DIGITAL BIOMARKERS SUMMIT

August 26th, 2024 @ 7AM

Johnson and Johnson
320 Bent St, Cambridge, MA 02141

EVERYTHING ALS
CARE TO CURE

ALS Patients and Caregivers

Brooke Eby
Person with ALS

Janie Gobeli
Person with ALS

When I received my diagnosis in 2021, the first thing I said to my loved ones was that I was going to fight! My husband calls me his fierce warrior. I knew I had a choice to remain positive or let ALS take everything from me, including my attitude. So, I decided to be positive, to have faith, hope, love, and Gratitude. It is my hope to inspire others to remain hopeful in our journeys. I live each day to its fullest. I enjoy travel, concerts, and having fun. I'm not going to let the ALS stop me because I have a lot to live for, including my grandson, who was just born on June 1st. It hasn't been an easy road by far, but I'm here if you need the encouragement, hope, and support to keep fighting!

John Hudacek
Person with ALS

John Hudacek is a 65-year-old male from Melbourne, Florida. He was enlisted in the US Army from 1977-1997 Infantryman, Aerial Photographer and

Special Forces Medic. Afterwards, John worked at a private military international boarding school in Florida from 1997-2009 where he coordinated the flight training, SCUBA, rock climbing, horse riding, martial arts and driver's education programs. From 2010 to 2020, he was a

federal civil servant working for the Army again as an educational advisor in a recruiting unit, then as a recruiter for officers at a college in Florida.

In 2020, John experienced three big events: retirement at 62 years old, COVID-19, and the development of his ALS. John shares that his first notice of ALS onset was his left hand/arm in the summer of 2019. After ruling out carpal tunnel and rotator cuff, he started seeing VA neurologists until an initial diagnosis in August 2021 with the confirmation diagnosis in November 2021. He started all 3 FDA approved medications as soon as they were available. John's ALSFRS-R score was constant at 44 points with no spreading yet and noticeable atrophy in left arm and hand. Currency, he is under VA care, does PT on his own daily, partakes in moderate exercise and watches his diet.

Steve Kowalski
Person with ALS

Steven currently lives in Boston Massachusetts with his three adult children and is originally from West Hartford Connecticut. He attended Keene State College in New Hampshire and graduated with a B.S. in Business Administration with a minor in Marketing and an A.S. in Computer Science. Upon Graduation in 1986, Steven moved to Boston MA and began working as a Manufacturer Sales Representative for Apple Inc. In 1996, Apple changed their go to market sales strategy, and he was hired directly by Apple to continue to serve the education market throughout New England. After 34 years in that line of work, Steven left Apple in 2018 on long term disability and fully retired in November 2020.

ALS Story: Steven was diagnosed in August 2017 after experiencing loss of movement in his toes on his right foot in early 2016. His time to diagnose, upon seeing a Neurologist in 2017, was VERY fast. Within 2 hours Steven was diagnosed with ALS. After a few days of shock and awe, he had an "aha moment". The City of Boston had announced they were proclaiming Sept 5th, 2017, as Pete Frates Day with a ceremony to be held on the steps of City Hall. Less than a week after he received the diagnosis, he was not at all emotionally ready to publicly attend an event for ALS. At this point, Steven hadn't even told his family or friends of his disease. Although, something kept whispering in his ear to go, and he did. At first, he stood as far away as possible. He was not ready to face this reality. As Steven listened to the mayor, members of the Red Sox organization, and others give speeches, he began to be drawn in. It wasn't until Pete's wife and mom spoke that he found himself moving closer and closer to the stage. What they said he desperately needed to hear. In summary, it was a lesson in courage, strength and resiliency. His fog began to lift, and he said to myself, if they have the strength to live with this disease so can he. The question then became; how he can make a difference. Since then, Steven has made ALS his full-time job.

Steven has raised over $250K for research and care, participated in several clinical trials at Mass General Hospital, and joined many ALS organizations in various capacities. He

has participated in many clinical research patients advisory committees, and has been a patient speaker at local and national pharmaceutical companies as well as local colleges and universities with medical programs in the Boston area. He currently serves on the Board of Directors at the Massachusetts ALSA Chapter as Secretary and Chair of the Advocacy Committee. Steven attended the National ALSA Advocacy Conference in Washington, D.C. and served on the ALSA Public Policy Committee. He is currently a NEALS Research Ambassador, Patient Fellow at the MND/ALS International Symposium, and a member of the I AM ALS Clinical Trials Committee. He serves on Team Gleason's Tech Advisory Committee and has consulted with many technology companies who are focused on the use of technology for mobility and communication. He also sits on the HEALEY ALS Platform Trial EAP Patient Advisory Committee. Steven has also recently formed a Massachusetts pALS and cALS group to begin to lobby at the state level. He was nominated and served as a member of the "Improving the Quality of Life for Persons Living with ALS" working group of the 2022 NIH ALS Strategic Planning effort. Recently invited to join AMP ALS, a project that involves the NINDS, FDA, C-Path, pharmaceutical companies, and nonprofits.

