ICCFASD
Interagency Coordinating Committee
on Fetal Alcohol Spectrum Disorders

# Spring 2024 Public Meeting

## Thursday, May 9, 2024

National Institute on Alcohol Abuse and Alcoholism
NIH Videocast, https://videocast.nih.gov/watch=54088

Report Prepared by Ripple Effect Communications

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# ICCFASD Spring 2024 Public Meeting

A videocast of the ICCFASD Spring 2024 Public Meeting held on May 9, 2024, is available on the NIH videocast website.

## Meeting Participants

A list of ICCFASD Executive Committee members and their contact information can be found on the ICCFASD website. The list is included in Appendix B: ICCFASD Membership List.

### ICCFASD Chairperson

Patricia A. Powell, PhD
Deputy Director
National Institute on Alcohol Abuse and Alcoholism (NIAAA)
National Institutes of Health (NIH)
The United States Department of Health and Human Services (HHS)

### ICCFASD Scientific Coordinator and Executive Secretary

Tatiana Balachova, PhD
Health Science Administrator
Division of Epidemiology and Prevention Research
National Institute on Alcohol Abuse and Alcoholism, NIH, HHS

### ICCFASD Primary Representatives

Jon Dunbar-Cooper, MA, CPP
Public Health Analyst
Division of Systems Development
Center for Substance Abuse Prevention
Substance Abuse and Mental Health Services Administration (SAMHSA), HHS

William Dunty, PhD
Program Director, NIAAA FASD Research Coordinator
Division of Metabolism and Health Effects
National Institute on Alcohol Abuse and Alcoholism (NIAAA), NIH, HHS

M. Sonsy Fermin, MSW, LCSW
Captain, US Public Health Service
Division of Healthy Start and Perinatal Services
Maternal and Child Health Bureau
Health Resources and Services Administration (HRSA), HHS

Christy Kavulic, EdD (online)
Associate Division Director
Office of Special Education Programs
Office of Special Education and Rehabilitative Services
The United States Department of Education (ED)

Shin Y. Kim, MPH (online)
Team Lead, Lead Health Scientist
Prenatal Substance Exposure Surveillance and Research Team
Infant Outcomes Monitoring, Research and Prevention Branch
Division of Birth Defects and Infant Disorders
National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention (CDC), HHS

Meghan O’Neill, MD, FAAP (online)
Medical Officer
Intellectual and Developmental Disabilities Branch
Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
National Institutes of Health (NIH)

Sharon Newburg-Rinn, PhD
Social Science Research Analyst
Office of Data, Analysis, Research and Evaluation
Children’s Bureau
Administration for Children and Families (ACF), HHS

Tina Pattara-Lau, MD, FACOG (online)
Maternal and Child Health Consultant
Office of Clinical and Preventive Services
Indian Health Service (IHS), HHS

Janani Prabhakar, PhD (online)
Program Officer
HEALthy Brain and Child Development (HBCD) Study
Division of Neuroscience and Behavior
National Institute on Drug Abuse (NIDA), NIH, HHS

Chris Sarampote, PhD
Chief, Biomarker and Intervention Development for Childhood-Onset Disorders Branch
Division of Translational Research
National Institute of Mental Health (NIMH), NIH, HHS

Kristina West, MS, LLM
Social Science Analyst
Division of Behavioral Health Policy
Office of Behavioral Health, Disability, and Aging Policy
Office of the Assistant Secretary for Planning and Evaluation (ASPE), HHS

## Participating Alternate ICCFASD Representatives

Elizabeth Parra Dang, MPH (online)
Behavioral Scientist
Health Communication and Research Translation Team
Infant Outcomes Monitoring, Research, and Prevention Branch
Division of Birth Defects and Infant Disorders
Centers for Disease Control and Prevention (CDC), HHS

Martha Sibley, PhD (online)
Social Science Research Analyst
Research and Rapid-cycle Evaluation Group
Center for Medicare and Medicaid Innovation (CMMI)
Centers for Medicare and Medicaid Services (CMS)

Mary Kate Weber, MPH (online)
Behavioral Scientist
Prenatal Substance Exposure Surveillance and Research Team
Infant Outcomes Monitoring, Research, and Prevention Branch
Division of Birth Defects and Infant Disorders

National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention (CDC), HHS

Tammy White, PhD (online)
Social Science Research Analyst
Data Analytics and Reporting Team
Administration for Children and Families (ACF), HHS

### Ad Hoc Members

CJ Lutke
Founding member
International Adult Leadership Collaborative (ALC) of FASD Changemakers

Jan Lutke
Manager
International Adult Leadership Collaborative (ALC) of FASD Changemakers

### Invited Speakers

Janine Austin Clayton, MD, FARVO (online)
Director
Office of Research on Women's Health (ORWH)
National Institutes of Health (NIH), HHS

Kenneth Lyons Jones MD
Distinguished Professor of Pediatrics
Department of Pediatrics
Division of Environmental Health and Science
School of Medicine
University of California San Diego (UCSD)

Kathleen T. Mitchell, MHS, LCADC
Senior Vice President of FASD Prevention and Recovery Services
FASD United

## Meeting Attendees

Tom Donaldson, President and CEO, FASD United
Emma Baldwin, Development Associate, FASD United

## Meeting Attendees on NIH Videocast

The meeting was NIH Videocast with 234 participants attending the live videocast. Attendees were able to submit questions and comments live online.

The archived meeting videocast is available on the NIH Videocast page.

## ICCFASD Agenda

| TIME | AGENDA |
|---|---|
| 10:00 am | **Welcome and Introductions**<br>*Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair*<br>*ICCFASD Members*<br>*Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and Executive Secretary*<br>*Members of the ICCFASD and alternate representatives* |
| 10:10 am | **SPECIAL PANEL: FETAL ALCHOL SPECTRUM DISORDERS 50 YEARS - LOOKING BACK AND MOVING FORWARD**<br>**A Retrospective Look at 50 Years of FASD - How We Got Here From Where We Started**<br>*Kenneth Lyons Jones, MD, Emeritus Professor, Department of Pediatrics, School of Medicine, University of California San Diego*<br>**Women, Alcohol and FASD: Lessons Learned from Mothers and their Families**<br>*Kathy Mitchell, MHS, LCADC, Senior Vice President of FASD Prevention and Recovery Services, FASD United*<br>**The White House Initiative on Women's Health Research**<br>*Janine Austin Clayton, MD, FARVO, Director, Office of Research on Women's Health, National Institutes of Health*<br>**DISCUSSION**<br>*Moderator: Patricia Powell and Tatiana Balachova* |
| 12:00 pm | **LUNCH BREAK** |
| 1:10 pm | **ICCFASD: Overview and Updates**<br>*Tatiana Balachova, Ph.D., NIAAA, ICCFASD Scientific Coordinator and Executive Secretary* |
| 1:20 pm | **Reports of Activities from FY2023: ICCFASD Federal Agencies**<br>*ICCFASD Agency Representatives*<br>Administration for Community Living (ACL)<br>*Amanda Reichard, PhD*<br>Office of the Assistant Secretary for Planning and Evaluation (ASPE)<br>*Kristina West, MS, LLM*<br>Administration for Children and Families (ACF)<br>*Sharon Newburg-Rinn, PhD*<br>Health Resources and Services Administration (HRSA)<br>*M. Sonsy Fermín, MSW, LICSW* |

| **TIME** | **AGENDA** |
|---|---|
| | **Q&A, Discussion**<br>Substance Abuse and Mental Health Services Administration (SAMHSA)<br>*Jon Dunbar-Cooper, MA, CPP*<br>Centers for Disease Control and Prevention (CDC)<br>*Shin Y. Kim, MPH*<br>Indian Health Service (IHS)<br>*Tina Pattara-Lau, MD, FACOG* |
| | **Q&A, Discussion** |
| **3:20 pm** | **Reports of Activities from FY2023: ICCFASD Federal Agencies (Continued)**<br>*ICCFASD Agency Representatives*<br>National Institute on Alcohol Abuse and Alcoholism (NIAAA)<br>*Bill Dunty, PhD*<br>National Institute of Mental Health (NIMH)<br>*Chris Sarampote, PhD*<br>National Institute on Drug Abuse (NIDA)<br>*Janani Prabhakar, PhD*<br>*Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)<br>*Meghan O'Neill, MD* |
| | **Q&A, Discussion** |
| | **Conclusion Discussion**<br>*Moderators:*<br>*Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair*<br>*Tatiana Balachova, PhD, NIAAA, ICCFASD Scientific Coordinator and Executive Secretary* |
| **4:30 pm** | **Adjournment** |

## Welcome and Introduction

*Patricia Powell, PhD, Deputy Director, NIAAA, NIH; ICCFASD Chair*

Dr. Patricia Powell, Deputy Director of NIAAA and Chair of the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD), opened the meeting by welcoming in person and virtual meeting participants and thanking Dr. Tatiana Balachova for her efforts in putting together this meeting. Dr. Powell then previewed the meeting agenda.

## Special Panel: Fetal Alcohol Spectrum Disorders 50 Years - Looking Back and Moving Forwards

### Fetal Alcohol Spectrum Disorders: Diagnosis, Prevention, Intervention, and Stigma

*Kenneth Lyons Jones, MD, Department of Pediatrics, Division of Environmental Health and Science, University of California, San Diego, School of Medicine, La Jolla, CA*

Dr. Powell introduced Dr. Kenneth Jones (See Appendix E for Dr. Jones's bio).

