Connecticut Rare Disease Forum - Biographies

Michael Aberman, M.D., General Partner, Regeneron Ventures

Prior to joining Regeneron Ventures, **Michael Aberman, M.D.**, was the CEO and co-founder of XenImmune Therapeutics, a seed stage biotech company. Previously, he was the president and chief executive officer of Quentis Therapeutics, an early-stage biotech company. Before Quentis, Aberman spent over seven years at Regeneron, most recently as the senior vice president of Investor Relations and Strategy. In that role, he was a member of the senior management team and responsible for investor relations, corporate communications, business development and corporate strategy. Aberman joined Regeneron after six years as a biotechnology analyst at Credit Suisse and Morgan Stanley. Previously, he was director of Business Development at Antigenics, Inc., an oncology-focused biotechnology company. He received his B.A. from Cornell University; his medical degree from the University of Toronto; completed residency training in internal medicine at New York Presbyterian Hospital; and received an M.B.A. from The Wharton School of Business.

Mark Adams, Ph.D., Interim Scientific Director and Professor, The Jackson Laboratory for Genomic Medicine

Mark Adams leads the clinical and research genomics services that provide access to next-generation sequencing platforms for JAX researchers. The CAP-accredited Advanced Precision Medicine Laboratory offers genetic testing to patients in the context of cancer and rare diseases.
Adams was a co-founder of The Institute for Genomic Research and Celera Genomics where he led the DNA sequencing and genome annotation groups responsible for sequencing of the initial human, mouse and Drosophila genomes. He then joined the Department of Genetics at Case Western Reserve University, where he was an associate professor. Prior to joining JAX, he was the scientific director and professor at the J. Craig Venter Institute where he directed programs that characterized genomic changes in the evolution of antibiotic resistance in hospital-acquired infections. Adams has a B.A. in Chemistry from Warren Wilson College and a Ph.D. in Biological Chemistry from the University of Michigan.

Angela Cacace, Ph.D., Chief Scientific Officer, Arvinas

Angela Cacace serves as chief scientific officer at Arvinas. She brings more than two decades of biopharmaceutical research and pharmacology experience, contributing to four marketed drugs and over 18 development candidates. Previously, Cacace served as the vice president of Biology at Fulcrum Therapeutics, where she built the biology platform and delivered the first development candidate for the treatment of facioscapulohumeral muscular dystrophy (FSHD).
Additionally, she was the director of Neuroscience and Genetically Defined Diseases at Bristol Myers Squibb, where she spearheaded alternative therapeutic modalities and was a co-inventor on several development candidates. Throughout her time at Bristol Myers Squibb, she was responsible for building research-wide teams and initiatives, including the Lead Profiling Function, GPCR High Throughput Screening Team and the Cellular Resource Team. While serving as a senior principal scientist in Cancer Biology at Pfizer, together with her team, she discovered a novel anti-angiogenic antibody development candidate. Cacace received her B.S. in Biology from Fairfield University, Ph.D. in Pharmacology from Columbia University and completed her postdoctoral research in Oncology at Bristol Myers Squibb and the National Cancer Institute.

Lon Cardon, Ph.D., FMedSci, President and CEO, The Jackson Laboratory

Lon Cardon, an internationally recognized human geneticist, joined The Jackson Laboratory (JAX) as president and CEO in November 2021. Since then, he has led the development and implementation of a strategic plan that leverages JAX's 95+ years of expertise in mouse models to expand into cellular modeling. This vision has led to the creation of a Rare Disease Translational Center on JAX's campus in Bar Harbor, ME. Cardon was previously the chief scientific officer and chief scientific strategy officer at BioMarin Pharmaceutical Inc., a rare disease biotechnology company. Before BioMarin, he held various R&D leadership roles as a Senior Vice President at GlaxoSmithKline. Cardon's academic career includes Professorships at the University of Oxford, the University of Washington and the Fred Hutchinson Cancer Research Center. His research groups have been involved in large international genetics initiatives that helped to create the present global genomics research infrastructure, including the first Genome-Wide Association Studies; the discovery of numerous genes responsible for rare diseases; and the development of new treatments for genetic disorders.