Fortunately, Steven's ALS is progressing slowly, but it has and continues to alter his life physically in so many ways. He is still able to walk with a cane and AFO's, and he tries his best to walk as much as he can every day with an Apple Watch that helps him track that.

Dave Shulman
Head of Enterprise Investment at Wells Fargo
Person with ALS
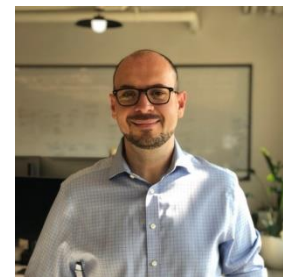
Consortia Members

Sam Alworth
Cofounder & Chief Executive Officer
AcuraStem Incorporated

Ari Azhir
Founder, Chief Executive Officer, & Board Member
Neuvivo

Viprali Bhatkar
Senior Director, Digital Health
Bristol Myers Squibb

Michelle Crouthamel
Head, Digital Science
AbbVie

Yossi Dagon
Associate Director, Lead Biomarker Discover Scientist
Quralis

Jennifer DiMartino
Executive Director
ALS ONE

Jennifer DiMartino is the Executive Director of ALS ONE, overseeing all aspects of the daily operations of the organization, a position she has held for the past 6 years, since its founding in December of 2015. Jen works closely with the ALS ONE research and care teams, ensuring that our goals of advancing critical research while providing essential care resources and equipment to individuals living with ALS are being met. Jen is also the ALS ONE liaison to the ALS community, helping newly diagnosed families navigate the complexities of the disease by connecting them with our partners and together, helping them live the best quality of life possible. Jen sits on the founding benefactor team for the Healey ALS Platform Trial and is a key member of the ALS ONE Board of Directors. Jennifer began her career in the healthcare industry, working at Dana-Farber Cancer Institute for over 5 years, managing the Brain Tumor Clinic under Howard Fine, MD and the leukemia and myelodysplasia laboratory of Dr. Richard Stone. Jennifer's true joy comes from helping others and has gained considerable personal reward throughout her life by helping individuals with heart valve and cardiac electrophysiology issues cope with the emotional aspects of their situation. She is truly honored to have been asked to lead ALS ONE by Its founder, Kevin Gosnell, who sought to change the trajectory of the disease with which he so courageously lived by uniting world leaders in ALS research and care before losing his battle just 14 months after his diagnosis, in August of 2016.

Prior to joining ALS ONE, Jen managed two of the largest categories in Global Marketing & Creative at PartyLite Worldwide, a Blyth Company, where she had been for over 9 years, overseeing high-profile collaborations with celebrity clients and helping to bring products to launch in over 18 countries. While at PartyLite, Jen received the Mabel Baker Positive Influence Award, an award given to the one employee annually who best exemplifies positivity among peers. Earlier in her career, Jen worked at Digitas for over seven years, where she managed global marketing campaigns for AT&T and IBM. In addition to Digitas, Jen worked as a consultant building strategic marketing campaigns for Ogilvy & Mather and Fidelity Investments. Jen's extensive background in marketing, mentoring, and public speaking, as well as leading award-winning volunteer fundraising efforts for various organizations including The American Heart Association, The American Cancer Society, South Plymouth Little League (where she was inducted into the Board of Directors Hall of Fame), among others, have been key to her success in her current role, having helped raise over 12 million dollars thus far for ALS ONE, over half of which as a result of grassroots marketing and fundraising campaigns.

Jen holds a Bachelor of Arts in Communications from Framingham State College and has been married for over 27 years to her husband, Bob, with whom they share their best friend and son. Jen is also the co-owner of Resolve Realty, located in Plymouth, MA, which is managed and run by her husband. Being fast-paced at heart, when not working,

Jen loves being with her family and engaging in all things active, including running and working out.

Kelley Erb
Director, Development Asset Lead
Biogen

Dan Fowler
Chief Medical Officer
Rapa Therapeutics

In 2017, Dr. Fowler became the founding Chief Medical Officer and Chief Scientific Officer at Rapa Therapeutics, building a team of scientists, research lab, and eventually a GMP manufacturing facility from scratch. His over-arching vision at Rapa has been to expand the bench-to-bedside paradigm developed during his NIH career to its full commercial application. His approach uses epigenetically reprogrammed, next-generation RAPA-T cells for the curative therapy of refractory cancer and the alleviation of devastating neurodegenerative diseases such as ALS.