Dr. Jones started his presentation by reviewing the history of FASD beginning with the identification of fetal alcohol syndrome (FAS) in 1973. Dr. Jones highlighted the contributions of Dr. David Smith, Dr. Christy Ulleland, Dr. Shirley Anderson, and Dr. Ann Pytkowicz Streissguth made in identifying that children born to women with alcohol use disorder exhibited growth deficiency, facial malformations (short palpebral fissures, long, smooth philtrum, and thin vermilion border), and neurobehavioral deficits that are now known to be characteristics of FASD. In 1996 the Institute of Medicine of the National Academy of Sciences put together a committee to review FAS and concluded that prenatal exposure to alcohol caused FAS, and later a spectrum of effects called Fetal Alcohol Spectrum Disorders (FASD) was identified.

Dr. Jones described that FASD is an umbrella term that includes three diagnoses: fetal alcohol syndrome, partial fetal alcohol syndrome, and alcohol-related neurodevelopmental disorder (ARND). Individuals with ARND have confirmed maternal alcohol use during pregnancy and a range of neurodevelopmental anomalies leading to learning, behavior, adaptive skills, and self-regulation problems. However, individuals with ARND do not exhibit the growth deficiency and facial malformations that are typically associated with FAS. Dr. Jones stated that in his clinic of the children who have prenatal alcohol exposure nine out of 10 children have ARND. Dr. Jones classifies ARND as an invisible disorder and stated that most of the individuals with this disorder will be undiagnosed or misdiagnosed.

Dr. Jones reviewed work that he's doing with the Office of Youth and Community Restoration in California to diagnose FASD, with a focus on ARND. They are developing a pilot program in San Diego to test children in Child Welfare Services and Probation Departments. Children will be tested for FASD using rapid Behavioral Impairment testing that can be administered by a trained non-medical provider along with traditional neuropsychological testing. This program aims to assess whether the rapid tests are as accurate as the neuropsychological testing that is typically administered by neuropsychologists and pediatricians. The ultimate goal of this program is to develop a program that can be used throughout California to diagnose 90% of individuals with FASD in California.

Dr. Jones then reviewed some FASD prevention and intervention efforts. Examples of efforts to prevent prenatal alcohol exposure included Surgeon General warnings, Project CHOICES,[1] and efforts to promote the early

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[1] Project CHOICES Intervention Research Group. Reducing the risk of alcohol-exposed pregnancies: a study of a motivational intervention in community settings. Pediatrics. 2003;111(5 Pt 2):1131-1135.

awareness of pregnancy.[2] Interventions for individuals with FASD and their families included Families Moving Forward, the Math Interactive Learning Experience program, and animal assisted therapy.

To conclude his presentation, Dr. Jones provided an anecdote illustrating the type of information that is most compelling to people. His findings that 24% of adolescents who are incarcerated in San Diego Juvenile Hall were prenatally exposed to alcohol gets more attention than more general FASD statistics. suggesting that highlighting the link between FASD and the criminal justice system may be a more effective way to make people aware of this disorder.

## Women, Alcohol and FASD: Lessons Learned from Mothers and their Families

*Kathy T. Mitchell, MHS, LCADC, Senior Vice President of FASD Prevention and Recovery Services, FASD United*

Dr. Powell introduced Ms. Kathy Mitchell.

Ms. Mitchell opened her presentation by discussing the crushing impact stigma has on individuals who have experience with FASD. In her experience, she has not met one woman that purposely wanted to "damage" their unborn child. It's her belief that inadequate screening, intervention, and treatment of substance use disorders during pregnancy are a primary contributor to FASD. She also discussed the impact stigma has on progress in FASD prevention, screening, and treatment.

Ms. Mitchell recounted her personal experience as part of the first FASD task force. As part of the task force, she effected change by telling her story as a birth mother of a daughter who was prenatally exposed to alcohol and advocated for more awareness about FASD. While some change has been made, given the stigma associated with FASD there is less funding and resources available to address issues surrounding FASD. Ms. Mitchell discussed how early public health messaging surrounding FASD increased stigma. She also discussed how studies have shown that mothers of children with FASD are perceived worse than mothers with other adverse health or social conditions.[3]. Individuals from stigmatized groups are marginalized by being locked out of systems of care that could help them, which can further exacerbate issues that they are facing. However, even if individuals can access systems of care, they may not receive care that meets their specific needs. Ms. Mitchell also mentioned that in the implementation of the screening, brief intervention, and referral to treatment (SBIRT) models the referral to treatment piece is often not happening, which makes it difficult for people to receive treatment after being identified as having a substance use disorder.

Ms. Mitchell shared her personal experience of having a child who was prenatally exposed to alcohol. She discussed her experiences with alcohol use disorder and getting her daughter diagnosed with FAS. She also talked about the pushback and criticism she received when she started talking about her experience publicly.

Ms. Mitchell then discussed challenges in getting people screened for alcohol use during pregnancy. Pregnant individuals are not routinely asked about alcohol use during pregnancy by their health care or social service providers. Ms. Mitchell talked about the need to increase FASD awareness in human service systems and proposed that systems that are receiving government funding should be required to learn about FASD.

Ms. Mitchell challenged meeting attendees to leverage their power and influence to continue to drive progress in the FASD field. She acknowledged that there may be pushback, but she implored attendees to continue to

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[2] McCormack C, Hutchinson D, Burns L, et al. Prenatal Alcohol Consumption Between Conception and Recognition of Pregnancy. Alcohol Clin Exp Res. 2017;41(2):369-378. doi:10.1111/acer.13305

[3] Corrigan PW, Lara JL, Shah BB, Mitchell KT, Simmes D, Jones KL. The Public Stigma of Birth Mothers of Children with Fetal Alcohol Spectrum Disorders. Alcohol Clin Exp Res. 2017;41(6):1166-1173. doi:10.1111/acer.13381

educate people about FASD and push for the much-needed change. She suggested that FASD should be included in request for proposals, curricula/exams, needs assessments, evaluations, and reports.

Ms. Mitchell ended her presentation by highlighting the resilience of families who have experienced FASD. She also shared information about the Recovering Mothers Anonymous support group and FASD United.

## The White House Initiative on Women's Health Research

*Janine Austin Clayton, MD, FARVO, Director, Office of Research on Women's Health (ORWH), National Institutes of Health (NIH)*

Dr. Powell introduced Dr. Janine Clayton.

Dr. Clayton started her presentation by reviewing statistics about concerning trends of increasing alcohol use problems amongst women. These included significant increases in average alcohol consumption, alcohol-involved suicide, and death due to excessive alcohol use. Dr. Clayton also reported that compared to men, women were less likely to obtain treatment and that disparities in accessing care for AUD are even greater for Black, American Indian/Alaska Native, and Latina women. These disparities may in part be due to stigma women face when accessing care for AUD and fears that reporting problems with substance use will lead to legal action and a removal of their children from their homes.

Dr. Clayton then went on to discuss the maternal mortality crisis in the United States. Maternal mortality rates in the United States are the highest compared to peer nations. These rates also exhibit significant racial and ethnic disparities with exceedingly high rates of maternal death among Black women. A majority of maternal death occurs one day to one year postpartum. Dr. Clayton posited that issues in the health of reproductive age women may contribute to high rates of maternal mortality.

Dr. Clayton reviewed the history and mission of the Office of Research on Women's Health (ORWH). ORWH was founded in 1990 in response to the lack of inclusion of women in clinical NIH research. In 2016, the 21st Century Cures Act expanded NIH clinical trial inclusion to individuals of all ages, pregnant and lactating women. The 21st Century Cures Act also required NIH-defined applicable Phase III clinical trials to report results disaggregated by sex/gender, race, and ethnicity. In 2016, NIH also released a policy that sex as a biological variable should be factored into research designs, analyses, and reporting in vertebrate animals and human studies. Dr. Clayton also announced the forthcoming NIH-Wide Strategic Plan for Research on the Health of Women. The plan lays out how NIH institutes and centers can collaborate to drive synergistic women's health research priorities.

Dr. Clayton then reviewed signature programs that ORWH has worked on with other institutes and centers including Building Interdisciplinary Research Careers in Women's Health (BIRCWH), Specialized Centers of Research Excellence on Sex Differences (SCORE), administrative supplements, and various NOFOs. Dr. Clayton also reviewed NIH supported research that has contributed to advances in women's health such as the Women's Health Initiative and NIMH funded research that led to the development of a treatment of postpartum depression. To address the maternal mortality and morbidity crisis, NIH created the IMPROVE Initiative which will fund Maternal Health Research Centers of Excellence which will address the biopsychosocial factors that are critical to improve the health of women and address the maternal mortality and morbidity crisis. Dr. Clayton also briefly mentioned the Community Partnerships to Advance Science for Society (ComPASS) program funded initiative that is examining ways to address maternal and infant health disparities in Mississippi. ORWH also has created a maternal morbidity and mortality web portal. Dr. Clayton emphasized the importance of utilizing a life course perspective when addressing women's health which is reflected in ORWH framework of the intersecting factors that affect women's health.

Dr. Clayton also briefly touched on the career programs and the importance of supporting work across sectors.