Monica Coenraads, Founder and Chief Executive Officer, Rett Syndrome Research Trust

Monica Coenraads' involvement with Rett syndrome began the day her then-two-year-old daughter was diagnosed with the disorder. A year later, in 1999, she co-founded the Rett Syndrome Research Foundation (RSRF) and held the position of scientific director, culminating with the groundbreaking work in 2007 that demonstrated the first global reversal of symptoms in preclinical models of the disorder. She launched the Rett Syndrome Research Trust in late 2008 to pursue the next steps. As chief executive officer, with her colleagues and with input from advisors and the scientific community, Coenraads sets and executes RSRT's research agenda. Under Coenraad's leadership at RSRF and RSRT, $123 million has been raised for Rett syndrome. In 2010 she co-founded the Rett Syndrome Research Trust UK. She is on the Advisory Council for The Research Acceleration and Innovation Network of FasterCures and the UNC Autism Research Center Advisory Board, and is a founding trustee of the American Brain Coalition. Coenraads has an M.B.A. from the University of Connecticut and honorary doctorate degrees from the University of Massachusetts Medical School and the University of Edinburgh.

Tom DeFay, Ph.D., Deputy Head of Diagnostics Strategy and Development, Alexion, AstraZeneca Rare Disease

Tom Defay is the deputy head of diagnostics strategy and development, Alexion, AstraZeneca Rare Disease. He has been a leader in pharmaceutical research for almost 30 years. Defay, who has led bioinformatics and genomics teams for AstraZeneca, co-founded the Diagnostics Center of Excellence at Alexion, and has been working with Rady Children's Hospital in San Diego over the past eight years on a rapid whole genome sequencing approach that's become an emerging standard of care in neonatal intensive care units. He is vice chair of the BeginNGS Newborn Sequencing consortium, which is led by the Rady Children's Institute of Genomic Medicine. Defay received his Ph.D. in Biophysics from the University of California, San Francisco and his B.S. in Chemistry from the University of Virginia. Defay did his postdoctoral studies in Computations Biology at Stanford University.

Birgit Fogal, Ph.D., Interim Vice President, Nonclinical Drug Safety U.S., Director, Nonclinical Drug Safety Strategies, Boehringer Ingelheim Pharmaceuticals

Dr. Birgit Fogal received her doctoral degree in Biomedical Sciences from the University of Connecticut (Health Center) in 2007. She pursued postdoctoral training at Yale University in the Department of Immunology until 2010. Her passion to translate scientific discoveries into impactful solutions for patients, then brought her to the pharmaceutical industry. Since 2010, she has held various scientific roles at Boehringer Ingelheim Pharmaceuticals, spanning both Research and Development.

Pamela Gavin, Chief Executive Officer, National Organization for Rare Disorders

Pamela Gavin was appointed chief executive officer of the National Organization for Rare Disorders (NORD®) in May 2024, becoming the third CEO in the organization's 42-year history. Gavin's deep connection to the rare disease community and extensive professional experience make her uniquely suited to lead NORD into its next chapter of innovation, advocacy and impact. Before joining NORD, she held several influential roles in healthcare innovation and safety, including as senior director, Strategic Business Initiatives at the University of Pittsburgh Medical Center, where she launched emerging technologies to improve healthcare delivery; government consultant responsible for developing the Federal Safety Reporting Portal for the NIH, FDA and other organizations; founder and executive of SafeCare Systems, a pioneer in safety management information systems; and division director at the Harvard Risk Management Foundation. Gavin holds a Master of Business Administration in Healthcare Management from Northeastern University and a bachelor's degree from Smith College.