Rapa Therapeutics is developing RAPA-T cell therapies for both "sides of the immunologic coin," that is,pro-inflammatory Th1/Tc1 cells for the therapy for refractory solid tumors (clinicaltrials.gov; NCT05144698) and anti-inflammatory hybrid TREG/Th2 cells for the therapy of ALS (NCT06169176; NCT04220190). At the NIH, Dr. Fowler investigated the role of regulatory T (TREG) cells and Th2 cells in experimental models of autoimmunity, gra_ rejection, and acute and chronic gra_-versus-host disease. These studies contributed to an understanding that both TREG and Th2 cells are candidate populations for down-regulating pathogenic Th1-type immune responses that contribute to the pathogenesis of autoimmune and neurodegenerative disease, including ALS. They showed that the ex vivo application of high-dose rapamycin during T cell polarization results in anti-apoptotic T cells that mediate increased in vivo responses upon adoptive transfer, including hybrid T Stem TREG/Th2 cells (RAPA-501) that are being evaluated in patients living with ALS (pwALS). Rapa Therapeutics collaborated with Mass General Hospital and Hackensack University to complete a Phase 1 trial of RAPA-501 cells in pwALS, which demonstrated that this new immune therapy approach is feasible, safe, biologically active, as well as potentially capable of modulating disease activity and extending lives. Given these favorable results, current efforts are directed toward evaluating T Stem Cell RAPA-501 therapy in additional pwALS on an expanded cohort Phase 2/3 trial and on an expanded access trial for individuals with severely compromised respiratory function.

Dan's distinguished career at NIH began in 1990 when he joined the National Cancer Institute for subspecialty training. Dan learned immunology from diverse investigators during a time of logarithmic growth in the field and rose to the rank of tenured NCI Senior Investigator through an integrated translational research focus on functional T cell subset immune therapy using a seamless dialogue between animal models and clinical trials. In this capacity, he was a long-standing contributor to the protocol review process and Institutional Review Board, which allowed him to learn from numerous luminaries at

the Bethesda, MD campus. The Fowler Lab's seminal research related to the invention and clinical translation of first-generation rapamycin-resistant RAPA-T cell therapy whereby ex vivo adaptation to mTOR (mechanistic Target Of Rapamycin) inhibition mediates potent in vivo immunity. In recognition of these efforts, Dr. Fowler received the NCI Director's Award, NIH Bench-to-Bedside Awards, and was inducted into the prestigious American Society of Clinical Investigation. Yet, the greatest reward at NIH emanated from the trust and confidence of the hundreds of patients with refractory cancer who participated in clinical trials of RAPA-T therapy.

Bryan J. Hansen, Ph.D
Director of Data Science and Digital Health Johnson & Johnson
Innovative Medicine

Dr. Bryan J. Hansen is a systems neuroscientist and data scientist with more than a decade of experience. As Director of Data Science and Digital Health at Johnson & Johnson Innovative Medicine, Dr. Hansen's responsibilities include leading the digital health strategy across several clinical trials focused on driving impact for J&J's neurodegeneration portfolio. Externally, he represents J&J within various consortia and partners closely with external innovation teams to identify novel datasets and solutions. Bryan's goals are to identify clinically meaningful digital biomarkers from biosensors, smartphones, and different types of active and passive data streams to obtain more objective, more continuous information about patients and their disease state. There are limitless possibilities to impact the field of neuroscience when you combine digital health technologies with sophisticated data science approaches.

Collin Hovinga
Vice President of Rare and Orphan Diseases
Critical Path Institute (C-Path)

Brendan O'Leary
Digital Health technology, regulation, and policy consultant

Brian Radecki
Chief Executive Officer
Rapa Therapeutics

Brian Radecki is a Founder, Chief Executive Officer, and member of the Board of Directors of Rapa Therapeutics ("Rapa"), a clinical stage start-up biotechnology company.

Brian co-founded Rapa after being introduced to Dr. Dan Fowler by his business partner, Bill Kapner, and learning about the exciting cell therapy technologies he has developed during his time at NIH that would revolutionize treatments for cancer, autoimmune, inflammatory, and neurodegenerative diseases. After losing his father to cancer and other close family members and friends to these deadly diseases, Brian has made it his mission to find a gentler, better way to treat these illnesses that help people live longer, so they can spend more quality time with their families and loved ones.

Rapa began at Brian's kitchen table in 2016 and was officially spun out of the National Cancer Institute in September 2017. Brian, and Dan built Rapa from the ground up, renting industrial warehouse space near the National Institutes of Health (NIH), constructing a state-of-the-art R&D lab and in-house cell therapy GMP manufacturing capabilities. From the beginning, the goal was to create a company and cell therapy platform focused on cutting-edge, curative immunotherapy treatments that utilize the body's own immune system. As CEO, Brian focuses on building the overall business, infrastructure, R&D labs, GMP manufacturing, and funding, while Dr. Fowler focuses on the science and IND, enabling research to create Rapa's next generation cell therapy 2.0 platform to treat a large spectrum of diseases. After years of hard work, the team has run successful clinical trials in ALS, relapsed refractory multiple myeloma, and solid tumors—all with promising data and stellar safety profiles, with every person treated in an outpatient setting.

