

Session - Taking on Rare Disease Through Advocacy, Research, and Investment

Companies and organizations in our state seek to treat, and ultimately cure, diseases seen as incurable. We hear from the innovators and advocates working to advance breakthroughs from the bench to the patient's bedside.

Panelists include:



(Moderator) Michele Oshman - Vice President for External Affairs, Biotechnology Innovation Organization (BIO) / Executive Director, Council of State Bioscience Associations (CSBA)

Michele M. Oshman is Vice President for External Affairs at the Biotechnology Innovation Organization (BIO) and serves as the Executive Director for the Council of State Bioscience Associations (CSBA). BIO is the world's largest

trade association representing member biotechnology companies focused on human health, agriculture, and the environment. BIO also represents state bioscience associations, academic institutions, and related organizations across the United States and over 30 countries around the world. As the leader of CSBA, a federation of state-based, non-profit trade organizations each governed by its own board of directors, she works to advance their mission to promote public understanding of, and advocate for public policies that support the responsible development of the bioscience industry. As the Vice President for External Affairs at BIO, she leads BIO's outreach to the patient, consumer, multicultural and research advocacy community.

Ms. Oshman joined BIO in January 2020 after a successful 18-year career at Eli Lilly and Company, where she led federal advocacy outreach. She started her career as a clinical neuroscience researcher and served in multiple clinical development and corporate leadership roles. She earned a Six Sigma Black Belt in 2005 and led multiple transformational efforts across the company before joining the advocacy team in 2007.

From 2012-2014, she served as Chair of the Biotechnology Innovation Organization Alliance Committee and held the same position with the PhRMA Alliance Development Section from 2015-2016. She chaired the Arthritis Foundation Industry Forum from 2014 - 2016, and currently co-chairs the Lupus Foundation of America corporate council. As well, she serves on the corporate advisory councils for a portfolio of national advocacy organizations.

Ms. Oshman serves on the Board of Directors of the American Brain Coalition, a non-profit organization comprised of the United States' leading professional neurological, psychological, and psychiatric associations. She recently completed her tenure on the Board of Directors for Capital Clubhouse, a Washington DC community mental health agency, which provides psychosocial, vocational, and housing support for people struggling with severe persistent mental illnesses.

An active member of the Japan America Society of Washington DC, Ms. Oshman graduated from American University with a dual degree in Political Science and Communications.



Jessica Wolfe - Head of Pipeline Patient Engagement, Jazz Pharmaceuticals

Jessica Wolfe is a seasoned Government Affairs, Public Policy, Patient Advocacy and ESG leader from Denver, Colorado. Jessica is a graduate of Vanderbilt University, where she studied Political Science and Communication

Studies and earned an Executive MBA at Daniels College of Business at the University of Denver. She has two decades of healthcare sales, consulting, advocacy, and lobbying experience, having worked for industry leaders like Allergan, Boehringer Ingelheim, Cardinal Health, Boston Scientific, and Greenwich Biosciences. She has created and run State Government Affairs Programs for three different biotech companies, Boston Scientific, Scilex and Jazz/GW Pharma, and recently led Jazz's first in-house ESG team. Jessica and her Patient Advocacy and Engagement Team work to help Jazz deliver on their commitment to innovate to transform the lives of patients. Jessica previously served as a founding member of the Patient Experience Advisory Group for the state's Health Insurance Exchange, Connect4Health Colorado. She is a kidney donor and rare disease caregiver and lives in Denver with her wife Jennifer, son Max, and two rowdy rescue dogs named George and Tucker.



Jeff Porter - CEO & Founder, Handbid

Jeff Porter is a visionary CEO with a long and eventful career in product development and executive management for tech companies. Having grown up in Washington DC and graduated from UVA with a B.S. in Electrical Engineering, Jeff was well-equipped to make his mark on the tech industry. After several years

of leading Internet companies, Jeff eventually became Vice President and General Manager of DexKnows.com before starting his own venture, MobilePeople USA - an innovative mobile apps developer for media enterprises. Following the success of MobilePeople, Jeff created Handbid - a pioneering mobile app that facilitates thousands of charity fundraisers every year and has helped organizations raise over \$750 million to this day.

It was Jeff's daughter Abby's diagnosis with Prader-Willi Syndrome (PWS) that inspired him to help others affected by the condition alongside his wife Kari by starting the Prader-Willi Syndrome Association of Colorado and joining the Foundation for Prader-Willi Research. For over 13 years, Jeff worked hard towards increasing public awareness about PWS while driving technological advancements in fundraising activities organized by both foundations he was involved in. In 2018, Jeff left FPWR board after an impressive tenure while still working closely with PWSA of Colorado as it continues funding research projects, providing assistance at multi-disciplinary clinics based at Children's Hospital and advocating on behalf of families affected by PWS today.



Clay Smith - CMO, OncoVerity

Clay Smith, MD is currently the CMO of OncoVerity which is devoted to developing cusatuzumab and anti-CD70 antibody as a novel therapy for AML and potential other cancers. He is also the CMO/CSO of RefinedSciences, a precision medicine company which uses single cell omics data and carefully

curated clinical data to identify new therapeutics and other breakthroughs for AML and other cancers. Previously, he served as the Director of the Blood Disorders and Cell Therapies Center at UCHealth, the Associate Chief of the Division of Hematology at the University of Colorado and the Medical Director for the CU and UCHealth Innovation Centers. He has been on faculty at Sloan Kettering, Duke, Moffitt and the BC Cancer Agency and has directed clinical blood cancer, BMT and cell therapy programs as well as translational research and clinical trials units for >20 years. He has authored >150

manuscripts, received dozens of grants, holds numerous patents, has helped found or consulted with several other companies and has received a number of awards including being the inaugural recipient of the CU Department of Medicine Innovator of the Year award.



Mike Mattoon - Vice President of Government Affairs and Policy, Acadia Pharmaceuticals

Mike Mattoon is Vice President of Government Affairs and Policy for Acadia Pharmaceuticals, joining Acadia in June 2022 after nearly 25 years working in nearly every facet of politics; from Capitol Hill, to campaigns at every level from

city council to presidential, to advocacy in the healthcare sector.

Before joining Acadia, Mike was Vice President of Federal Government Relations for the Biotechnology Innovation Organization (BIO), a trade association representing nearly 1,000 biopharmaceutical companies at every stage of research, development, and commercialization. Prior to joining BIO, Mike led federal relations for Vertex, a leading biotech company based in Boston. Previous to that, Mike spent seven years lobbying for Boston Scientific, a major, diversified medical device manufacturer.