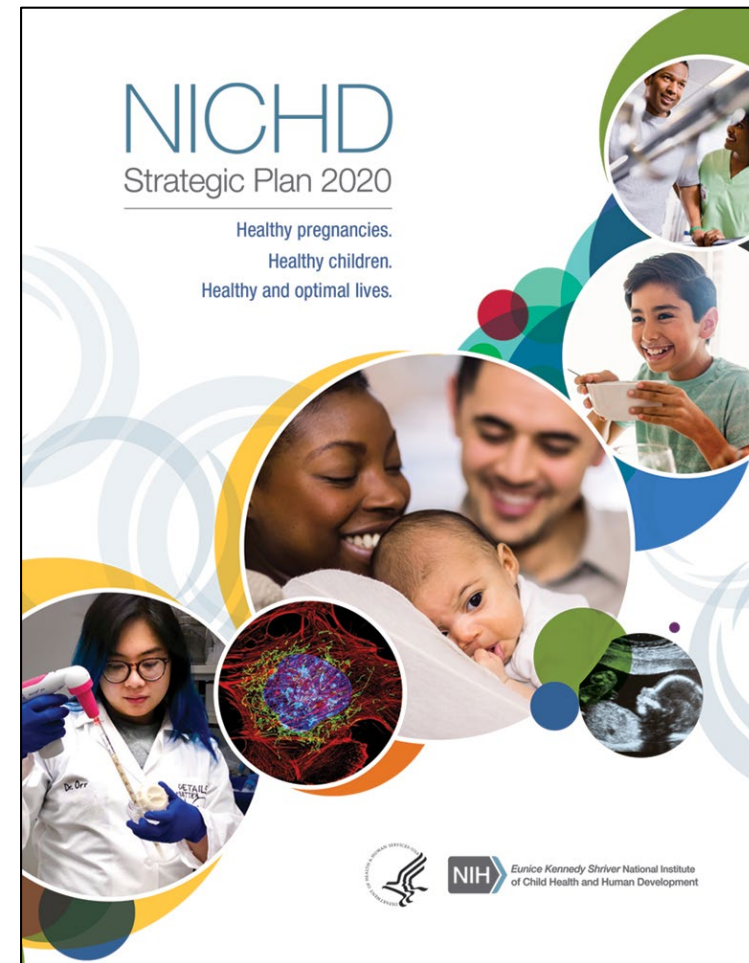
**CLOSING DATE:** January 3, 2020

**THE POSITION:** The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), a major research component of the National Institutes of Health (NIH) and the Department of Health and Human Services (HHS), seeks to identify an exceptional and visionary leader to serve as the Institute's Director of the National Center for Medical Rehabilitation Research (NCMRR).



# NICHD Strategic Plan: Overview

- Guides NICHD's research activities for the next 5 years
- Supports NICHD's new mission and vision statements
- Addresses 5 broad research themes and cross-cutting topics, such as global health
- Lays out NICHD research goals and objectives as well as aspirational goals to drive future activities
- Reaffirms NICHD's commitment to research aimed at improving the health and well-being of women, children, and people with disabilities
- Available at:  
<https://www.nichd.nih.gov/about/org/strategicplan>





# NICHD Strategic Plan: Revised Mission and Vision Statements

- **Mission:** NICHD leads research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all.
- **Vision:** Healthy pregnancies. Healthy children. Healthy and optimal lives.





# Agenda (Day 2)

- NICHD DER DIRECTOR'S REPORT AND DISCUSSION Dr. Hann
- R35 SUBCOMMITTEE UPDATE Dr. Tabin/Dr. Twombly
- RARE PEDIATRICS DISEASES ARE COMMON AND DEMAND MECHANISM DISCOVERY TO UNDERSTAND THE DISEASE PROCESS Dr. Khokha
- RARE DISEASE IS DEVASTATING TO FAMILIES – HOPE FROM GENE DISCOVERY Kendra Haifley
- DIRECTOR - National Center for Complementary & Integrative Health Dr. Langevin
- CLOSED SESSION



# Presentation Implementing an *Outstanding Investigator Award* (R35)

- R01 (Research Project): Supports discrete, specified, and circumscribed projects to be performed by the named investigators. Up to 5 years of support.
- R37 (MERIT Award): Provides the investigators with distinctly superior records a 5-year award, based on a specific project, with the possibility of extension for up to 5 additional years. Up to 10 total years of support.
- R35 (Outstanding Investigator Award): Provides long-term support to experienced investigators with an outstanding record of research productivity. Allows investigators to continue, or to embark on, long-term projects of unusual potential. Up to 8 years of support.

**Cliff Tabin (Council Member), Co-Chair**



# Presentation Implementing an *Outstanding Investigator Award* (R35) (continued)

## Objectives of R35:

- Providing long-term support to PIs to conduct innovative and high-impact research
- Reducing administrative burden and grant writing
- Providing flexibility to PIs to pursue new research directions (limited constraints)
- Gives NIH participating ICs the opportunity to tailor it to suit their mission-specific needs



# DAY 2 (continued)

## RARE PEDIATRIC DISEASES ARE COMMON AND DEMAND MECHANISM DISCOVERY TO UNDERSTAND THE DISEASE PROCESS

- Dr. Khokha, a pediatric critical care physician at Yale University, spoke about the inordinate impact of birth defects and rare disorders on children.

## VOICE OF THE PARTICIPANT

- Ms. Kendra Haifley presented her experience as the mother of children with a rare genetic disorder. She described the heart wrenching experience of two children dying before the age of 3 years and not knowing the cause. Dr. Khokha eventually identified the genetic disorder. The family created the *Warrior Princess Foundation* to help other families struggling with rare diseases.





Comments or Questions?

<https://nichd.nih.gov/About/Advisory/Council>



# EXTRA --- Experience of Other ICs with R35 Grants

Six institutes—the National Institute of General Medical Sciences (NIGMS); the National Institute of Environmental Health Sciences (NIEHS); the National Cancer Institute (NCI); the National Heart, Lung, and Blood Institute (NHLBI); the National Institute of Dental and Craniofacial Research (NIDCR); and the National Institute of Neurological Disorders and Stroke (NINDS)—currently have R35 grants. These institutes reported that the R35 mechanism has been a net positive. No other ICs are considering starting an R35 program, however. All the ICs require bundling of an investigator's grants, and all R35s have a duration of 7 or 8 years.

The ICs have set up their R35s in a variety of ways, but most require an investigator to have at least two R01 grants or equivalents to bundle together in order to be eligible. The exception is NIEHS, which has a different approach. Most of the ICs cap at either \$600,000 or \$750,000, though NIGMS has a lower cap. The NHLBI is unique among the ICs in that investigators who have an R35 are allowed to apply for other grants. NIGMS issues many more R35 grants (798) than other ICs using this mechanism; NCI, with 133 R35 grants, was ranked second.