Brian has 30 years of experience building both small private and large public companies across various industries at all the stages of the corporate life cycle. Brian is also an active angel investor in and advisor to companies across many industries — from start-ups with zero revenue, to pre-IPO and large public companies. Brian has taken several companies public and served on public company boards of directors.

Prior to co-founding Rapa, Brian worked for nearly 20 years at public companies, retiring in 2016 from CoStar Group Inc. ("CoStar") (NASDAQ: CSGP), a provider of commercial real estate information, analytics and online marketplaces, where he held several senior operational and financial roles over 18 years, including Executive Vice President, Chief Financial Officer and VP of Research Operations (the Company's largest operating area). Brian was instrumental in nearly every aspect of building CoStar from a small pre-IPO start-up, with fewer than 50 employees, to a multi-billion-dollar public company with thousands of employees. During his tenure, CoStar's substantial growth resulted in an over 2,000% shareholder return. Brian helped lead CoStar's 1998 initial public offering, multiple follow-on equity offerings raising nearly $1.1 billion of equity and debt, international expansion, as well as over a dozen acquisitions and the integration of public companies. He also helped found CoStar's charity and community outreach program, which has helped thousands of local Washington, DC area residents in need. Before joining CoStar, Brian worked at Axent Technologies, Inc. (Nasdaq: AXNT), an international security software company located in Rockville, MD; Azerty, Inc. and at the public accounting firm, Lumsden & McCormick, LLP, both based in Buffalo, NY. Brian completed a Bachelor of Science from the University of New York at Buffalo, with a dual degree in Accounting and Finance in 1993.

Seth Rotberg
Senior Manager, Patient Advocacy and Engagement
Prilenia

Henk Schuring
Chief Regulatory & Commercialization Officer
Prilenia

Henk Schuring is a senior executive with over 30 years' experience in the pharmaceutical industry. Henk is a pharmacist with a proven track record in rare diseases and as a creative strategic thinker. He has worked on several 'first treatments" for rare diseases and has been working in industry at various positions in Regulatory Affairs and Commercial at both regional and global level. In his role at Prilenia, he plays a critical role in defining the regulatory pathway for marketing authorization development and clinical programs.

Joel Schwartz
Scientific Director
Bristol Myers Squibb

Nick Seneca
Scientific Director of Precision Medicine
AbbVie

Hiro Takada
Director of Digital Healthcare Innovation
Mitsubishi Tanabe Pharma America, Inc.

Validation of remote monitoring technologies in ALS and implementation of digital biomarkers/decentralized clinical trial technologies in clinical trials.

Sharon Tamir
Sr. Director, Digital Healthcare Innovation
Business & Research Strategy
Mitsubishi Tanabe Pharma America, Inc.

Sharon Tamir, Leading the DHI team at MT-Pharma. Spearheading initiatives to integrate cutting-edge technologies into MT-Pharma's clinical development. With a background in program leadership in a broad array of indications and a focus on CNS research, Sharon led the cross-functional product team in developing the strategy and driving the efficient execution of the approved strategy.

March 2019-2024, Sharon served as the Co-Chair and then the Chair of the program committee of ASENT- American Society for Experimental Neurotherapeutics. Currently, she is serving as a board member for ASENT.

Ajay Verma
Consultant, Regeneron

Ajay is a neuroscientist, neurologist and a military and biotech veteran. He practiced neurology at Walter Reed Army Medical Center for 15 years prior to his 20 yr career in Biopharma, which included executive positions at Merck, Novartis, Biogen, United Neuroscience, Codiak and Yumanity. Ajay has worked of a variety of drug and biopharma platforms and is currently a General Partner at a Venture Studio called Formation Venture Engineering and CEO of an immunotherapy start-up called Twilight Bioscience in Massachusetts. He is a consulting advisor to the Regeneron Genetic Medicines Group.

