



Congressional BRAIN Initiative Briefing on the Importance of Neuroethics

On June 23, 2022, the American Brain Coalition (ABC) joined with the American College of Neuropharmacology, the Dana Foundation, the International Neuroethics Society, and the Simons Foundation, to host a virtual briefing in cooperation with the Congressional Neuroscience Caucus. The briefing focused on the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, specifically the importance of neuroethics.

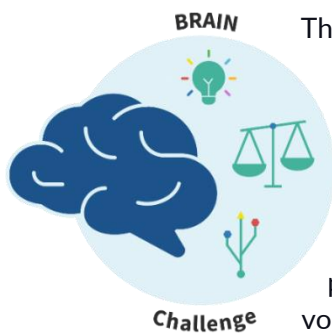
The briefing began with opening remarks from Congressional Neuroscience Caucus Co-Chairs **Congressman Earl Blumenauer** (D-OR) and **Congresswoman Cathy McMorris Rodgers** (R-WA).



*Congresswoman
Cathy McMorris Rodgers
(R-WA)*



*Congressman
Earl Blumenauer
(D-OR)*



The winners of the 2022 BRAIN Initiative Teen Challenge were highlighted and announced by ABC Chair, Matthew Rizzo, MD, the briefing moderator. This competition highlighted significant neuroethical issues that technology and treatment need to consider in all phases of implementation. The winning video featured a high school student highlighting his experience with a neuromuscular disease called Friedreich's Ataxia, which fueled his passion to advocate for brain research. His video spotlighted the importance of voluntary consent, de-identified data, and continuous research.



*Joseph J. Fins, MACP, FRCP
President
International Neuroethics Society*

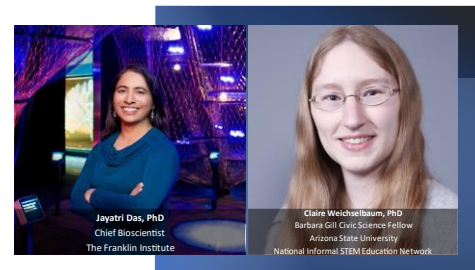
Dr. Joseph J. Fins, President of the International Neuroethics Society, and the E. William Davis, Jr. MD Professor of Medical Ethics at Weill Cornell Medical College and the Solomon Center Distinguished Scholar in Medicine, Bioethics and the Law and Visiting Professor of Law at Yale Law School began by presenting a project he has developed through grant funding from the BRAIN Initiative, titled, "Cognitive Restoration: Neuroethics and Disability Rights." He conducted interviews with subjects and families participating in the Central Thalamic Stimulation for Traumatic Brain Injury Study led by Dr. Nicholas D. Schiff and also funded by the BRAIN Initiative. Dr. Fins noted the significance of TBI and its threat to public health, as well as the current lack of active treatment for this type of injury.

In TBI, deep brain stimulation targets behavioral improvement through activation of the mesocircuit, to improve cognition and consciousness. The work began in minimally conscious subjects. Those results published in *Nature* in 2007 showed increased cognitively-mediated behaviors, language, limb control, and oral feeding in individuals with severe impairments. The 2022 data, as yet unpublished, reveals promising preliminary results: all five subjects who completed it had a greater than ten percent improvement in processing speed and executive function.

Dr. Fins reported that pre-operative interviews in his study revealed that subjects and their families viewed the risks of surgery differently with families being hesitant to delegate authority to subjects and acknowledge their agency even though they had decision-making capacity and were legally competent. Dr. Fins discussed the impact of brain injury on the transformation of individual identity with restoration of "former" selves post-operatively. While this was viewed as a positive development by subjects and families these changes led to altered expectations and the challenge of social

reintegration. One concern of subjects was that of post-trial access maintenance related to costs, access, and battery replacement. Dr. Fins concluded his presentation by emphasizing the importance of social networks for patients, vocational and academic reentry, and social structures to advance the rights of individuals with severe brain injury. Moreover, he emphasized the absolute need for improved rehabilitation, medical management, and overall civil/disability rights for patients who have experienced brain injuries. In collaboration with his students at Yale University, he has written and proposed an "Americans with Abilities Act" in his NIH grant and in a forthcoming article in the *Boston College Law Review* a proposal that, "empowers individuals and adopts a capabilities approach."

Dr. Jayatri Das, Chief Bioscientist at The Franklin Institute, and **Dr. Claire Weichselbaum**, a Barbara Gill Civic Science Fellow at Arizona State University, then highlighted the importance of public engagement with neuroethics. Both are involved in developing strategies to facilitate dialogue around neuroethics issues through their work with the National Informal STEM Education (NISE) Network, a consortium of local community partners across the United States such as museums and science centers. Dr. Das introduced the significance of bidirectional public engagement, as stated by the BRAIN Initiative Working Group 2.0, which emphasizes the interdependent relationship between science and community perspectives to advance research and policy. This concept is being applied to the subject of neuroethics to reflect on how neuroscience technology will affect society.



Dr. Weichselbaum introduced guiding ethical questions developed by the International Brain Initiative to better understand the issues and consequences of this research. These questions consider social and cultural implications, ethical standards of data collection, the moral significance of experiments, reduction of autonomy by brain interventions, and contexts in which technology might be deployed. Dr. Das noted current strategies for public engagement found in a study she conducted with funding from The Kavli Foundation. The five categories of strategies included structured assessment of public opinion, exhibits/public programs, inspirational media, expert discussions, and clinical partnerships. Dr. Das concluded her points by emphasizing the improvement opportunities for neuroethics engagement by fostering collaborations, supporting local networks, expanding training resources, and creating shared resources.

The presentation concluded with polls asking viewers to reflect on ethical issues of data privacy, identity, and autonomy in the context of various neurotechnologies, as a demonstration of neuroethics engagement in practice. The speakers highlighted actions that would aid in public engagement for this research. These included the investigation of neuroethics concerns of both BRAIN investigators and the public, development and evaluation of neuroethics education programs, and identification of successful strategies for engagement.

Dr. Rizzo closed the briefing by asking that members of Congress and their staff continue to support robust funding for biomedical research, including the BRAIN Initiative.