Dr. Clayton discussed the first White House initiative on women's health research and Executive Order 14120 which prioritized funding for women's health across federal research portfolios. Executive Order 14120 allows agencies to identify and prioritize research gaps, integrate innovation in women's health research and ensure that data standards are appropriately developed to assess differences in clinical effectiveness. There are 11 federal agencies working on this initiative to advance new interdisciplinary collaborative and transformative women's health research. During the State of the Union address, President Biden requested $12 billion from FY25 going forwards to support a central fund of women's health research. To meet the needs of the Executive Order, NIH has implemented a variety of efforts including releasing a NIH-wide notice of special interest (NOSI) for Women's Health Research, examining ways to standardize and share women's health data, increasing investment in private sector businesses that support women's health research, creating a comprehensive agenda on menopause, and launching a new initiative to research women's health related biomarkers.

Dr. Clayton ended her presentation by emphasizing that considering sex and gender across the research continuum (e.g., laboratory studies, pre-clinical studies, clinical studies) leads to more rigorous research, innovation, and health equity which can in turn can support the delivery of individualized care.

## Q&A and Discussion

*Moderators: Patricia Powell, Ph.D., Deputy Director, NIAAA, NIH; ICCFASD Chair and Tatiana Balachova, Ph.D., ICCFASD Scientific Coordinator and Executive Secretary, NIAAA, NIH*

Dr. Powell opened the questions by asking Dr. Jones whether the participants in his ARND identification pilot project have confirmation of prenatal alcohol exposure. Dr. Jones confirmed that the individuals who participate in the pilot program will have confirmation prenatal alcohol exposure.

Dr. Powell then asked Dr. Clayton what ways NIAAA could continue to partner with ORWH to support the Women's Health Initiative. Dr. Clayton stated that NIAAA has been a terrific partner and that NIAAA could continue this partnership by helping to enhance collaborations with other ICs (e.g., NIDA). These collaborations could help leverage the work that is already being done to focus on the health women. Dr. Clayton also stated the NIAAA could help by helping to spread the word about this initiative.

Ms. CJ Lutke asked Dr. Clayton if there are any initiatives or projects that focus on women with FASD, women with FASD who are giving birth, or the grief and acceptance processed associated with FASD diagnosis. Dr. Clayton mentioned that Ms. CJ Lutke highlighted the importance of considering whether an individual has FASD prior to pregnancy. She stated that NICHD has a component that focuses on individuals with different abilities, which could possibly include FASD, but she will follow up to see if that is the case. However, she stated the women's health NOSI that was just published allows for researchers to apply for funding to answer the questions Ms. CJ Lutke posed. Dr. Clayton also mentioned that there has been work done on stigma and mental health but there needs to be more research that focuses on the physical and mental health of women of reproductive age. Dr. Clayton also highlighted the importance of having these conversations to ensure that the perspectives of people with lived experience are included in the programs that are designed so that the programs can address their needs.

Dr. Chris Sarampote asked Ms. Mitchell if she could share her experiences trying to interface with mental health services when trying to get help for herself and her children. Ms. Mitchell stated that in her experience mental health providers are not aware of FASD and that can result in poor outcomes. There seems to be a disconnect from early childhood and adulthood which leads to people being misdiagnosed with a whole array of mental health issues. Ms. Mitchell expressed that she is happy to hear about the White House initiative. She stated that there has been great research that has come from the different ICCFASD agencies but there seems to be a disconnect in getting that information out there. Ms. Mitchell stated that there hasn't been enough done to make an impact and there needs to be more measurable outcomes, education and testing about FASD, and considerations of how to integrate FASD into broader government funded programs.

Ms. Jan Lutke asked if women with FASD are considered as a part of OWRH understudied, underrepresented, and underreported groups. Ms. Jan Lutke expressed that there has been significant oversight of women with FASD considering the physical and mental health challenges they face. Dr. Clayton responded that NOSI's are broad so they don't specifically mention women with FASD, but they would be receptive to receiving research applications that focus on women with FASD.

Dr. Powell mentioned that there is still a long way to go when it comes to FASD and that NIAAA has a core resource for providers that focuses on FASD.

## ICCFASD: Overview and Updates

*Tatiana Balachova, PhD, ICCFASD Scientific Coordinator and Executive Secretary, NIAAA, NIH*

Dr. Balachova gave a presentation that provided an overview of ICCFASD and updates.

In recognition of the seriousness of consequences of prenatal alcohol exposure, the United States Congress mandated that the Institute of Medicine (IOM) of the National Academy of Science conduct a study of fetal alcohol syndrome (FAS) and related birth defects. In its final report it recommended that NIAAA/NIH establish and lead an interagency committee comprised of representatives from relevant federal agencies to coordinate national efforts on FAS. [4] The committee's purpose is to improve communication, cooperation, and collaboration among disciplines and federal agencies that address issues related to FASD and its prevention. The committee is supported and administered by NIAAA.

Dr. Balachova then took the time to recognize former ICCFASD members who have passed away within the past year and their numerous contributions to the field of FASD and the ICCFASD. These members included Sally Anderson, PhD, Erin Bagalman, MSW, and JB Kinlacheeny, MPH.

Dr. Balachova reviewed the agencies that have representatives that are part of ICCFASD. During this review she announced that a representative from the Department of Education (ED) has joined ICCFASD. Dr. Balachova also announced that Dawn Levinson and Dr. Tracy King are no longer part of ICCFASD after transferring to other positions within their respective agencies. Dr. Balachova then introduced new ICCFASD members Cpt. Sonsy Fermin (HRSA), Dr. Meghan O'Neil (NICHD), Dr. Christy Kavulic (ED), Dr. Tammy White (ACF), Dr. Marth Sibley (CMMI), Dr. Kristi Anderson (HRSA) and Dr. Keisher S. Highsmith (NIDA) (See Appendix C: Member Updates for new member bios). Dr. Balachova also introduced Ms. CJ Lutke and Ms. Jan Lutke who will serve as ad hoc members representing people with lived experience with FASD (See Appendix D: Ad Hoc Members for ad hoc member bios).

Dr. Balachova spoke about the wide variety of areas that the agencies work on, such as prevention, basic and clinical research, and community living and support. She then discussed ICCFASD's special focus Working Group on Screening and Brief Intervention (ISBI) for Pregnant and Postpartum People. The working group was established as an initiative by ICCFASD members from the CDC. The ISBI group has a broad representation of relevant federal agencies. The group's objectives are to exchange information and resources, identify gaps for improved implementation and research, and expand partnerships among federal agencies related to screening, brief intervention, and referral to treatment SBIRT) for pregnant and postpartum people. Dr. Balachova also spoke about ICCFASD efforts over the last three years to include the voices of people with FASD and their caretakers in ICCFASD meetings. These efforts were critically important and contributed to the decision to add ad hoc members with lived experience to ICCFASD. These efforts have included presentations, panel discussions, and opportunities to provide consultation and feedback on programs.

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[4] Stratton K, Howe C, Battaglia FC, eds. Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment. National Academies Press; 1996. doi:10.17226/4991

## Reports of Activities from FY2023: ICCFASD Federal Agencies: ASPE, ACF, HRSA

Dr. Balachova opened the session stating that ICCFASD members will present on their agencies' FY23 activities related to FASD. She noted that after each block of three to four members presentations, there is time for discussion, and invited videocast participants to submit questions and comments online.

### Office of the Assistant Secretary for Planning and Evaluation (ASPE)

*Kristina West, MS, LLM, Social Science Analyst, Division of Behavioral Health Policy, Office of Behavioral Health, Disability, and Aging Policy, Office of the Assistant Secretary for Planning and Evaluation (ASPE), HHS*

Ms. Kristina West reviewed ASPE's scope of work and the inclusion of FASD in the Office of Behavioral Health, Disability, and Aging Policy (BHDAP)'s substance use portfolio. BHDAP's FY23 FASD's work focused primarily on policy support and research which included:

- Leading the federal interagency Prenatal Substance Exposure workgroup which serves as a forum for federal staff to share updates and get feedback on proposed programs in SUD prevention and treatment, including co-occurring AUD, for pregnant, postpartum and reproductive age people
- Reviewing and providing technical assistance on draft legislation relevant to FASD identification, prevention, and treatment
- Participating in ICCFASD's Screening and Brief Intervention for Pregnant and Postpartum People (ISBI-PPP) working group
- Leading workshops on prenatal substance exposures, FASD, and Neonatal Abstinence Syndrome (NAS)
- Participating in the HHS Taskforce on Maternal Mental Health, which will release a national strategy and report on best practices to address prevention, treatment, and recovery for pregnant and postpartum women with mental health needs and SUD. This strategy will be updated yearly for the next five years.

ASPE also published a study that examined neonatal abstinence syndrome (NAS) and prenatal substance exposure (PSE) rates that found decreasing rates of NAS and increasing rates of PSE.[5] Ms. West stated that these findings suggest the need to improve early identification and treatment of substance use during pregnancy and to integrate maternity and SUD care.

### Administration for Children and Families (ACF)

*Sharon Newburg-Rinn, Ph.D., Social Science Research Analyst, Office of Data, Analysis, Research and Evaluation, Children's Bureau, Administration for Children & Families, ACF, HHS*

Dr. Sharon Newburg-Rinn opened her presentation by reflecting on earlier conversations about the fear individuals who use substances during pregnancy have about having their children taken away. Dr. Newburg-Rinn mentioned that one third of states have laws that children can be removed from the home if the child was prenatally exposed to alcohol. Dr. Newburg-Rinn reported that in discussions she's had with social workers they believe that they can identify children with FASD by just looking at them, which is a misconception as the majority of children with FASD do not have facial features associated with FAS.