Matt Wipperman
Associate Director, Digital Medicine
Regeneron Pharmaceuticals, Inc.
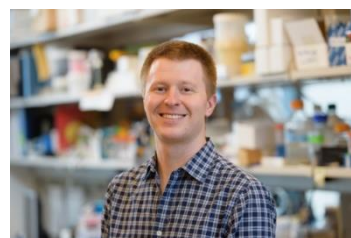
Dr. Matthew Wipperman works in Digital Medicine at Regeneron Pharmaceuticals, where he focuses on the strategy and application of digital sensor technology-derived digital biomarkers to the Regeneron portfolio. Matthew joined Regeneron in 2019 as a Quantitative Translational Scientist in Early Clinical Development & Experimental Sciences. Across biomarker and clinical research studies, he contributes to strategy, design, and exploratory data analyses across biomarker modalities.
This work drives the discovery and understanding of innovative biomarkers and clinical trial endpoints, the elucidation of mechanisms of action and drug pharmacodynamics, identification of sub-populations where pharmaceutical interventions will be effective, and exploration of alternative indications for approved drugs. He drives digital biomarker strategy for clinical development programs, aiming to transform drug trial outcome measures by quantifying patient function in real-world settings.
Matthew actively initiates and leads collaborations with diverse teams across clinical, research, regulatory, and external functions, to ensure scientific and clinical success of projects. He holds a BA and PhD in Chemistry, and an MSc in Clinical and Translational Science, with 15 years of experience in laboratory, computational, and basic scientific domains. Prior to Regeneron, he worked in clinical biomarker research at Sloan Kettering, where he led clinical biomarker and immunology work in infectious disease clinical research. He also continues to sit on the faculty in the Department of Medicine at Weill Cornell Medicine as a courtesy appointment, reflecting his ongoing connection to academic medicine.

Gayle Wittenberg
VP, Neuroscience Data Science and Digital Health
Janssen R&D

Gayle is VP and Head of Neuroscience Data Science and Digital Health at Janssen R&D, focused on embedding data science and digital health to add value to the pipeline end-to-end across the Neuroscience portfolio. She and her team leverage molecular data, deep phenotyping, digital health and realworld data to enable decision-making and solution development for Neuroscience compounds from target identification to product launch.

Gayle has over 15 years of experience across the pharmaceutical and diagnostics industries, driving data science research into products. Gayle joined Janssen Neuroscience in 2011 as Director, Integrative Solutions and Informatics. She founded and was Head of Translational Research and Precision Medicine, Research IT in 2016. She created and led the Intelligent Automation team in Pharm IT in 2019, before moving back to the NS TA as Senior Director, Neuroscience Data Science. Prior to Janssen, Gayle was Head of Personalized Healthcare, at Siemens. She earned her doctorate linking Computational and Experimental Neuroscience at Princeton University in 2003.

Key Opinion Leaders

Jinsy Andrews
Director of Neuromuscular Clinical Trials
Columbia University

Jinsy A. Andrews, MD, MSc, FAAN is an Associate Professor of Neurology, in the Division of Neuromuscular Medicine and serves as the Director of Neuromuscular Clinical Trials. She currently oversees neuromuscular clinical trials and cares for patients with neuromuscular disease, primarily with Amyotrophic Lateral Sclerosis (ALS). Dr. Andrews has extensive experience in all phases of human clinical trials and drug development in both the academic and industry settings. Dr. Andrews is the elected co-chair of the Northeastern ALS (NEALS) Consortium, which is a network of over 100 ALS clinical research centers internationally. She is also elected to the National Board of Trustees of the ALS Association and is a Fellow of the American Academy of Neurology (FAAN). Dr. Andrews has also received the Diamond Award for ALS clinical research from Wings Over Wall Street and the Muscular Dystrophy Association.

Dr. Andrews received her BS from Union College, M.Sc. in Biostatistics (Patient-Oriented Research) from Columbia University's Mailman School of Public Health and M.D. from Albany Medical College. She completed her residency training in Neurology at the University of Connecticut and served as the Chief Neurology Resident in her final year. Dr. Andrews completed fellowship training in Neuromuscular Disease/ALS and Clinical

Neurophysiology at Columbia University. She is board certified in Neurology, Neuromuscular Disease, and Electrodiagnostic Medicine.

James Berry
MGH Neurological Clinical Research Institute, Director
Winthrop Family Scholar in ALS Sciences
Averill Healey Endowed Chair in ALS

Dr. Berry provides care for people with amyotrophic lateral sclerosis (ALS). He is the Winthrop Family Scholar in ALS Sciences, the Director of the Massachusetts General Hospital (MGH) multidisciplinary ALS clinic and Chief of the Division of ALS and Motor Neuron Diseases. He has worked to better serve people with ALS by building the tools and team required to extend the reach of the MGH clinic team beyond the walls of the physical clinic. The ALS House Call program and video televisit program are examples of exciting initiatives at the MGH ALS clinic.
Dr. Berry works as an ALS researcher, designing, overseeing, and carrying out trials at MGH and centers across the country. His work is focused on the identification of markers of ALS in blood and spinal fluid, with an emphasis on markers of abnormal inflammation. He collaborates broadly with researchers around the globe on these biomarker efforts. He is also actively working to develop mobile health and digital phenotyping methods to better understand ALS and hasten the development of new therapies, while reducing the burden of trial participation for people with ALS.
Dr. Berry is also the Director of the MGH Neurological Clinical Research Institute (NCRI) and Director of the Mass General Brigham Neurodegenerative Clinical Research Fellowship. He is a member of the Massachusetts ALS Registry team and CDC/ATSDR National ALS Registry and Biorepository Expert Panels. In addition, he is on the Executive Committee of the NEALS Consortium, a national organization for ALS clinical researchers, where he also leads the NEALS Biorepository and Technology in ALS subcommittee.