Connecticut State Senator Tony Hwang

A chief deputy Republican leader, **Senator Tony Hwang** is serving his fifth term representing Connecticut's 28th Senatorial District, which includes the towns of Bethel, Easton, Fairfield, and Newtown. He serves as the ranking member of the Transportation and Insurance and Real Estate Committees. He is a member of the Planning and Development Committee and the Finance Revenue and Bonding Committee. He is the Ranking Member of the Bonding Subcommittee of the Finance, Revenue and Bonding Committee, and serves as co-chair of the legislature's bipartisan Bioscience Caucus. Previously, Hwang served as vice-chair of the Aging and Energy & Technology Committees and Ranking Member of the Housing, Higher Education, Public Health, Planning & Development, and Public Safety & Security Committees. Hwang graduated with a Bachelor's Degree in labor relations and organizational behavior from Cornell University. After working briefly with United Technologies, he entered the executive search business, ultimately founding his company recruiting technology executives. For the past several years, he has been involved in residential real estate.

Cat Lutz, Ph.D., M.B.A., Vice President, Rare Disease Translational Center, The Jackson Laboratory

Cat Lutz is the vice president of the Rare Disease Translational Center at The Jackson Laboratory (JAX). With 25 years of experience in mouse genetics, Lutz has focused her research efforts on patient organizations and families diagnosed with rare diseases. The JAX Rare Disease Translational Center incorporates precision mouse models and broad-based drug efficacy testing to support IND enabling studies. She serves as the principal investigator of multiple NIH-sponsored programs, including the Center for Precision Genetics, The Somatic Cell Genome Editing Center, and Mouse Mutant Research and Resource Center. As a neuroscientist by training, Lutz has worked on models of the central nervous system such as spinal muscular atrophy, amyotrophic lateral sclerosis and Friedreich's ataxia. Lutz was recently awarded a 2021 Rare Impact Award by the National Organization for Rare Disorders.

Rebecca Riba-Wolman, M.D., Associate Professor, University of Connecticut School of Medicine

Rebecca Riba-Wolman is an associate professor at the University of Connecticut School of Medicine. She has been an attending physician in the Division of Pediatric Endocrinology at Connecticut Children's Medical Center since 2012. Her dual clinical focus is in neuroendocrinology, endocrine tumors and endocrine late effects of cancer survivors as well as disorders of hypoglycemia, including glycogen storage diseases. She is the director of Glycogen Storage Disease and Disorders of Hypoglycemia Program. Her research focuses on diagnosis and management of disorders of hypoglycemia. She is the site primary investigator of two novel genetic therapy trials for treatment of glycogen storage disease type 1a currently conducted at the Clinical Trials Unit, Department of Pediatrics, UConn Health. These are cutting-edge trials that include gene therapy as well as nucleotide editing done in collaboration with sites around the world. She is the medical director of Endocrine-Oncology and had prior educational and administrative roles including clinical director of the Division of Endocrinology and Program Director of the Pediatric Endocrinology Fellowship program.

Nicholas Vita, Co-Founder, Apriligen, Inc.

Nicholas Vita is a co-founder and board member of Apriligen, Inc., a private CGT platform company founded to develop therapies for rare pediatric hematologic diseases. Apriligen's lead candidate has received rare pediatric and orphan designation and is expected to enroll its pivotal trial in 2025. Previously, he was CEO, co-founder and member of the board of Columbia Care Inc. Prior to that, he was a partner, healthcare PM and a member of the IC at Arx Investment Management, a multibillion-dollar investment fund. He joined Arx from Goldman, Sachs & Co. Inc., where he was a vice president on the Healthcare Investment Banking team. Vita co-founded several nonprofits, including The Styrke Foundation for Rare Disease and Treatment and the Hundred Million Ways Foundation. Among his personal and professional acknowledgements, Vita was awarded a Tribeca Film Festival Disruptive Innovation Award and a Manhattan Project Award for his continuing efforts to combat the national opioid crisis. He was named "Captain of Industry" by the American Trade Association for Cannabis and Hemp (ATACH), and was selected as a "Top 100" Most Influential/Corporate Chiefton/Innovator by several periodicals of record. Vita has been a guest lecturer at various universities and media outlets and currently serves as a member of the board of Nantucket Community Sailing and the Brunswick School.