

Advocating for Individuals and Families Living with Fetal Alcohol Spectrum Disorders
November 12, 2021
Speaker Bios

Tom Donaldson, President and CEO of FASD United (formerly NOFAS), is responsible for formulating and carrying out the FASD United strategic and business plans, and all programmatic, development and policy initiatives. He has extensive experience in non-profit governance, public policy, government affairs, media relations, social marketing, financial management, and public health. Under his leadership, FASD United has established a network of over 30 affiliated organizations, expanded services to all 50 states, and ensured a four-fold increase in federal and state investment in FASD-related research, public health and services, among numerous other achievements.

He served as a member of the Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence Steering Committee and as a liaison representative to the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect. He also served on maternal/child health and alcohol-related policy boards and committees, including the National Healthy Mothers, Healthy Babies Coalition Executive Committee, the National Association of Broadcasters Alcohol Policy Advisory Board, and as a member of the National Advisory Council on Alcohol Abuse and Alcoholism. In 2014, he received the Senator Harold Hughes Memorial Award from the National Institute on Alcohol Abuse and Alcoholism (NIAAA), part of the National Institutes of Health.

Tom Masseur is the Executive Director of Disability Rights Arkansas (DRA). DRA is a private nonprofit organization advocating for and enforcing the legal rights of people with disabilities in Arkansas.

Tom has over 30 years of experience advocating for the rights of individuals with disabilities. Prior to arriving at Disability Rights Arkansas in 2013, Mr. Masseur served as the Executive Director of Disability Rights Wisconsin from January 2012 to February 2013. He worked at Michigan Protection and Advocacy Service, Inc. (MPAS) since 1987 serving as the Director of Government & Media Relations from 2002 – 2012.

Throughout his roles, he has provided strategic direction and leadership on public policy efforts at the state and federal levels; represented the agencies position and interest on issues before State legislatures and Congress; and coordinated the agencies' media relations activities.

At the national level, Tom serves as the President on the National Disability Rights Network (NDRN) Board of Directors, member of the National Association of Rights Protection and Advocacy (NARPA) Board of Directors and serves as a National Advisor for the Self-Advocates Becoming Empowered (SABE) Board of Directors.

On a state level, Tom serves on the Arkansas Governor's Council on Developmental Disabilities, Arkansas Rehabilitation Council, and the Arkansas Supreme Court Commission on Children,

Youth and Families. He was also a member of the Youth Justice Reform Board. Tom is also involved in many state coalitions working to advance disability rights.

While in Michigan, Tom served as a Township Trustee in Lansing Township from 2000 to 2012. Tom is married to Penny and they have three boys. They make their home in Maumelle.

David Deere, MSW, MTh, retired in 2020 as the director for Partners for Inclusive Communities (AR UCEDD) and training director for Arkansas Regional LEND. For 15 years, he worked on FASD projects funded by the CDC and SAMHSA. He currently serves as the co-director of the Specialty Diagnostic Resource Center, which is the first clinic and resource center in Arkansas devoted to children and adolescents suspected of having an FASD. He is the founder of the FASD Special Interest Group at the Association of University Centers on Disabilities. David is a member of the Arkansas None for Nine Board and is active with the FASD United Affiliate Network. He is a social worker by training and a retired member of the United Methodist clergy.

Larry Burd received his PhD from the University of Manitoba Health Science Center in Winnipeg, Manitoba in Community Health Sciences. Dr. Burd currently is a professor in the Department of Pediatrics at the University of North Dakota School of Medicine and Director of the North Dakota Fetal Alcohol Syndrome Center and FAS Clinic. Dr. Burd has been with the Pediatric Therapy Program for 40 years where he has evaluated over 18,000 children with birth defects, developmental disorders and mental illness. Dr. Burd has conducted research in 41 countries around the world. He has ongoing longitudinal studies of linked cohorts of subjects with Tourette syndrome, autism, fetal alcohol syndrome and infant mortality risk that are in their 28th consecutive year of data collection. He published over 220 professional papers on topics dealing with development and behavior in children and adolescents. He has had clinics for children with developmental disabilities and mental health disorders on Tribal Nations for over 30 years.

