

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

One Hundred and Seventy-First Meeting  
**NATIONAL ADVISORY CHILD HEALTH AND HUMAN DEVELOPMENT COUNCIL**

September 18-19, 2019  
Conference Rooms 1425 and 1427  
6710B Rockledge Drive  
Bethesda, Maryland 20892  
Closed Circuit Viewing Overflow (Conference Room 1411)  
Closed Circuit Viewing Overflow (Conference Room 1417)  
NIH Videocast Website: <http://videocast.nih.gov/>

**AGENDA**

**OPEN SESSION: Thursday, September 19, 2019 (9:00 a.m. – 11:30 a.m.)**

|                      |   |                                |
|----------------------|---|--------------------------------|
| <b>9:00 - 9:10</b>   | <b>CALL TO ORDER AND INTRODUCTORY REMARKS</b>   | Diana Bianchi                  |
| <b>9:10 – 9:30</b>   | <b>NICHD DER DIRECTOR’S REPORT AND DISCUSSION</b>   | Della Hann                     |
| <b>9:30 – 9:50</b>   | <b>R35 SUBCOMMITTEE UPDATE</b>  | Cliff Tabin/<br>Dennis Twombly |
| <b>9:50 – 10:20</b>  | <b>RARE PEDIATRICS DISEASES ARE COMMON AND<br/>DEMAND MECHANISM DISCOVERY TO UNDERSTAND<br/>THE DISEASE PROCESS</b> | Mustafa Khokha                 |
| <b>10:20 – 10:40</b> | <b>RARE DISEASE IS DEVASTATING TO FAMILIES –<br/>HOPE FROM GENE DISCOVERY</b>                                       | Kendra Haifley                 |
| <b>10:40 – 11:00</b> | <b>BREAK</b>  |                                |
| <b>11:00 – 11:30</b> | <b>NCCIH DIRECTOR’S UPDATE</b>  | Helene Langevin                |

**CLOSED SESSION: Thursday, September 19, 2019, 11:30 am – Adjournment**

This portion of the meeting is closed to the public in accordance with the provisions set forth in Section 552b(c)(4) and 552b(c)(6), Title 5, U.S.C. and Section 10(d) of the Federal Advisory Committee Act, as amended U.S.C. Appendix 2.

|                      |                           |                       |
|----------------------|---------------------------|-----------------------|
| <b>11:30 – 12:30</b> | <b>DIR CLOSED SESSION</b> | Constantine Stratakis |
| <b>12:30 – 1:30</b>  | <b>LUNCH</b>              |                       |
| <b>1:30 – 4:45</b>   | <b>DER CLOSED SESSION</b> |                       |

## REVIEW OF APPLICATIONS

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

Lou De Paolo  
Rohan Hazra  
Andrew Bremer  
Lisa Halvorson  
James Griffin  
Melissa Parisi  
Valerie Maholmes  
Daniel Johnston  
Theresa Cruz  
Aaron Pawlyk  
James Coulombe  
Rebecca Clark  
Andrew Bremer

**4:45 – 5:00**      **REMARKS**

Diana Bianchi

**5:00**              **ADJOURNMENT**

## PRESENTERS

Dr. Diana W. Bianchi, M.D.  
Director  
NICHD/NIH, Bethesda, MD

Dr. Della Hann, Ph.D.  
Associate Director for Extramural Research  
Director, Division of Extramural Research  
NICHD/NIH, Bethesda, MD

Dr. Helene Langevin  
Director  
NCCIH/NIH, Bethesda, MD

Dr. Todd S. Macfarlan  
Principal Investigator  
NICHD/NIH, Bethesda, MD

Dr. Constantine Stratakis  
Director  
Division of Intramural Research  
NICHD/NIH, Bethesda, MD

Dr. Clifford J. Tabin  
George Jacob and Jacqueline Hazel Leder  
Professor and Chairman  
Harvard Medical School  
Boston, MA

Dr. Dennis Twombly  
Deputy Director  
Office of Extramural Policy  
NICHD/NIH, Bethesda, MD

Dr. Mustafa Khokha  
Yale New Haven Hospital  
Associate Professor of Pediatrics (Critical Care) and of Genetics  
Director of the Pediatric Genomics Discovery Program  
New Haven, CT

Voice of the Participant Speaker  
Ms. Kendra Haifley