Merit Cudkowicz
Chief of Neurology Sean M. Healey & AMG Center for ALS,
Director Harvard Medical School, Director and the Julieanne Dorn

Dr. Merit Cudkowicz is the Director of the Sean M. Healey & AMG Center for ALS, Chief of Neurology at Mass General, Director and the Julieanne Dorn Professor of Neurology at Harvard Medical School. Dr. Cudkowicz's research and clinical activities are dedicated to the study and treatment of people with ALS. She is one of the founders and past Co-Chairs of the Northeast ALS Consortium (NEALS), a group of over 134 clinical sites in the United States, Canada, Europe and the Middle East dedicated to

performing collaborative clinical trials and research in ALS. She has brought innovations to accelerate the development of treatments for people with ALS, including senior role in first antisense oligonucleotide treatment for a neurological disorder (SOD1 ALS), adaptive trial designs, central IRB - all with the goal to bring the best treatments rapidly. She is Principal Investigator of the Clinical Coordination Center for the National Institute of Neurological Disorders and Stroke's Neurology Network of Excellence in Clinical Trials (NeuroNEXT). She has launched the first platform trial initiative in ALS, the HEALEY ALS Platform Trial, a program that will greatly accelerate therapy development in ALS.

Dr. Cudkowicz has received many awards, including the 2019 Ray Adams American Neurological Association Award. A dedicated educator, she mentors many young neurologists in clinical investigation of ALS and related neurodegenerative disorders. Dr. Cudkowicz completed her undergraduate degree in chemical engineering at MIT and obtained a medical degree in the Health Science and Technology program of Harvard Medical School. She served her internship at Beth Israel Hospital in New York and her neurology residency and fellowship at MGH.

Cassandra Haddad
ALS advocate, CRNP, Twin mom

By combining expertise and skills from the IT, apparel and beauty industries, I am committed to creating innovative cross-field opportunities. I believe that the power of IT can bring unprecedented progress and development to the clothing and beauty industry. I am passionate about collaborating with industry professionals to explore new possibilities in these fields and provide customers and users with superior products and services.

Ernest Fraenkel
Professor of Biological Engineering, Massachusetts Institute of Technology

Professor Fraenkel received his A.B. in Chemistry and Physics from Harvard College and his Ph.D. in Biology at the laboratory of Professor Carl Pabofrom at MIT. He continued his post-doctoral research as a fellow at the laboratory of Professor Stephen Harrison at Harvard University. He was a Whitehead Fellow and a Pfizer Computational Biology Fellow at the Whitehead Institute. Prof. Fraenkel joined MIT as a Research Affiliate at the MIT Computer Science and Artificial Intelligence Laboratory. He became an Assistant Professor at the Department of Biological Engineering in 2006.

The Fraenkel laboratory is developing computational and experimental approaches to search for new therapeutic strategies for diseases. New experimental methods make it possible to measure cellular changes across the genome and proteome. These

technologies include genome-wide measurements of transcription, of protein-DNA interactions (ChIP-Seq), of genetic interactions, and of protein modifications. Each data source provides a very narrow view of the cellular changes. However, by computationally integrating these data the group can reconstruct signaling pathways and identify previously unrecognized regulatory mechanisms that contribute to the etiology of disease and may provide new approaches for treatment.

Melanie Leitner
Scientific Advisory Board Member
Carney Institute for Brain Science at Brown University

Passionate and supportive scientific leader with 20+ years of unique, cross-functional experience in the academic, government, industry, and non-profit sectors who thrives on solving challenges and developing innovative solutions to important societal problems. Surmounts translational hurdles in the neuroscience space by applying intellectual and interpersonal strengths towards building effective and innovative new organizations, initiatives, and teams.

Founded Accelerating NeuroVentures specifically to help clients in the neuroscience sector with their scientific and translational initiatives.

If you are an investor, senior executive of a foundation or a company, or a senior business development professional interested in pursuing drug development, diagnostics, or devices for neuro-based indications I would look forward to accelerating your efforts. Please contact me to explore how I might be able to contribute.

Terry Heiman-Patterson
Professor of Neurology
Lewis Katz School of Medicine at Temple University
MDA/ALS Center of Hope, Director of the Center for Neurodegenerative Diseases

Dr. Heiman-Patterson is Professor of Neurology at the Lewis Katz School of Medicine at Temple University where she is Director of the Center for Neurodegenerative Diseases and for the MDA/ALS Center of Hope. Her research has focused on ALS and includes both clinical and laboratory interests. She has been principal investigator for more than 30 trials in amyotrophic lateral sclerosis (ALS). Her clinical research is directed at extending survival and improving the quality of life including application of technologies to enable independence and optimizing

respiratory interventions. In the laboratory, Dr. Heiman-Patterson has worked with murine models of ALS to identify genetic modifiers of disease that can be translated to human disease.