Dr. Newburg-Rinn also discussed conversations she's had with foster and adoptive parents of children with FASD to understand their experiences and what information they would like to know. Parents reported that they were not told that their children had FASD or were told that they were not allowed to know that information. Parents also reported having to do research on how to handle their child's behavior and needing more

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[5] West KD, Ali MM, Blanco M, Natzke B, Nguyen L. Prenatal Substance Exposure and Neonatal Abstinence Syndrome: State Estimates from the 2016–2020 Transformed Medicaid Statistical Information System. Matern Child Health J. 2023;27(Suppl 1):14-22. doi:10.1007/s10995-023-03670-z

information or tools about how to address their child's behavior problems. Dr. Newburg-Rinn stated that increased awareness of FASD and the associated behavioral challenges may decrease the likelihood of parents getting angry at children with FASD and decrease the likelihood of maltreatment of these children.

Dr. Newburg-Rinn also discussed findings that the proportion of children of color (e.g., Black/African American, American Indian/Alaska Native) in foster care is disproportionate to their numbers in the general population. This disproportionate representation may be due to oversurveillance in these communities or higher rates of adverse social and economic factors in those communities. The Children's Bureau is working on ways to prevent children from going to foster care and provide services in the home. One proposed piece of legislation provides states with the opportunity to use money that is allocated to foster families for prevention services.

Dr. Newburg-Rinn then briefly touched on publications that the Children's Bureau released with the Child Welfare League of America, resources that the Children's Bureau is developing related to PAE, and webinars the Children's Bureau is hosting with the Child Welfare League of America.

## Health Resources and Services Administration (HRSA)

*M. Sonsy Fermín, MSW, LICSW, Captain, US Public Health Service, Division of Healthy Start and Perinatal Services, Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA), HHS*

Cpt. Sonsy Fermin opened her presentation with an overview of the mission, vision, and goals of HRSA's Maternal and Child Health Bureau (MCHB). Cpt. Fermin then discussed MCHB's Supporting Fetal Alcohol Spectrum Disorders (FASD) Screening & Intervention Program (SFASDSI) which aims to reduce alcohol use among pregnant women and to improve the developmental outcomes for children & adolescents with a suspected or diagnosed FASD. The program targets* areas that have high rates of binge drinking among pregnant women. As part of SFASDSI program primary care providers that serve pregnant people and children received FASD SBIRT training. The first SFASDSI cycle is ending this year, and applications are open for the next cycle.

Cpt. Fermin then reviewed outcomes from the first round of the SFASDSI program. The SAFEST Choice Learning Collaborative consisted of three cohorts of clinics that underwent 10 prenatal and/or pediatric ECHO® sessions. The prenatal ECHO® sessions taught healthcare teams how to screen for and counsel people about the risks of alcohol use during pregnancy and the pediatric ECHO® sessions trained healthcare teams how to identify and care for children and adolescents with suspected or diagnosed FASD. Cohort one lasted for 10 months and included 22 practices (10 prenatal and 11 pediatric) from 15 community health systems across seven states. Cohort two lasted 10 months and included 22 practices (12 prenatal and 12 pediatric) from 18 community health center systems across seven states. Cohort three is still in progress and implemented a condensed schedule to increase engagement. In cohort three, each ECHO® will last for five months with bimonthly meetings. The prenatal sessions are still ongoing. The pediatric cohort three included 13 practices from 15 community health systems across 13 states. Cohort three also included two auditors from practices that were unable to meet the participation threshold to fully enroll in the initiative. All cohorts included representatives from tribal health centers.

The core content of the ECHO® modules was similar for the prenatal and pediatric session but they were geared towards the populations of interest. Aside from the ECHO® modules, participants were also provided with additional resources. Providers and their clinics also received technical assistance as part of the program. The sessions were taught by faculty with diverse backgrounds including medical doctors, registered nurses, midwives, clinical social workers, and nurse practitioners. There was also an advisory board that helped guide the training and aid with recruitment. The project advisory board consists of researchers, clinicians, patient advocates, and individuals with lived experience.

Cpt. Fermin reported that the results from the program evaluation of cohorts one and two show the program had a positive impact. The was a high rate of participation in both cohorts. Participants reported increased FASD knowledge, improved confidence in screening for alcohol use, increased utilization of appropriate methods for screening, intervening, and implementation of tangible practice change.

Cpt. Fermin ended her presentation by promoting National Maternal Mental Health hotline for individuals that may need support during and after pregnancy.

## Q&A and Discussion

Dr. Bill Dunty voiced a comment from a videocast participant that Maine benefited greatly from the SAFEST Choice program. There was also a question whether there are efforts underway to compile FASD relevant data (e.g., prevalence, treatment outcome, Medicaid diagnostic code, PRAMS data, NSDUH data)? The participant suggested this could help with emphasizing the importance of the issue to legislators. Dr. Powell responded that it would be valuable to pull all this data together and that this effort is something the ICCFASD should consider. Dr. Dunty suggested that a first step in this effort would be to compile all of the agency updates on the ICCFASD website.

Dr. Powell asked Cpt. Fermin whether participants in SAFEST Choice volunteered to participate or did their practices ask them to participate. Cpt. Fermin responded that participation was voluntary and that there was great interest in the program due to the lack of FASD information during clinical training. There was a waitlist to join the program, so the initial award was extended to four years. Also practices from cohort one are continuing their participation by sending new staff to the program.

Dr. Meghan O'Neil asked whether there are any efforts to study an ECHO® curriculum for trainees, especially in pediatric programs? At the medical school level there are no uniform requirements for disability curriculum. Dr. Powell responded by inquiring whether something like this would be doable at the medical school level due to timing constraints. Dr. O'Neil was unaware of the mechanisms required to add areas to the medical school curriculum but suggested there may need to be some changes at the policy level to require a disability curriculum. Dr. O'Neil also mentioned that a lot of curriculum changes are led by student interest. Ms. Mary Kate Weber mentioned that the CDC funded an American Academy of Pediatrics (AAP) initiative to explore the best way to reach pediatric primary care providers. The CDC also had a resident training program where preceptors were trained to work with a group of students and teach them about FASD. The CDC also had a small ECHO® program for pediatricians.

Ms. Mitchell talked about her experience teaching medical school courses, working with the CDC to get funding to educate medical and allied health professional students, and working with the AAP to develop their ECHO®. Ms. Mitchell emphasized that while those efforts are great there needs to be exam questions about FASD or a national push to increase education surrounding FASD.

Dr. Jones mentioned the need to utilize social workers and public health workers to drive efforts to address FASD due to his belief that medical professionals have struggled to address this issue fully.

Ms. West asked what providers' perspective is of framing the messaging around FASD and the potential child protective services (CPS) implications of treating individuals who are using substances during pregnancy. Cpt. Fermin responded that normalizing conversations about substance use through asking everyone about the use and standardizing, utilizing questionnaires can help reframe the messaging. Cpt. Fermin also mentioned the difficulties providers have reported building trust with patients if they are in a state where CPS could get involved if substance use is reported during pregnancy. Some providers report that to avoid surprises they tell patients upfront when developing their care plan that CPS will come after they give birth. Cpt. Fermin stated that until there is a national policy on how to protect the child and provide services to the family this will continue to be a challenge. Dr. Newburg-Rinn stated there needs to be more collaboration between agencies to find out how to support families that struggle due to socioeconomic issues.

Ms. CJ Lutke stated that the fear of having their baby taken away may keep people from coming forward about their alcohol use during pregnancy. Ms. CJ Lutke also emphasized that taking a baby to foster care may not be in the baby's best interest due to the concerns that foster care is not always a safe environment.

# Reports of Activities from FY2023: ICCFASD Federal Agencies: SAMHSA, CDC, IHS

## Substance Abuse and Mental Health Services Administration (SAMHSA)

*Jon Dunbar-Cooper, MA, CPP, Public Health Analyst, Division of Systems Development, Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration (SAMSA), HHS*

Mr. Jon Dunbar-Cooper opened his presentation by stating that SAMHSA does not currently have an FASD portfolio, but that SAMHSA does have behavioral health resources and programs that may benefit clinicians, families, and individuals with FASD. During his presentation Mr. Dunbar-Cooper shared several of those programs and resources including:

- NOFOs for Screening, Brief Intervention, and Referral to Treatment (SBIRT) and Treatment for Pregnant and Postpartum Women
- Webinars and resources about the delivery of treatment and recovery
- Information about medication for substance use disorders
- SAMHSA's implementation of the National Plan to End Gender-Based Violence
- The Early Serious Mental Illness Treatment Locator which is a confidential and anonymous source of information for persons and their family members who are seeking treatment facilities for a recent onset of serious mental illnesses
- Mental Health Awareness Training which prepares individuals and communities to respond appropriately and safely to persons with mental health challenges or disorders, particularly those with serious mental illness and/or serious emotional disturbances
- The Protection & Advocacy for Individuals with Mental Illness (PAIMI) Program which protects and advocates for the rights of adults with Significant (Serious) Mental Illness and children with Significant (Serious) Impairment or Emotional Disturbances through activities to ensure the enforcement of the Constitution, and Federal and State statutes
- The National Network to Eliminate Disparities in Behavioral Health which is a network of community-based organizations across the U.S. focused on the mental health and substance use issues of diverse racial and ethnic communities
- Early Childhood Mental Health programs which promote and support the health and wellness of young children and their families
- The National Child Traumatic Stress Initiative which aims to improve treatment and services for children, adolescents, and families who have experienced traumatic events
- Hotlines and Helplines such as the 988 Suicide & Crisis Lifeline and the National Disaster Distress Helpline (DDH)

