CMT PATIENT AND RESEARCH SUMMIT

2022 SPEAKER BIO'S

Michael Ahlijanian, PhD

Chief Scientific Officer, Orthogonal

Michael Ahlijanian, PhD, joined Orthogonal as chief scientific officer (CSO) in June 2019, after a stint as director of genetically defined disease biology and head of clinical biomarkers at Bristol Myers Squibb. In this role, he led scientific discovery teams that produced clinical candidates for large and small molecule therapeutics for neurologic and muscle-wasting diseases. He also led the preclinical and clinical implementation and analysis of translational biomarkers for these assets. Ahlijanian also held senior management roles as CSO of Pinteon Therapeutics, head of neuroscience at FORMA Therapeutics, vice president of research at EnVivo Pharmaceuticals and executive director of neuroscience operations at Pfizer. He is a recognized leader in the development of novel therapeutics for central nervous system diseases and is accomplished in promoting cultural change in research organizations. Ahlijanian has a PhD from the University of Minnesota Department of Pharmacology and a bachelor's degree in pharmacy with distinction from the University of Rhode Island.

Jonah Berger

CMTA National Youth Programs Manager

Jonah Berger, who has CMT 1X, has dedicated his career to working with kids and adults with disabilities. Berger served on the CMTA Advisory Board for more than seven years, leading youth outings during annual conferences. He also consulted for the CMTA in building out Camp Footprint, the country's only sleepaway camp for kids with CMT, and the creation of the CMTA Youth Council. Berger joined the CMTA staff full-time in early 2020 as the national youth programs manager and is thrilled to be serving the CMTA community by working to celebrate and engage its youth. He is married to Megan, and they have two children: a beautiful little girl named Amelia Rose, who has CMT, and baby Arthur, who does not. In his spare time, Jonah loves writing, music, travel, pizza, his dog Banjo and getting the most out of this wonderful life.

Diana Bharucha-Goebel, MD

Associate Professor, Neurology and Pediatrics, Children's National Hospital, Washington, D.C. & Clinical Research Collaborator, National Institutes of Health NINDS/ Neurogenetics Branch/ NNDCS

Dr. Diana Bharucha-Goebel is director of the neuromuscular program and associate professor in the Division of Neurology at Children's National Hospital in Washington, D.C., and the Division of Pediatrics and Neurology at the George Washington University School of Medicine & Health Sciences. She completed her medical training at Drexel University College of Medicine in 2007, followed by a general pediatric residency in 2009 and a child neurology residency in 2012, both at the Children's Hospital of Philadelphia. She completed a neuromuscular fellowship in 2013 at the Children's Hospital of Philadelphia and the Hospital of the University of Pennsylvania. Bharucha-Goebel is certified by the American Board of Psychiatry and Neurology (ABPN) in neurology with a special qualification in child neurology. In 2013, she was recruited to the Division of Neurology at Children's National Hospital, Washington, D.C., and concurrently brought on as a clinical research collaborator in the Neuromuscular and Neurogenetic Disorders of Childhood Section at the National Institutes of Health (NIH) in Bethesda, Md., where she works clinically with senior researcher Dr. Carsten Bönnemann. Her interests include translational research in early onset neuromuscular diseases, with a particular focus on the evaluation and identification of disease-focused outcome measures in rare diseases and on better understanding functional outcomes for clinical trial readiness. She led efforts for the clinical development of a Phase I first-in-human gene transfer trial for individuals with giant axonal neuropathy, while concurrently performing a parallel natural history study to assess outcome measures in this disorder. This work has led to a heightened interest in clinical trial readiness for neuromuscular disorders, particularly hereditary neuropathies. Bharucha-Goebel is also interested in better understanding how to target the peripheral nervous system with viral-mediated gene transfer approaches efficiently and safely, studying total vector genome dose, concurrent prophylactic immune modulation and immune surveillance following gene transfer.

Gilles Bouchard

CMTA Chairman of the Board

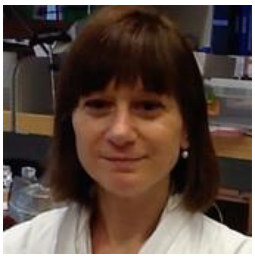
Gilles Bouchard's son Yohan was diagnosed with CMT1A in 2001. Gilles became a volunteer advisor to the Board of Directors in 2007 when he organized the strategic retreat in Palo Alto where the STAR (Strategy to Accelerate Research) program was initially defined and launched. Bouchard has been delighted to see how fast the STAR program has progressed since then though he recognizes there is still a way to go. He was appointed chairman of the board in March 2016.

On the professional side, Bouchard was most recently chairman and CEO of Livescribe, a venture-backed company that is the leader in the smartpen market. Previously, he was the CEO of Opnext, a maker of fiber optic components. The majority of his career (17 years) was spent at Hewlett-Packard, working his way up to executive vice president of Global Operations and CIO, reporting directly to CEOs Carly Fiorina and Mark Hurd. He holds an MS in engineering from UC Berkeley and an executive education degree from Harvard Business School. He was born in France, grew up in the Alps and loves cycling, mountaineering, and skiing. Yohan also introduced him to horseback riding, so he is an aspiring cowboy now.