She has authored or co-authored numerous papers, abstracts and book chapters on ALS and related motor neuron diseases. She is president and co-founder of the ALS Hope Foundation, a nonprofit committed to making a difference to people living with ALS, she has served as Co-Chair of the Northeast ALS (NEALS) Consortium and has served on multiple grant review committees including the Congressionally Directed Military Research Program. She is committed to patient care and education actively participating in the Clinical Research Learning Institute to train PALS to be Research Advocates. She is a member of the American Academy of Neurology and the American Neurological Association.

Lauren Gray
Director, Cathy J Husman ALS Center
Assistant Professor
Nova Southeastern University
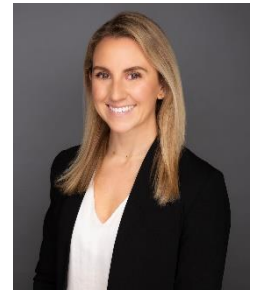
My research focuses on proactively identifying changes in swallowing and airway protection functions to optimize interventions that mitigate bulbar decline. Our work focuses on novel approaches, including behavioral interventions and drug repurposing, to enhance care of bulbar dysfunction for individuals with ALS. Key areas of our research include early intervention respiratory muscle strength training, lung volume recruitment, and the application of Nuedexta for bulbar dysfunction. I am particularly interested in the development and use of digital biomarkers for the remote assessment of swallowing in pALS, with a specific focus on tools that evaluate changes in airway defense capacity, such as cough.

Eduardo Locatelli
Physician Executive Director
Neurologist & Researcher
NSU Neuroscience Institute

Lyle Ostrow
Associate Professor of Neurology
Lewis Katz School of Medicine at Temple University

Dr. Ostrow is an ALS Neurologist and Researcher at the Lewis Katz School of Medicine and MDA/ALS Center of Hope at Temple University. He is a member of the Scientific Advisory Board for Everything ALS, and the Board of Directors of the ALS Hope Foundation.

He is Director of the Temple University ALS Postmortem Core, which is funded by a collaboration with the CDC National ALS Registry. He also is Director of the new Temple Nerve and Muscle Biopsy Service and Neuromuscular Pathology Lab.

Dr. Ostrow is Chair of the Programmatic Panel for the Department of Defense ALS Research Program (ALSRP), presently the largest dedicated annual funder of ALS therapeutic discovery and validation. He led ALSRP efforts to develop and refine funding mechanisms to help novel treatments move though the drug development pipeline, prioritize the development and incorporation of biomarkers and clinical outcome measures, and encourage open data and resource sharing. He serves on several ALS steering committees, advisory boards, and review panels, and has given 50+ invited talks, grand rounds, and keynote lectures on ALS research, biomarkers, postmortem tissue banking, and harmonizing multicenter research efforts and core resources.

EverythingALS

Indu Navar
Founder and CEO

Over the past 20 years, Indu has served as CEO, founder, board member, and investor of several Silicon Valley software companies, during which she led the development of innovative products resulting in successful exits. In 2019, after she lost her husband to ALS, a neurological disease, she has focused on bringing her skills in building scalable platforms and technology innovations to patient-driven health ventures.

Since 2019, Indu has been CEO and founder of the Peter Cohen Foundation, which functions as EverythingALS.org, a 501(3) non-profit organization focused on technology-based solutions to the discovery of biomarkers for neurological diseases. EverythingALS brings together researchers and providers from esteemed institutions as well as patients to conduct research and openly share data for potential treatments and a cure for ALS, with implications for other neurological diseases.

In addition, Indu is a board member of Global Genes, a non-profit organization, whose mission is to connect, empower and inspire the rare disease community and on the advisory board of Answer ALS, a non-profit focused on creating open data platforms in ALS. Indu is focused on bringing the technology framework from Peter Cohen Foundation into larger rare disease communities.

Earlier, Indu was managing director at Woodside Capital Partners, where she played an instrumental role in advising software companies on strategic financing transactions and M&A. She advised Inmage (Acquired by MSFT.), KarmaSphere (Acquired by FICO.), Total Immersion (Acquired by Qualcomm.).

From 2001 to 2014, she was founder and CEO of Serus Corporation, provider of the SAAS platform for companies with outsourced manufacturing. Serus was acquired by a public company, E2Open.

Early in her career, Indu was on the ground floor of several successful technology companies, including WebMD (formerly Healtheon) and Silicon Graphics. She started as an engineer at NASA in Moffett Field.

