

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.)

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

11:30 – 12:30	DIR CLOSED SESSION	Constantine Stratakis
12:30 – 1:30	LUNCH	
1:30 – 4:45	DER CLOSED SESSION	

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