

# IACC Committee Business

IACC Full Committee Meeting  
April 19, 2018



**Susan A. Daniels, Ph.D.**  
Director, Office of Autism Research Coordination  
Executive Secretary, IACC  
National Institute of Mental Health

# Thanks to OARC Staff



**Susan Daniels, Ph.D.**  
Director

**Oni Celestin, Ph.D.**  
Science Policy Analyst

**Rebecca Martin, M.P.H**  
Public Health Analyst

**Angelice Mitrakas, B.A.**  
Management Analyst

**Karen Mowrer, Ph.D.**  
Science Policy Analyst

**Julianna Rava, M.P.H.**  
Science Policy Analyst

**Matthew Vilnit, B.S.**  
Operations Coordinator

**Jeff Wiegand, B.S.**  
Web Development Manager



# April is National Autism Awareness Month



# NIMH Special Event for Autism Awareness Month



## The Story Behind Julia, Sesame Street's Muppet with Autism April 9, 2018



- Panel presentation featuring speakers from [Sesame Workshop](#), the nonprofit educational organization behind *Sesame Street*
- Meet-and-greet with a costumed Julia character

Archived video available:  
<https://iacc.hhs.gov/meetings/autism-events/2018/april9/sesame-street.shtml#video>

# Autism Awareness Month News



- 2018 Presidential Proclamation:  
[President Donald J. Trump Proclaims April 2, 2018, World Autism Awareness Day](#)
- 2018 UN Secretary-General Message:  
[António Guterres' Message on World Autism Awareness Day](#)

# Autism Awareness Month Events



- **Autism Awareness Interagency Roundtable**

*Indian Health Service*

April 2, 2018; Bethesda, MD

- **Empowering Women and Girls with Autism**

*United Nations*

April 5, 2018; New York, NY

Event page: <https://www.un.org/en/events/autismday/>

Archived video available: <https://www.youtube.com/watch?v=Tyhm7p8Gr2A>

- **Developing Individuals Who Have Different Kinds of Minds,  
featuring Temple Grandin, Ph.D.**

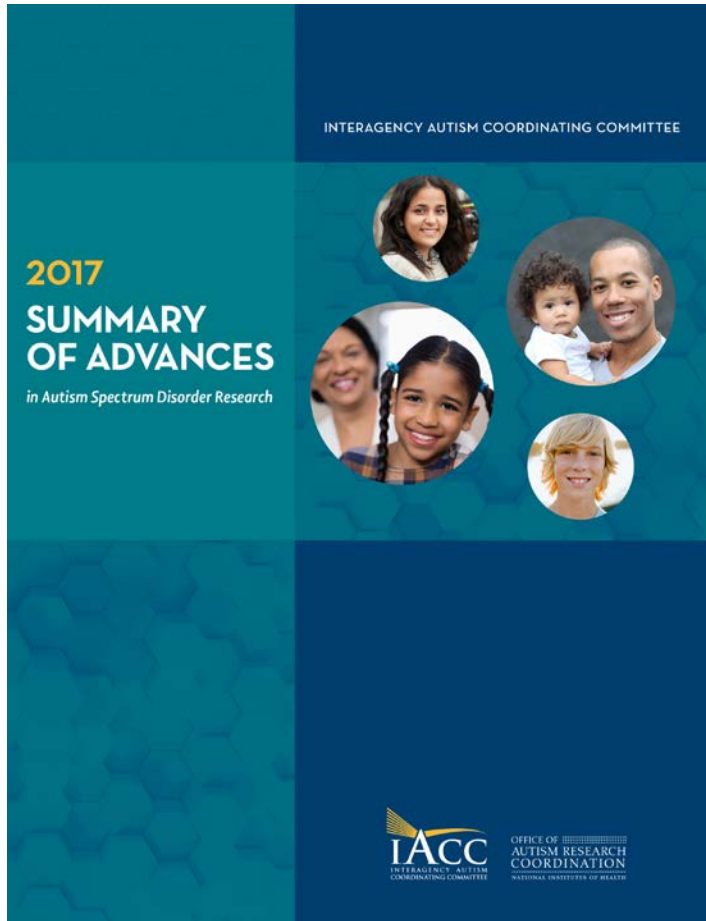
*National Institute of Environmental Health Sciences*

April 12, 2018; Research Triangle Park, NC

Archived video will be available: <https://videocast.nih.gov>



# 2017 Summary of Advances



- Annual publication – required by the Autism CARES Act
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Covers articles aligning with all seven Strategic Plan Question areas

<https://iacc.hhs.gov/publications/summary-of-advances/2017>

# 2016 ASD Research Portfolio Analysis



- OARC is currently analyzing data for the 2016 *IACC ASD Research Portfolio Analysis Report*
- Using 2016 data, OARC/NIMH/NIH, Autistica (UK), and the Canadian government are planning to collaborate to produce the first International Autism Research Portfolio Analysis Report
  - Preliminary results of this analysis will be presented at the INSAR Annual Meeting, May 2018
  - Hope to stimulate broader international participation in future years