Tom Dubensky, PhD

Tempest Therapeutics, President

CMTA Board Member Tom Dubensky is the founding CEO of the oncology-focused Tempest Therapeutics. He has significant expertise in the discovery, development and translation of novel small molecule, biologic and vector-based cancer therapies, having advanced several first-in-human drug candidates. He previously held roles leading discovery biology, development and clinical translation in cancer immunotherapy and infectious disease indications at multiple biotech companies, including Viagene, Chiron, Onyx, Cerus and Immune Design. Tom received his BA in bacteriology and immunology from UC Berkeley and his PhD at the University of Colorado Health Sciences Center. Afterward, he went to Harvard Medical School for post-doctoral studies in the Department of Pathology and received executive training at the University of California, San Diego, Executive Program for Scientists and Engineers.



Laura Feltri, MD

SUNY Distinguished Professor, Professor of Biochemistry and Neurology. Acting Director, Institute for Myelin and Glia Exploration

Dr. Laura Feltri earned her medical degree from the University of Milano, Italy, where she also completed a residency in neurology. She was a neuroscience post-doctoral fellow at Thomas Jefferson University and the University of Pennsylvania. From 1993 to 2011, Feltri worked at the San Raffaele Scientific Institute in Milano, Italy, where she was the head of the Unit of Neuro-Glia. Her scientific interest is myelin and myelin diseases. Working with the laboratory of Dr. Lawrence Wrabetz, she developed the first Cre transgene that specifically targets Schwann cells and pioneered conditional transgenesis to understand the role of extracellular matrix components and their receptors in developing and pathological peripheral nerves. Her laboratory has identified the diverse roles and many of the downstream signals for laminin receptors in nerve development. The National Institutes of Health (NIH), National Multiple Sclerosis Society, Hunter Hope Foundation, CMTA, Telethon Italy, and the European Community have funded her research and she has written more than 100 peer-reviewed publications. Currently, she is president-elect of the Peripheral Nerve Society and a member of the CMTA's Scientific Advisory Board, the CMT4B3 Research Foundation and Krabbe Connect. Feltri also served as a member and chair of the Cellular and Molecular Biology of Glia study session at the NIH and as a member of the National Multiple Sclerosis Study Session. She also served as an editorial member of the Journal of Neuroscience, Glia and Experimental Neurology. At SUNY Buffalo, Feltri received an Exceptional Scholar Award for Sustained Achievements, the SUNY Chancellor's Award for Excellence in Scholarship and Creative Activities and the Distinguished Post-doc Mentor Award.

Katherine Forsey, PhD

CMTA Chief Research Officer

Katherine Forsey is the CMTA's newly appointed chief research officer, bringing to the job expertise in science communication, education, and program leadership. After earning her PhD in 2007, Katherine led the creation and growth of a new education and outreach program at the Yorkshire Arboretum, managing a large team of volunteers to support thousands of children in experiencing science in a woodland environment. She also established a part-time freelance consulting business to support other non-profit and commercial organizations to develop their resources. Forsey worked for the Association for Science Education, the United Kingdom's largest subject association, leading their provision across the north of England and promoting excellence in science teaching and learning. In 2012, Forsey moved on to lead a program at the UK's National STEM Learning Centre, working with over 70 higher education institutions to provide professional development and networks for their technical specialists. In 2017, Forsey took her growing freelance consulting business full-time, working with industry, education providers and non-profits, leading development programs, providing professional development and acting as a liaison between research, education, and commercial stakeholders.

Forsey is a research biologist by training and holds a doctorate in biology from the University of York in the area of expression, activity, and localization of metabolic enzymes during preimplantation embryo development. During her industry-funded PhD, she spent time at the University of Cambridge, UK, in Sygen-sponsored research laboratories and at the Veterinary Research Institute, Brno Czech Republic. She also earned a BSc Hons. in molecular cell biology from the University of York. During her undergraduate degree, she completed a year in industry undertaking a genetic toxicology research project at Syngenta to develop in vitro alternative assays.

Forsey and her family members have CMT1A. She lives in Yorkshire, England with her husband and two children, making her the CMTA's only international staff member.

Amy Gray

CMTA Chief Executive Officer

Amy Gray leads the CMTA with more than two decades of extensive fundraising and management experience. Her expertise in fundraising, staff development, financial and operational management, strategic planning, and community engagement were shaped by her roles working with three national voluntary health organizations.

The CMTA has grown substantially since Gray took over as CEO in May 2017. She has worked closely with the board of directors and key stakeholders to establish aggressive fundraising efforts to support new research initiatives and community programs. Under her leadership, the organization has expanded its Strategy to Accelerate Research and Center of Excellence network, launched Patients as Partners in Research, gone through a rebranding effort and launched a new website. In addition, the CMTA earned a 4-star charity rating from Charity Navigator and a Platinum Seal of Transparency from GuideStar.