Indu has B.S Electrical Engineering from Bangalore University, India and M.S. in Computer Science from California State University, Chico.
Indu is now pursuing her Ph. D, Neuroscience in King's College. London.

Silviya Bastola
Clinical Project Research Manager

My educational foundation lies in Neuroscience, complemented by a postgraduate program in advanced sciences, broadening my expertise in data analysis, research methodologies, and clinical operations. With over four years of hands-on experience, I specialize in Phase II-IV clinical study management across biotechnology, pharmaceuticals, and medical devices, focusing on areas such as Infectious Disease, Vaccines, Rare Diseases, and Neurology (CNS). My career is firmly rooted in a commitment to healthcare reform, driven by the fusion of biotechnology, research innovation, and healthcare technology. At EverythingALS, I'm at the forefront of healthcare innovation, championing patient-centered care and advancing the care to cure cause for ALS. I aspire to catalyze transformative change by crafting solutions that amplify the quality and accessibility of patient care and research. In essence, my professional journey remains an unceasing pursuit of redefining the healthcare landscape, with a relentless focus on innovation, accessibility, and, above all, the well-being of people.

Stephanie Henze
Design | Clinical Study | Strategy Leadership

Over 30 years of global experience in all aspects of rapid innovation and E2E development of first-to-world, physical and digital medical products, customer experience and correlating, regulated processes.
Integrated background of medicine and industrial design.

Natalia Luchkina
Research Lead

Natalia brings over 15 years of experience in healthcare and life sciences, encompassing consulting, startups, and academic research. As a part of the EverythingALS team, she drives digital health research and innovation strategy for ALS and related neurodegenerative diseases. Previously, Natalia

served as a consultant at McKinsey, where she provided strategic guidance to clients across healthcare, social, and public sectors. Her expertise includes corporate strategy, research and innovation, data-driven solutions, and organizational transformation. Natalia has a robust scientific background, having conducted research at Harvard Medical School and McLean Hospital, where she investigated brain networks involved in psychiatric disorders to advance drug development. She holds PhD in Physiology and Neuroscience from the University of Helsinki (Finland), with a specialization in brain development and neuropharmacology.

Julian Peller
Lead Data Scientist

I currently lead a Data Science team of seven researchers in the search for digital biomarkers to enable early diagnosis and track the progression of ALS. To achieve this, we leverage various machine learning, deep learning, and statistical techniques on data from multiple modalities.
I am an autonomous and self-driven Data Scientist with a solid theoretical background—MSc in Computer Science with a GPA of 9.4—and over 15 years of experience in the software industry. Throughout my career, I have worked in various roles, teams, projects, and companies, developing a versatile, result-oriented mindset and a generalist toolbox. I am a Python expert and enthusiast, and a Kaggle Code Grandmaster, specializing in Deep Learning and Foundational Models. My goal is to make a significant impact through innovative research and technology.

Esteban Roitberg
Senior Data Scientist

Esteban Roitberg is a data scientist at EverythingALS, where his research focuses on the early diagnosis and prognosis of ALS using data from multiple modalities, including speech, video, respiratory, and gait data. He utilizes advanced analytical techniques, including machine learning, deep learning, and statistical methods, to extract meaningful insights from these diverse data sources.
In addition to his work at EverythingALS, Esteban holds a teaching position at the University of San Martín (UNSAM) in Argentina, where he teaches an introductory course on machine learning in the newly established Data Science degree program. Beyond teaching, he also collaborates in research projects that apply machine learning to address environmental challenges.
Esteban holds an MSc and a PhD in Physics from the University of Buenos Aires (UBA). During his PhD, he specialized in using computational techniques to characterize forest dynamics and detect illegal deforestation in the Argentinean Chaco Forest.

Christian Rubio
Executive Director & Head of Development

An experienced executive in patient engagement & identification,
working at the nexus of healthcare, research, and advocacy
alliances. Passionate about improving equity in diagnostics, research, and care through
digital health and data strategy-driven strategic partnerships. Inspired to turn experience
into a career in digital media and technology to engage patients and care partners,
improve research participation, and develop scalable, impactful capacity building
tools that empower healthcare communities.
10+ years of agile work experience with proven high-growth end-user
acquisition strategist of consumer and professional networks & platforms.
Consistent record in innovating monetization strategies to unlock the underlying value in
companies and organizations.

Sarita Sanjoy
Chief of Staff | Program Manager

Sarita is a passionate Learning and Development tech leader with a
track record of driving growth, innovation, and engagement. She
develops training program strategies that engage learners, boost
performance, and align with business goals, leveraging GenAI and data-driven insights in
educational technologies. At EverythingALS she supports the team in achieving the
organization's vision and goals.

Alan Taitz
Advanced Computer Scientist Speech Language Researcher