## Centers for Disease Control and Prevention (CDC)

*Shin Y. Kim, MPH, Team Lead, Lead Health Scientist, Prenatal Substance Exposure Surveillance and Research Team, Infant Outcomes Monitoring, Research, and Prevention Branch, Division of Birth Defects and Infant Disorders, National Center on Birth Defects and Developmental Disabilities (NCBDDD) Centers for Disease Control and Prevention (CDC), HHS*

Ms. Shin Kim opened the presentation by reviewing the CDC's priorities to protect health and improve lives. Ms. Kim then discussed the Division of Birth Defect and Infant Disorder's priority of addressing and reducing the impact of substance use and substance use disorder during pregnancy. The division addresses this priority through strategies that focus on prevention, identification, and intervention, along with surveillance and research. Ms. Kim reviewed CDC's research and surveillance activities which included:

- A study that surveyed clinicians about their practices surrounding screening and brief intervention (SBI) for excessive alcohol use during pregnancy.[6] The study found that most clinicians reported using SBI practices but they were not confident in the abilities.
- Studies that reviewed PRAMS survey data on postpartum drinking behaviors [7] and polysubstance use during pregnancy[8]
- A cooperative agreement called Understanding Clinical Data and Pathways through Care to Inform Surveillance of Children with Fetal Alcohol Spectrum (I-FASD), which aims to enhance understanding of existing healthcare data and explore opportunities to leverage these data for public health surveillance
- The Maternal and Infant Clinical Network, which is a surveillance system of clinical sites whose purpose is to sustain, improve and expand existing pregnant people-infant linked longitudinal surveillance efforts to ensure timely reporting and improved data quality of key exposures and outcomes that impact pregnant people and infants. In 2023, 11 clinical sites were selected to collect data on medication for opioid use disorder, polysubstance use, cytomegalovirus, and stillbirth

Ms. Kim then reviewed CDC's prevention, identification, and intervention efforts which included:

- The FASD National Partner Network which aims to build a collaborative framework of national partner organizations that contribute to reducing prenatal alcohol and other substance use, improving support services and access to care, and improving identification and health of children with FASD and their families. Some successes of this network were adding 90 new champions across the champions network, sharing 56 products and educational resources between partners, and offering over 50 educational opportunities.
- Starting an initiative to create a pregnancy and postpartum continuing education certificate program for the peer recovery workforce
- Wrapping up the Prenatal Alcohol and Other Drug Exposures Project in Child Welfare which conducted descriptive studies of knowledge, attitude, policies, practices and needs of child welfare agencies for identifying and caring for children and families with prenatal substance exposures.

Ms. Kim also reviewed recent communication research efforts which culminated in the development of a toolkit for how to discuss alcohol use during pregnancy. Ms. Kim also announced that the CDC will be launching a new website on May 15 that will have separate but crosslinked sites on FASD and alcohol use during pregnancy.

## Indian Health Service (IHS)

*Tina Pattara-Lau, MD, FACOG, CDR, US Public Health Service, Maternal and Child Health Consultant, Office of Clinical and Preventive Services, Indian Health Service, (IHS), HHS*

Dr. Tina Pattara-Lau opened her presentation by providing a brief overview of the IHS and the impact that history and historical trauma can have on health outcomes and health seeking behaviors. Dr. Pattara-Lau then reviewed IHS's innovative approaches to increase access to care in the community and support the maternal infant dyad before, during and after pregnancy. Dr. Pattara-Lau discussed the development of an obstetric readiness (OB-RED) in the emergency department program to provide sites in obstetric (OB) care deserts with the tools and resources to safely triage, stabilize and transfer pregnant patients and newborns. The program

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[6] Green C, George N, Park Y, et al. Screening and Brief Interventions for Alcohol Use During Pregnancy: Practices Among US Primary Care Clinicians, DocStyles 2019. Prev Chronic Dis. 2023;20:E25. doi:10.5888/pcd20.220226

[7] Board A, D'Angelo DV, von Essen BS, et al. The Postpartum Period: An Opportunity for Alcohol Screening and Counseling to Reduce Adverse Health Impacts. J Addict Med. 2023;17(5):528-535. doi:10.1097/ADM.0000000000001169

[8] Board A, D'Angelo DV, Salvesen von Essen B, et al. Polysubstance use during pregnancy: The importance of screening, patient education, and integrating a harm reduction perspective. Drug Alcohol Depend. 2023;247:109872. doi:10.1016/j.drugalcdep.2023.109872

manual, which is currently under review, includes protocols for screening for alcohol and substance use in pregnant persons. To date 51 IHS sites and 225 staff have undergone OB-RED simulation training.

Dr. Pattara-Lau also discussed the monthly Indian Country ECHO® for Care and Access for Pregnant People series, which includes the work of Indigenous community leaders. The ECHO® series has been attended by over 1,400 participants. IHS is also piloting a Maternity Care Coordinator program that will fund site specific maternity care coordinators to provide telehealth and home visit support to individuals during the pregnancy and postpartum period. The maternity care coordinators will also be able to provide SBIRT for alcohol and substance use during pregnancy. IHS plans to fund several maternal care coordinator sites across six IHS areas.

## Q&A and Discussion

There was a question from an online participant to Ms. Kim regarding intention to change practices she mentioned in her presentation. Is it possible to identify which practices, policies, and outcomes have improved? Is there an effort to move to scaling up pilot projects? Ms. Kim responded that it can be challenging to measure impact given the lack of data on how alcohol use trends are affecting FASD estimates. Ms. Kim also mentioned that the CDC is trying to address alcohol use during pregnancy as an upstream way to address FASD. The CDC is also working on how to get better FASD estimates to see how their work may possibly impact FASD estimates. Mr. Kim also stated that the ability to scale up pilot projects is dependent on funding and collaborating with partners to determine whether the work is effective and impactful. Ms. Eizabeth Para Dang stated that the CDC has started to move away from a training approach because while there was reported increase in knowledge and intent to change that was not enough. The CDC is moving towards activities that aim to increase SBIRT in large Health Care Systems and fostering collaboration across groups.

Ms. Jan Lutke inquired whether a peer mentoring model for adults with FASD has been developed? She also mentioned that kids with FASD grow to be adults with FASD who have different needs when they get older. Ms. Jan Lutke said there needs to be more consideration of how to support individuals with FASD as they get older. Ms. Jan Lutke also mentioned an initiative at the University of British Columbia where physicians and experts in FASD, including individuals with lived experiences, are working to develop a training that would be mandatory for providers who are working in the health care system. Ms. Kim agreed with the need for peer support for adults with FASD but acknowledged that silos within agencies and divisions can limit the ability to develop initiatives for FASD past childhood. However, Ms. Kim mentioned that there are efforts in place to bridge those silos. Ms. Kim also acknowledged that while we can learn from initiatives in different countries the differences in the systems can make it hard to translate here.

Dr. Balachova asked what is needed if training is not enough. Dr. Balachova also inquired if mentoring models have been implemented for individuals affected by FASD. Ms. Kim replied that clinicians receive a lot of training but even with training they still don't have the tools or knowledge of where to refer patients. Ms. Mitchell mentioned a mentorship model for birth mothers of children with FASD that is based on a 12-step model.

Ms. Mitchell also responded that it is important to include people with lived experiences in these knowledge building initiatives because people become more motivated after learning about their experience firsthand. Ms. Mitchell also echoed the point of needing to move away from measuring what people have learned and move towards looking at how the system is going to improve.

Ms. CJ Lutke discussed the need to tackle stigma for people with FASD and the birth mothers of people with FASD. She stated the need to see humanity of birth mothers who have children with FASD and remove the victim and perpetrator narrative.

# Reports of Activities from FY2023: ICCFASD Federal Agencies: NIAAA, NIMH, NIDA, NICHD

## National Institute on Alcohol Abuse and Alcoholism (NIAAA)

*Bill Dunty, Ph.D., Program Director, Division of Metabolism and Health Effects, National Institute on Alcohol Abuse and Alcoholism (NIAAA), NIH, HHS*

Dr. Bill Dunty opened his presentation by acknowledging the death of Dale Herald MD, PhD. He then provided a brief overview of the mission of NIAAA and NIAAA support of FASD research in the areas of etiology, interventions, prevention, and diagnosis.

Dr. Dunty then reviewed NIAAA budget data. Over the last five years FASD awards have made up around 7% of NIAAA's research and training budget. In FY23, around $30 million was invested in FASD research which included 96 awards, 16 of which were new awards in FY23. Dr. Dunty reviewed how the 16 new grants address the FASD focus areas and recommended going to the NIH Reporter for more information about NIAAA's FASD-related grants. Dr. Dunty also showed that NIAAA supports FASD research across the country with six research hubs of institutes that have more than four FASD awards.

Dr. Dunty then discussed additional research that is needed to address challenges in areas such as prevention, early detection, interventions, chronic disease impact, stigma reduction, awareness surrounding FASD as a developmental disorder, and the impact of alcohol on the placenta and gut microbiome. Dr. Dunty then reviewed the pregnancy and FASD-related funding opportunities that NIAAA funded or participated in including the following:

- Prevention and Intervention Approaches for Fetal Alcohol Spectrum Disorders (R34 and R61/R33)
- Administrative Supplements for Research of Emerging and Existing Issues of COVID-19 Related to the Health and Well-Being of Women, Children and Individuals with Physical and/or Intellectual Disabilities
- Screening, Brief Intervention and Referral to Treatment or Prevention (SBIRT/P) for alcohol, tobacco, and other drugs (ATOD) use and misuse in adult populations that experience health disparities
- Notice of Special Interest (NOSI): Addressing Evidence Gaps in Screening
- Notice of Special Interest (NOSI): Increasing Uptake of Evidence-Based Screening in Diverse Populations Across the Lifespan
- Notice of Special Interest (NOSI): Secondary Analyses of Existing Alcohol Research Data

Dr. Dunty also mentioned NIAAA resources about alcohol and pregnancy such as a fact sheet, brochure, and a short takes video. In 2023, NIAAA also launched a series of review articles in Alcohol Research Current Reviews. Dr. Dunty concluded his presentation by highlighting the NIH-wide pediatric initiatives that NIAAA participates in.