# Autism CARES Act Report to Congress



- Report details progress on activities related to ASD and other developmental disorders across the federal government (required by the Autism CARES Act)
- OARC is coordinating preparation of the Report
- Requests for data have been received from relevant federal agencies
- Report expected in Fall 2018



# Improving Health Outcomes for Individuals on the Autism Spectrum WG



- The IACC is in the process of convening a working group on health and wellness issues
- Co-chairs: Dr. David Amaral and Dr. Julie Taylor
- Scope
  - General health and wellness for individuals with ASD
  - Co-occurring conditions and preventative approaches to address them, e.g. obesity
  - Co-occurring mental health conditions
  - Long-term medication use
  - Premature mortality (e.g. epilepsy, suicide, chronic health conditions)
  - Patient-provider interactions
  - Medical practitioner training
  - Parental/family mental health
  - Reproductive/maternal health care

# Improving Health Outcomes for Individuals on the Autism Spectrum WG



- Next steps
  - Working Group workshop in Summer 2018
    - Select 1-2 topics from:
      - General health and wellness for individuals with ASD
      - Co-occurring conditions and preventative approaches to address them, e.g. obesity
      - Co-occurring mental health conditions
      - Long-term medication use
      - Premature mortality (e.g. epilepsy, suicide, chronic health conditions)
      - Patient-provider interactions
      - Medical practitioner training
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# 2018 Summary of Advances Discussion

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Director, Office of Autism Research Coordination  
Executive Secretary, IACC  
National Institute of Mental Health

**Joshua A. Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health  
Chair, IACC

# Question 1: Screening and Diagnosis



AUTISM  
RESEARCH  
January, 2017 | Volume 10 | Number 1

Mar 2018

## **Parent and clinician agreement regarding early behavioral signs in 12- and 18-month-old infants at-risk of autism spectrum disorder.**

Sacrey LR, Zwaigenbaum L, Bryson S, Brian J, Smith IM, Roberts W, Szatmari P, Vaillancourt T, Roncadin C, Garon N

# Question 2: Underlying Biology



The logo for the Proceedings of the National Academy of Sciences (PNAS) is located on the left side. It features the letters 'PNAS' in a large, blue, serif font. Below the letters, the text 'Proceedings of the National Academy of Sciences of the United States of America' and the website 'www.pnas.org' are written in a smaller, blue font.

Apr 2018

## **Neuron numbers increase in the human amygdala from birth to adulthood, but not in autism.**

Avino TA, Barger N, Vargas MV, Carlson EL, Amaral DG, Bauman MD, Schumann CM



Feb 2018

## **Overlapping and Distinct Cognitive Impairments in Attention-Deficit/Hyperactivity and Autism Spectrum Disorder without Intellectual Disability.**

Karalunas SL, Hawkey E, Gustafsson H, Miller M, Langhorst M, Cordova M, Fair D, Nigg JT



# Question 3: Risk Factors



Feb 2018

## **Shared molecular neuropathology across major psychiatric disorders parallels polygenic overlap.**

Gandal MJ, Haney JR, Parikshak NN, Leppa V, Ramaswami G, Hartl C, Schork AJ, Appadurai V, Buil A, Werge TM, Liu C, White KP; CommonMind Consortium; PsychENCODE Consortium; iPSYCH-BROAD Working Group, Horvath S, Geschwind DH



Mar 2018

## **Air Toxics in Relation to Autism Diagnosis, Phenotype, and Severity in a U.S. Family-Based Study.**

Kalkbrenner AE, Windham GC, Zheng C, McConnell R, Lee NL, Schauer JJ, Thayer B, Pandey J, Volk HE

# Question 4: Treatments and Interventions



The International Journal of Research and Practice ● Volume 21 Number 5 July 2017

**autism**

Feb 2018

**Meta-analysis of parent-mediated interventions for young children with autism spectrum disorder.**

Nevill RE, Lecavalier L, Stratis EA

# Question 5: Services



Journal of the American Academy of  
**CHILD & ADOLESCENT  
PSYCHIATRY**

Feb 2018

## **Effects of State Autism Mandate Age Caps on Health Service Use and Spending Among Adolescents.**

Kennedy-Hendricks A, Epstein AJ, Mandell DS, Candon MK, Marcus SC, Xie M, Barry CL

**PUBLIC  
HEALTH**  
*Reports*

Jan/Feb 2018

## **Trends in Special Education Eligibility Among Children With Autism Spectrum Disorder, 2002-2010.**

Rubenstein E, Daniels J, Schieve LA, Christensen DL, Van Naarden Braun K, Rice CE, Bakian AV, Durkin MS, Rosenberg SA, Kirby RS, Lee LC

# Question 5: Services



Mar 2018

## JAMA Pediatrics

### **Vaccination Patterns in Children After Autism Spectrum Disorder Diagnosis and in Their Younger Siblings.**

Zerbo O, Modaresi S, Goddard K, Lewis E, Fireman BH, Daley MF, Irving SA, Jackson LA, Donahue JG, Qian L, Getahun D, DeStefano F, McNeil MM, Klein NP

# Question 6: Lifespan Issues



*(There were no nominations covering Question 6 topics from January – April 2018)*

# Question 7: Infrastructure and Surveillance



*(There were no nominations covering Question 6 topics from January – April 2018)*