Dr. Kenneth Lyons Jones is the Chief of the Division of Dysmorphology & Teratology at the Department of Pediatrics at UCSD, Medical Director of the MotherToBaby California Pregnancy Health Information Line, and co-Director of the Center for Better Beginnings. He is a pediatrician by training, specializing in the identification and treatment of birth defects. He is actively involved in research, teaching, clinical work, and University and public service. He is considered the leading expert of Fetal Alcohol Syndrome (FAS), as he was one of two doctors at the University of Washington who first identified FAS in the United States in 1973.

Dr. Jones' research has focused on the evaluation and diagnosis of birth defects, identifying the mechanisms of normal and abnormal fetal development, and the recognition of new environmental agents that cause birth defects. His work on the recognition of new human teratogens is primarily focused through MotherToBaby California, a counseling and research program funded in part by the State of California and monies received from the Organization of Teratology Information Specialists (OTIS) as part of a cooperative agreement with the Health

Resources and Services Administration (HRSA) of the US Department of Health and Human Services.

Dr. Jones has authored over 400 publications in scientific journals as well as several books, and is the author of the textbook titled Smith's Recognizable Patterns of Human Malformation.

Dr. Christina Chambers is a Professor in the School of Medicine at UC San Diego. She is Co-Director of the Center for Better Beginnings, Program Director of MotherToBaby, a service providing evidence-based information on exposures during pregnancy and lactation, and is Program Director of Mommy's Milk, a human milk biorepository for research.

Dr. Chambers leads a number of national and international complex longitudinal cohort studies and clinical trials of prenatal exposures and child health and development. Her research has been instrumental in identifying previously unrecognized human teratogens, as well as ruling out substantial risk for medications and vaccines.

Dr. Paul Connor is a clinical neuropsychologist who is a licensed psychologist in the states of Washington and Oregon. He obtained a Bachelor's Degree from the University of Washington, majoring in psychology. Following this, he received a Ph.D. in clinical psychology with a specialization in neuropsychology from Brigham Young University and completed an internship at Henry Ford Health System, specializing in neuropsychology. He received post-doctoral training in neuropsychology and Fetal Alcohol Spectrum Disorders (FASD) at the University of Washington. For over 13 years, he conducted research focusing on the effects of prenatal alcohol exposure as it pertains to neuropsychological and mental health functioning and the structural and functional brain anomalies often seen in these disorders. He continues to consult on research studies relating to impacts of prenatal alcohol exposure. Dr. Connor has authored or co-authored nearly 20 peer reviewed manuscripts and 3 book chapters focusing on the neuropsychological, neuroimaging, and psychiatric implications of the long term effects of prenatal alcohol exposure into adolescence and adulthood. In addition, he has presented and consulted internationally about assessment and diagnosis of FASD. Dr. Connor continues to be a Clinical Assistant Professor in the Department of Psychiatry and Behavioral Sciences' Fetal Alcohol and Drug Unit (FADU) at the University of Washington. He is currently in private practice, conducting neuropsychological evaluations in clinical and forensic settings, utilizing a battery of tests that have been shown to be sensitive to the effects of prenatal alcohol exposure in over 30 years of research on this subject.

Stephen Greenspan, Emeritus Professor at the University of Connecticut, is a psychologist who specializes in developmental disability. He resides in Northern California, where he has become active in several appeals of DD turn-downs of services for people with FASD and other brain-based disorders. He also consults around the US in criminal (especially death penalty) cases, where FASD can serve as a penalty mitigator. Within the DD field, he is especially known for many papers on the role of social incompetence, particularly unawareness of social risk, as a defining feature. His most recent book is "Anatomy of Foolishness" and he is under contract for

a follow-up book titled “Naïve Offenders: Neurodevelopmental Disorders in Forensic Context.” He can be contacted at stephen.greenspan@gmail.com

Diane Smith Howard is a litigator with more than 26 years of experience in juvenile and education law. Her work at NDRN focuses on conditions for children, youth and adults with disabilities in institutional systems. Specifically, youth in the juvenile justice, child welfare, education, and refugee resettlement systems, and adults with disabilities in the criminal justice and mental health systems. Diane provides training and technical assistance to the P&As on these issues. In addition, she advocates on these issues within the Administration and on the Hill, working with a number of civil rights coalitions.