## National Institute of Mental Health (NIMH)

*Chris Sarampote, Ph.D., Chief, Biomarker and Intervention Development for Childhood-Onset Disorders Branch, Division of Translational Research, National Institute of Mental Health (NIMH), NIH, HHS*

Dr. Chris Sarampote provided an overview of NIMH and the strategic plan for research. Dr. Sarampote discussed that individuals with FASD are at an increased risk for psychological disorders (e.g., ADHD, mood disorder, anxiety) and they are not getting the needed services for those disorders. Dr. Sarampote stated that understanding the relationships between alcohol exposure, behavior, psychiatric symptoms, and other variables like environment, can lead to a better understanding of the developmental trajectories for children with FASD, and determine how and when to intervene to promote health. He also discussed the need to better understand how existing mental health services are utilized by and benefit people with FASD.

Dr. Sarampote also reflected on the conversation from the meeting that is pertinent to NIMH such as that individuals with FASD do not feel heard and that FASD is an invisible disorder. He mentioned that FASD may be invisible in mental health disorder research due to the fact that individuals with FASD may be screened out of studies or improperly included with other mental health disorders. Dr. Sarampote mentioned that NIMH does not currently fund FASD research, but it does partner with other institutes that are doing FASD research.

## National Institute on Drug Abuse (NIDA)

*Janani Prabhakar, Ph.D., Program Officer, HEALthy Brain and Child Development (HBCD) Study, Division of Neuroscience and Behavior, National Institute on Drug Abuse (NIDA), NIH, HHS*

Dr. Janani Prabhakar started her presentation with an update on the HEALthy Brain and Child Development (HBCD) Study, which aims to examine neurodevelopmental trajectories and determine how substance exposure and other environmental factors affect those trajectories. The study began enrollment in July 2023, and they are well on their way to meeting their enrollment goals. So far, the study is finding relatively low levels of opioid use but relatively high levels of alcohol use on its own and though co-use.

Dr. Prabhakar also reviewed several other NIDA initiatives including the following NOFOs and NOSIs:

- The Opioid Exposure and Effects on Placenta Function, Brain Development, and Neurodevelopmental Outcomes is a collaboration NICHD on understanding the influence opioid exposure in utero exerts on the development of placenta and the fetal brain
- The Translating Socioenvironmental Influences on Neurocognitive Development and Addiction Risk (TranSINDA) anticipates supporting planning grants aiming to uncover mechanisms mediating the impact of early life social environment on neuro behavioral development using rat models
- This NOSI sought applications that test innovative models of service delivery to address maternal and family needs from mothers experiencing OUD during pregnancy and in the postpartum period
- This NOFO aims to elucidate the effect of HIV and substance use comorbidity on the growth, development and functioning of the placenta in pregnant individuals and on maternal outcomes

Dr. Prabhakar also highlighted the work of the NIDA Women and Sex/Gender Research Workgroup which aims to promote careers of women scientists and promote the conduct, translation, and dissemination of research on sex and gender differences in pharmacology and socioeconomic determinants of substance use disorders and responses to substances abuse. This workgroup has contributed to NIDA NOFOs and is hosting an Early Career Investigator Seminar series which spotlights the research of early career investigators through presentations and sharing of resources.

## Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

*Meghan O'Neill, MD, Intellectual and Developmental Disabilities Branch Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), NIH*

Dr. Meghan O'Neil opened her presentation by providing a brief overview of NICHD's mission and scope of work. Dr. O'Neil mentioned that while NICHD only funds a few awards specific to FASD and alcohol use during pregnancy, NICHD supports basic science research on the effects of prenatal exposures using cellular or animal models, investigations of high-risk behaviors during pregnancy such as polysubstance abuse, and research involving children with intellectual and developmental disabilities. NICHD also participates in trans-NIH collaborations that can inform the field of FASD. Dr. O'Neil discussed the IMPROVE initiative which supports research to reduce preventable causes of maternal deaths and improved health for women before, during, and after delivery. Research includes assessing contributing health conditions and social factors. Dr. O'Neil also discussed the Ableism in Medicine and Clinical Research initiative which aims to combat ableism in medicine and research. Both NICHD and NIH as a whole have released funding opportunities to address health care disparities faced by individuals with disabilities.

Dr. O'Neil then reviewed NICHD's FASD portfolio which includes:

- Two NICHD awards that focus on documenting the Safe Passage data in the NICHD Data and Specimen Hub. The Safe Passage Study investigated the effect of prenatal exposure to alcohol and drugs on the risk of sudden infant death syndrome (SIDS), stillbirth, and fetal alcohol spectrum disorders. Findings from this data included that prenatal alcohol exposure during the periconception period and second trimester had a more significant impact on fetal growth. [9]
- Studies investigating lipid biomarkers that could potentially predict the risk of FASD and offer target for therapeutic interventions
- A fellowship award to develop a FASD-informed website for teachers to provide them with adequate training about the needs of students with FASD and effective strategies for providing support

## Q&A and Discussion

Ms. Mitchell discussed the importance of the findings from the Safe Passage project, especially surrounding SIDS and stillbirth. She mentioned that it is unfortunate that these findings are not more widely known. Dr. Dunty responded that there was a press release and blog post about the Safe Passage findings showing a tenfold increased likelihood of SIDS with PAE in the first trimester, but that press release came out right before the pandemic hit. Dr. Dunty and Dr. O'Neil both expressed the difficulty of getting research out to the public and clinical practice. Dr. O'Neil mentioned that there has been a push to move into the dissemination and implementation space and hopes that the NICHD data hub could aid in those efforts.

## Conclusion Discussion

*Moderators: Patricia Powell, Ph.D., Deputy Director, NIAAA, NIH; ICCFASD Chair and Tatiana Balachova, Ph.D., ICCFASD Scientific Coordinator and Executive Secretary, NIAAA, NIH, HHS*

Dr. Powell noted that several NIH research institutes are around the table at the ICCFASD meeting. She inquired to hear from other agencies' representatives and the videocast audience on what research would be critical to better publicize scientific data to prevent FASD and help individuals with FASD and families?

Ms. CJ Lutke spoke about the life trajectories of people with FASD and discussed the need for more positive representation of people with FASD. She suggested studies that examine positive life trajectories of individuals with FASD, including those who live with their birth parents, and called for more longitudinal studies of individuals with FASD. Dr. Prabhakar responded by mentioning that part of HBCD is examining protective and resilience factors in participants' environments.

Dr. Jones mentioned that one of the missing links is to recognize that people from the middle class and above drink more alcohol, therefore there may be children with FASD that are born to middle- and upper-class families than are accounted for. Much of the FASD research is focused on people of lower socioeconomic status so the FASD data for individuals of higher socioeconomic status is missing. Dr. Dunty mentioned that the HBCD study data showed that alcohol biomarkers were detectable in dried blood spots collected at birth from mothers who resided in urban high median income neighborhoods. Dr. Powell stated that normalizing the conversation surrounding FASD may lead to more individuals being screened. She spoke about the need to normalize conversations around alcohol, i.e. that everybody is asked, and everybody who could benefit from help gets help.

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[9] Pielage M, El Marroun H, Odendaal HJ, et al. Alcohol exposure before and during pregnancy is associated with reduced fetal growth: the Safe Passage Study. BMC Med. 2023;21(1):318. doi:10.1186/s12916-023-03020-4

Ms. Jan Lutke echoed Dr. Jones's statement that we need to remove stigmatizing language surrounding birth mothers of individuals with FASD. She spoke about the complexity of stigma. There are unspoken values, biases and beliefs that people grew up with, that they don't talk about and don't think about that. Ms. Lutke mentioned the importance of finding ways for the birth and adoptive mothers of children with FASD to work together to address issues surrounding FASD. Dr. Jones said that there is need to look at FASD in a different way and change the culture and attitudes to this disorder than blaming the mother. Ms. Mitchell suggested more research on whether there are paternal factors that contribute to FASD as well. Dr. Powell and Dr. Dunty both briefly mentioned studies that are underway that are examining potential paternal contributors to FASD.

Dr. Balachova mentioned a new Trans-NIH funding announcement that addresses SBIRT or Prevention (SBIRT/P) for alcohol, tobacco, and other drug use and misuse that was mentioned previously during NIH presentations. The prevention aspect of this announcement is new. It changes the focus from referral to treatment for AUD or SUD solely to referrals to prevention services which might help to address stigma and encourage considerations of other factors that may be contributing to alcohol use.

Ms. Emma Baldwin discussed conversations she's been seeing about reframing the idea that FASD is 100% preventable. Given the timing of pregnancy awareness, access issues, and other social determinants of health it is difficult to claim that FASD is 100% preventable. Ms. Baldwin suggested that reframing that FASD is 100% preventable may also help address some of the issues associated with stigma. Ms. Baldwin also discussed the need to include FASD in infrastructure (e.g., screening) and conversation within the neurodiversity community. Ms. Baldwin also briefly touched on the different attitudes toward ADHD and FASD and how adopted children with FASD may become isolated and stigmatized due to the stigma associated with their birth parent. Ms. CJ Lutke also shared a personal story about her experience as an adoptive mother of a child with FASD.

Mr. Tom Donaldson stated that it is remarkable what these agencies have been able to do with very limited to no funding. He shared his hope that legislation will provide greater attention and funding to FASD.

## Adjournment

Dr. Balachova encouraged ICCFASD members to continue thinking about what they want to do within their agencies and how ICCFAD can help put those actions into place. Dr. Powell thanked everyone for their time and attention and encouraged meeting attendees to let ICCFASD know what issues are the most important to them.

# Appendix A: Abbreviations

| Abbreviation | Term |
|---|---|
| AAP | American Academy of Pediatrics |
| ACF | Administration for Children and Families |
| ACL | Administration for Community Living |
| ADHD | Attention-deficit/hyperactivity disorder |
| ALC | Adult Leadership Committee (of the FASD Changemakers) |
| ASPE | Office of the Assistant Secretary for Planning and Evaluation |
| AUD | Alcohol Use Disorder |
| CDC | Centers for Disease Control and Prevention |
| CMMI | Center for Medicare & Medicaid Innovation |
| CMS | Centers for Medicare & Medicaid Services |
| CPS | Child Protective Services |
| FAS | Fetal Alcohol Syndrome |
| FASD | Fetal Alcohol Spectrum Disorder |
| HBCD | HEALthy Brain and Child Development study |
| HHS | U.S. Department of Health and Human Services |
| HRSA | Health Resources and Services Administration |
| IC | Institutes and Centers |
| ICCFASD | Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders |
| IDD | Intellectual and Developmental Disabilities |
| IHS | Indian Health Services |
| IMPROVE | Implementing a Maternal Health and Pregnancy Outcomes Vision for Everyone |
| MCHB | Maternal and Child Health Bureau |
| MMWR | Morbidity and Mortality Weekly Report |
| MOM | Maternal Opioid Misuse (Model) |
| NIAAA | National Institute on Alcohol Abuse and Alcoholism |
| NICHD | The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development |
| NIDA | National Institute on Drug Abuse |
| NIDILRR | National Institute on Disability, Independent Living, and Rehabilitation Research |
| NIH | National Institutes of Health |
| NIMH | National Institute of Mental Health |
| NOFAS | National Organization on Fetal Alcohol Syndrome |
| NOFO | Notice of Funding Announcement |
| NOSI | Notice of Special Interest |
| OUD | Opioid Use Disorder |
| ORWH | Office of Research on Women's Health |
| PAE | Prenatal Alcohol Exposure |
| SAMHSA | Substance Abuse and Mental Health Services Administration |
| SBI | Screening and brief intervention |
| SBIRT | Screening, brief intervention, and referral to treatment |
| SUD | Substance Use Disorder |

# Appendix B: ICCFASD Membership List

## Primary Representatives

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## Appendix C: Member Updates

**Martha (Sonsy) Fermin, MSW, LICSW**

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## Biographical Summary

CAPT Martha (Sonsy) Fermín, a Licensed Clinical Social Worker, currently serves as a Senior Public Health Analyst in the Maternal and Child Health Bureau, Division of Healthy Start and Perinatal Services. She provides guidance for the Supporting Fetal Alcohol Spectrum Disorders Screening and Intervention Program and the Screening and Treatment for Maternal Mental Health and Substance Use Disorders Program.

CAPT Fermin has over twenty years of experience in various roles within HHS, including Project Officer, Program Manager, and Designated Federal Official for the Secretary's National Advisory Council on Migrant Health. Previously, she managed national programs such as Migrant Health, spearheaded LGBTQ+ initiatives, and administered grants to support individuals with mental illness during her time at the Substance Abuse and Mental Health Services Administration.

Before joining the US Public Health Service Commissioned Corps, CAPT Fermin held significant roles, including contributing to the Department of Defense as a civilian, advocating for juvenile justice with the State of Florida's Department of Juvenile Justice, and providing essential support to refugees seeking political asylum in Valencia, Spain.

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## Biographical Summary

Christy Kavulic is the Associate Division Director of the Early Childhood and Family Team in the Office of Special Education Programs in the US Department of Education. In this position, she oversees the development and management of discretionary grants funded under the Individuals with Disabilities Education Act that prepare an effective early childhood workforce; support the implementation of evidence-practices; and support high-quality early childhood systems at the State and local levels. She also supports collaboration with other Federal partners to ensure that infants, toddlers, and preschool children with disabilities and their families have access to and full participation in high-quality inclusive early childhood programs and services. She has a master's degree in speech-language pathology, a master's degree in public health, and a doctorate in early childhood special education.

**Meghan O’Neill, M.D., FAAP**
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## Biographical Summary

Meghan O’Neill, MD, FAAP, is a Medical Officer who joined the Intellectual and Developmental Disabilities (IDD) Branch at The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) in late 2023 after five years of clinical work in the Developmental Pediatrics and Child Neurology divisions at Lurie Children’s Hospital, where she also directed a clinical Down syndrome program. She manages a portfolio of grants relevant to individuals with IDD and is a member of the leadership team for the INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) Project, an NIH-wide initiative to enhance research specifically involving individuals with Down syndrome. Dr. O’Neill completed her MD at the Johns Hopkins School University of Medicine, her pediatrics residency at Lurie Children’s Hospital/Northwestern University, and her fellowship in neurodevelopmental disabilities at the Kennedy Krieger Institute/Johns Hopkins Hospital. She is triple board certified in General Pediatrics, Neurology with special qualifications in Child Neurology, and Neurodevelopmental Disabilities. She hopes to cultivate diverse research initiatives that will positively impact the DS and IDD populations from both a medical and neurodevelopmental/behavioral standpoint. She also continues to provide clinical care to children with disabilities in the Chicagoland area.

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## Biographical Summary

CDR Kristi Anderson, MD, MPH, FACOG, is a Medical Officer in the Division of Healthy Start and Perinatal Services (DHSPS), Maternal Child Health Bureau (MCHB), Health Resources Services Administration (HRSA). In this role, she provides clinical consultation and technical assistance on priority issues and special maternal health projects across the bureau, including advisory guidance for the Alliance in Innovation for Maternal Health (AIM) and Women's Preventive Services Initiative (WPSI) grants. She also serves as the bureau's federal liaison to the US Preventive Services Taskforce (USPSTF).

CDR Anderson began her career in the Indian Health Service (IHS) in 2013 as an OB/GYN providing comprehensive care to the American Indian/Alaska Native community at Northern Navajo Medical Center (NNMC) in Shiprock, NM and implementing interventions to build healthy lifestyle behaviors in pregnant women. She then served as the Chief Medical Officer for the World Trade Center Health Program (WTCHP), National Institute of Occupational Safety and Health from 2017-2023 where her responsibilities stretched broadly across healthcare administration and research activities, including leading the development of operational policies and procedures that utilize research findings of the 9/11 attack-related health impacts to optimize the clinical outcomes, medical treatment, and overall well-being of WTC Health Program members.

CDR Anderson received her medical degree from the Uniformed Services University of the Health Sciences (USUHS) in 2009 and completed her OB/GYN residency at the Naval Medical Center Portsmouth (NMCP) in 2013. Board certified in OB/GYN, she completed a second board certification in Preventive Medicine in 2020 through the CDC's Population Health Training in Place Program/Preventive Medicine Residency. She continues to enjoy direct patient care as an Associate Professor of Gynecology and Obstetrics at Emory University School of Medicine in Atlanta, GA.

## Martha Sibley, Ph.D.

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## Biographical Summary

Martha Sibley, Ph.D., is a Social Science Research Analyst at the Center for Medicare and Medicaid Innovation (CMMI), evaluating models related to episode-based payments and maternal-child health. Her research priorities include health equity, preventative care, and pregnant and postpartum health.

Prior to joining CMMI in 2023, Dr. Sibley's research centered on the influence of social identity on behavior and policy, such as the social, economic, environmental, and policy impacts of women's representation in national parliaments. She has served as a Christine Mirzayan Science and Technology Policy Fellow and researcher at the National Academies of Sciences, Engineering, and Medicine within the Gulf Research Program. Dr. Sibley has also supported projects related to mental health and substance abuse programs in tribal healthcare systems in Oklahoma with the American Indian Research Group. Dr. Sibley earned her Ph.D. in sociology from Oklahoma State University with concentrations in social psychology and environmental sociology.

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## Biographical Summary

Tammy White, PhD, is a Social Science Research Analyst on the Data Analytics and Reporting Team in the Children's Bureau (CB). She is primarily responsible for managing, analyzing, and reporting on the data submitted to the National Youth in Transition Database. She also provides guidance and consultation to the Child and Family Services Review unit on performance measurement and sampling issues. Before joining the CB, Tammy worked in the nonprofit sector in Philadelphia, where her research and evaluation experience focused on issues related to youth aging out of foster care and youth development, violence, and substance use disorder. She has a Master of Social Work from Virginia Commonwealth University and a PhD in Social Welfare from the University of Pennsylvania.