Diane holds a B.A. with honors from Colby College, Waterville, ME, and a J. D. from Wayne State University Law School, Detroit, MI. She retains active bar licenses in Michigan and Maine. In addition to working previously at NDRN’s earlier iteration, NAPAS, she has also provided direct client representation, including systemic case representation, at the P&As in Maine and Michigan, and for a legal services office in rural Michigan. She has classroom teaching experience at the graduate, undergraduate, and high school level.

Diane’s passion for this work is rooted in a family connection to foster and adopted children with disabilities, and to adults who are at risk of institutionalization due to a lack of community supports.

William “Billy” Edwards is considered one of the early pioneers in the training of attorneys around issues involving fetal alcohol spectrum disorders (FASD). Mr. Edwards is a Deputy Public Defender in Los Angeles California, working in the Los Angeles County Mental Health Court, representing clients with mental illness and developmental disorders. Prior to that Billy worked on capital habeas appeals in Florida, and a paper he co-authored on people with intellectual disabilities on death row in the United States was cited by the United States Supreme in *Atkins v. Virginia*. The *Atkins* decision finally exempted defendants with Intellectual Disabilities from the death penalty. In 2006, Edwards was appointed to serve on the *President’s Committee for People with Intellectual Disabilities* and later was appointed for a second term. This is a federal advisory committee established by presidential executive order to advise the President of the United States and the Secretary of the Health and Human Services on issues concerning the lives of citizens with intellectual disabilities.

While serving on this Presidential Committee he became interested in FASD and initiated a series of workshops (still ongoing) on the disorder for attorneys around the US and the world. In 2011, he served as the editor of a landmark two-volume issue of the *Journal of Psychiatry and Law* which focused on the legal aspects of FASD. In 2012 he helped to draft and secure the passage of a resolution by the *American Bar Association*, calling on all people working in the criminal justice system to be aware of FASD.

On March 13, 2014, Mr. Edwards was appointed to serve on the Board of Directors for the *National Organization on Fetal Alcohol Syndrome* in Washington, D.C. On August 2014, Mr. Edwards was presented in Seattle with the *Dr. Ann Streissguth, Ph.D. Annual Award for Outstanding Contribution to the Field of FASD and the Law*. The award was named after Dr.

Ann Streissguth who in 1973 was the first psychologist to administer psychological testing on children who were born with FAS. He currently serves as the Chair for the National Organization on Fetal Alcohol Syndrome Justice Task Force.

In 2014, NOFAS inducted him into the *Tom and Linda Daschle* FASD Hall of Fame. In 2019, he was invited to assist the *U.S. Department of Health and Human Services (DHHS) Office of the Assistant Secretary for Planning and Evaluation (ASPE)* to develop policies aimed at reducing the lifelong burden on children and families that arise from *in-utero* exposure to alcohol.

John C. Williams is an Assistant Federal Public Defender at the Federal Public Defender's Office for the Eastern District of Arkansas. He primarily represents death-sentenced prisoners in federal habeas-corpus proceedings.

Tonya Y Willingham, PhD is a Mitigation Investigator with the Federal Public Defender Eastern District- Arkansas. She has served in that role since 2007 where she has worked with individuals sentenced to death by the State of Arkansas. She works as a member of the defense team to investigate the client's life history and identify emerging themes that may provide insight on how the client came to commit his crime. Dr. Willingham's employment background includes administrative positions in juvenile justice, residential care, foster care and counseling, She has authored and co-authored publications in the field of criminal and juvenile justice and has served as an adjunct faculty member at the University of Arkansas at Little Rock. She has served as a Contract Trainer of Foster and Adoptive Parents for the State of Arkansas and has authored and administered local, state and federal grants. She earned her doctorate in Juvenile Justice at Prairie View A & M University, Master's degree in Counseling at Louisiana Tech University and Bachelor's degree in Psychology at the University of Central Arkansas.

Douglas Waite, MD is Division Chief of Developmental-Behavioral Pediatrics at Bronxcare Health System and Assistant Clinical Professor of Pediatrics at Mount Sinai Hospital. Dr. Waite serves as Vice Chair on the board of the National Association on Fetal Alcohol Syndrome (NOFAS), serves on the FASD task force for the American Academy of Pediatrics, is a member of the AAP Executive Council on Foster Care, Adoption and Kinship Care, and previously served on the Board of Directors of the Child Welfare League of America. He has special interests in neurodevelopmental disorders associated with prenatal alcohol and substance exposure, post-traumatic stress disorder and the effects of child abuse and neglect upon child development.