# Appendix D: Ad Hoc Members

**CJ Lutke**, who is 40 years old, was diagnosed with fetal alcohol syndrome when she was a baby. She was adopted when she was five, along with an older brother and sister who also have FASD and has dealt with most of the usual consequences of FAS. She is a founding member of the International Adult Leadership Collaborative (ALC) of FASD Changemakers, a group of 16 adults from seven countries who work together to change outdated perceptions about FASD, and guides much of its work. CJ is a well-known speaker on FASD, having presented widely and internationally at, and participated in, many conferences, seminars, training sessions and other events for many years, sharing her experiences and what she has learned living with FASD. She writes all of the presentation work done by the ALC team. She sits on numerous advisory committees for university research projects on FASD, has taught medical students, and sat on a committee chaired by the Chief Justice of the Supreme Court of British Columbia to begin to reform the family justice system, is currently on its new Community of Action for Children and Youth. She was involved as one of the trainers in 3- year mentoring program for FASD in Ontario to develop trained mentors who have FASD. She is the author of an on-line blog that is hosted by NOFASD Australia and followed globally and does media work. CJ also provides on-line mentoring to young adults with FASD. In 2016-2017, she was co-lead of a ground-breaking Changemakers study on the health and physical issues of 500 adults with diagnosed FASD that has received wide international attention and was published in 2020. She is the lead of the Changemakers' second survey on the Quality of Life for 461 teens and adults with FASD, which will be published in May 2024. She is also the adoptive parent of a 11-year-old son with FASD who came from the foster care system at age four. CJ believes those with FASD must take charge of changing the future, challenging perceptions about possibilities and outcomes. Her goal is to help others with FASD find their voice and to help society understand that we are greater when we are united and work together.

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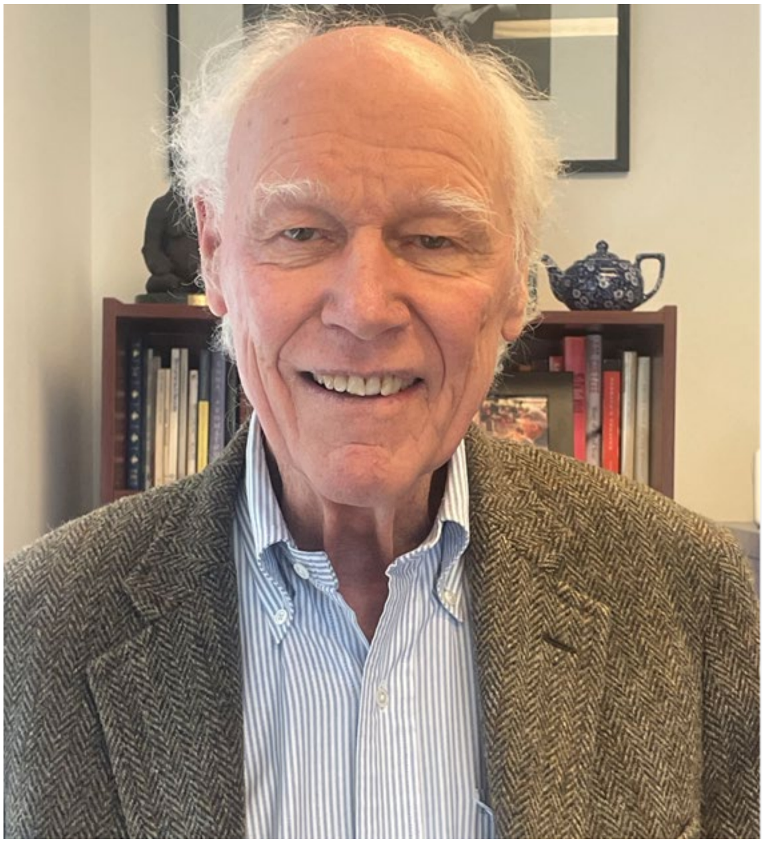
**Jan Lutke** was the co-chair of the former National Advisory Committee on FASD to Health Canada, Government of Canada, for five years, appointed by the Federal Minister of Health, and chaired its sub-committee on Quality of Life. She has been a member of many additional provincial and national advisory committees with respect to FASD and was invited to present at the inaugural WHO invitation only Forum on Alcohol, Drugs and Addictive Behaviours in 2019 and attended as an invited FASD expert in 2021. She was the Clinical Research Manager for the Canada FASD Research Network (CanFASD) for ten years until her ‘official’ retirement. She developed, guided, and chaired the annual international FASD research and adult conferences held in Vancouver for the last 34 years and developed and manages the FASD Changemakers and their work. Jan Lutke chaired the 9th International Research Conference on Adolescents and Adults with FASD held on April 11-15, 2024, in Seattle, WA. She is a published author on many papers, including the Canadian FASD Diagnostic Guidelines, and book chapters for the University of Washington and University of Alaska Presses, and has written much material on FASD that is widely used. She and her late husband adopted 22 children from foster care, 16 of whom have a diagnosis of FASD and now range in age from 32 to 50.

## Appendix E: Invited Speakers



**Kenneth Lyons Jones, MD**, is Distinguished Professor of Pediatrics and was for 50 years Chief of the Division of Dysmorphology and Teratology in the School of Medicine at the University of California, San Diego, I co-direct the Center for Better Beginnings. I am one of two physicians who first described the fetal alcohol syndrome (FAS) in 1973, and I have clinically evaluated hundreds of children prenatally exposed to alcohol in the United States, Russia, Ukraine, Italy, South Africa, South Korea, and Poland. I have led numerous research studies involving pregnant women, environmental exposures, and birth and child health outcomes. For 40 years I directed the Birth Defects Clinic at UCSD where I evaluated children from throughout southern California. In 1976 I founded the California Teratogen Information Service which is now referred to as Mother To Baby. Similar programs have been started throughout the United States, Canada, Europe, Ukraine, Japan Australia and South America all modeled after our program. I am the author of Recognizable Patterns of Human Malformation, which is in its 8th edition

**Kathleen T. Mitchell, MHS, LCADC,** is Senior Vice President of FASD Prevention and Recovery Services, FASD United**.** She served as Vice President and Spokesperson for FASD United (formerly the National Organization on Fetal Alcohol Syndrome-NOFAS) for 24 years. She holds a Master of Human Services (MHS) degree and is a licensed clinical alcohol and drug counselor (LCADC). Ms. Mitchell served as principal investigator (PI) and project officer for government projects that aimed to prevent FASD, reduce stigma, and support families and individuals living with FASD. She taught at Georgetown and Northwestern University Medical Schools and served on the special committee of the World Health Organization (WHO) developing guidelines for the identification and management of substance use disorders in pregnancy. In 2004, she founded the international birth mother mentorship program, the Circle of Hope (COH) and in 2020, founded Recovering Mothers Anonymous (RMA). She is a noted invited speaker on Fetal Alcohol Spectrum Disorders (FASD), Women and Addiction and Stigma and has presented for over three decades both nationally and globally. In 1990, Ms. Mitchell testified to Congress at the first hearing on FAS/FAE and in 1992 and 1994 she testified at hearings that later resulted in warning labels on all alcohol products. She has served as an expert to advise media and has been featured in documentaries, television, and news stories, including National Public Radio, NBC's Later Today Show, BBC Radio, Washington Post, and other. She authored or co-authored twenty-three published papers, and authored handbooks, chapters, and curricula. Ms. Mitchell continues to speak at conferences and provide training and supports the COH speakers bureau that partners with the American College of Obstetricians and Gynecologists (ACOG) in speaking at grand rounds at medical facilities across the U.S.

**Janine Austin Clayton, M.D.**, Associate Director for Research on Women's Health and Director of the Office of Research on Women's Health (ORWH) at the National Institutes of Health (NIH), is the architect of the NIH policy requiring scientists to consider sex as a biological variable across the research spectrum. This policy is part of NIH's initiative to enhance reproducibility through rigor and transparency. As co-chair of the NIH Working Group on Women in Biomedical Careers with the NIH Director, Dr. Clayton also leads NIH's efforts to advance women in science careers. In 2021, Dr. Clayton was elected to the Board of Directors of the American Association for the Advancement of Science (AAAS).

Prior to joining the ORWH, Dr. Clayton was the Deputy Clinical Director of the National Eye Institute (NEI) for seven years. A board-certified ophthalmologist, Dr. Clayton's research interests include autoimmune ocular diseases and the role of sex and gender in health and disease. She is the author of more than 120 scientific publications, journal articles, and book chapters.

Dr. Clayton, a native Washingtonian, received her undergraduate degree with honors from Johns Hopkins University and her medical degree from Howard University College of Medicine. She completed a residency in ophthalmology at the Medical College of Virginia. Dr. Clayton completed fellowship training in cornea and external disease at the Wilmer Eye Institute at Johns Hopkins Hospital and in uveitis and ocular immunology at NEI.

Dr. Clayton has received numerous awards, including the Senior Achievement Award from the Board of Trustees of the American Academy of Ophthalmology in 2008 and the European Uveitis Patient Interest Association Clinical Uveitis Research Award in 2010. She was selected as a 2010 Silver Fellow by the Association for Research in Vision and Ophthalmology. In 2015, she was awarded the American Medical Women's Association Lila A. Wallis Women's Health Award and the Wenger Award for Excellence in Public Service. Dr. Clayton was granted the Bernadine Healy Award for Visionary Leadership in Women's Health in 2016. She was also selected as an honoree for the *Woman's Day* Red Dress Awards and the American Medical Association's Dr. Nathan Davis Awards for Outstanding Government Service in 2017. In 2023, Dr. Clayton received the American Medical Women's Association AMWA Presidential Award.