Gray plays an important role both nationally and internationally in advocating for the CMT community. She serves as the CMT patient advocacy leader on NIH's Rare Disease Consortium Research Network Steering Committee, and she is a committee member of the TREAT- Neuromuscular Disease International Consortium. In addition, she has spoken at conferences including Global Genes, the World Orphan Drug Conference and Launch Bio on CMTA-STAR and the importance of patient engagement in the drug development process.

Taleen Hanania, PhD

EVP, External Scientific Affairs, PyschoGenics

Taleen Hanania received her PhD in pharmacology at the University of Texas Medical Branch, Galveston, and completed her post-doctoral training at the University of Colorado Health Sciences Center where she became a faculty member of the Department of Pharmacology. Hanania joined PsychoGenics in 2004, where she expanded the company's *in vivo* testing capabilities and helped set up numerous assays for various psychiatric disorders, CMT, pain, trauma, abuse liability, neurodegeneration models, autism spectrum disorders and Alzheimer's disease.

Valery Hanks, OTR/L, C/ND

Occupational Therapist, Pi Beta Phi Rehabilitation Institute

Valery Hanks, OTR/L, C/NDT is an occupational therapist at Pi Beta Phi Rehabilitation Institute at Vanderbilt Medical Center Bill Wilkerson Center in Nashville, Tenn. She provides outpatient-based services as part of an interdisciplinary team for adolescents and adults with neurological impairments. Hanks graduated from the University of Tennessee Health Sciences Center in 2000 and has focused the entirety of her career treating people with neurological impairments. She serves as chair of the Mentorship Committee for the Tennessee Occupational Therapy Association and sits on multiple committees advocating for occupational therapy.

David Herrmann, M.B.B.Ch., MD

Unit Chief of the Neuromuscular Unit and Director of the Peripheral Neuropathy Clinics. University of Rochester

Dr. David Herrmann is chief of the Neuromuscular Unit and director of the Peripheral Neuropathy Clinics (including the CMTA Center of Excellence) and Cutaneous Innervation Laboratory at the University of Rochester. Clinically, his interests are in the diagnosis and care of patients with various types of peripheral neuropathy, with a particular interest in inherited neuropathies like CMT. Herrmann also established one of the first cutaneous innervation laboratories in the United States at the University of Rochester in 2000, for diagnosis of small fiber neuropathy. Herrmann is the principal investigator in Rochester for the NIH-sponsored Inherited Neuropathy Consortium Rare Disease Clinical Research Center. Herrmann focuses on new gene identification for inherited neuropathies, development of novel neuropathy outcome measures and biomarkers and experimental therapeutics.

Kenneth Hill Jr.

Eight-time Hall of Fame/Hall of Honors Inductee, Author and CMT Community Member

Kenneth Hill's martial arts journey began at the age of nine, inspired by the film “Enter the Dragon” starring Bruce Lee. Hill was a little guy with a stutter, quiet and shy, and was often bullied or overlooked. While he didn’t want to focus on anything other than martial arts, he struggled with constant ankle injuries. At the age of 22, he was advised to stop training and have surgery on both ankles and told that even with surgery, he would be confined to a wheelchair by the age of 35. He declined the surgery. Hill was diagnosed with CMT in his early thirties, which helped to explain the weakness in his lower extremities and the lack of fine motor skills in his hands.

After accomplishing his goals of practicing martial arts and continuing to walk at the age of 35, Hill taught martial arts to special needs students. Having the opportunity to show kids that they have worth, even when others do not see it, is what motivates him. He went from being a kid who was picked last or not at all to an eight-time Hall of Fame/Hall of Honors inductee.

Yeshua Holiday

CMTA Community Member

Yeshua Holiday, who has both CMT1D and 4E, was born and raised in New York. He is an ordained elder, former pastor and former member of the U.S. Army. Holiday also lives with myasthenia gravis. He advocates for CMT and other causes.

Michael Huang, PhD

Chief Medical Officer, DTx Pharma

Dr. Michael Huang is the chief medical officer at DTx Pharma, where he is responsible for leading the company’s clinical development programs in CMT1A and other projects in its drug development pipeline. Before DTx Pharma, Huang held key leadership roles at AmMax Bio and Spruce Biosciences. Throughout his career, he has led programs in RNA therapeutics, biologics and small molecules from initial investigational new drug application through clinical proof-of-concept, late-stage development and beyond. With extensive leadership experience in advancing drug candidates through all phases of clinical development, his contributions have led to marketing authorizations for numerous therapeutics including Potiga®, Zevalin®, Uceris®, Ruconest® and Austedo®. Huang has also been recognized for supporting successful financing and business-development activities. He is the author of a multitude of peer-reviewed journal articles, abstracts and scientific publications. Huang holds a BS in molecular and cell biology fromUC Berkeley and a medical degree from the Chicago Medical School.

Kim Hughes

Yoga Teacher and Speech-Language Pathologist

Kim Hughes is an ASHA-certified Speech-Language Pathologist with 22 years of experience working with children, teenagers and adults. She received her master's degree in speech and language pathology at George Washington University in 2000. Her passion is treating children with language disorders, ADHD, ASD and dyslexia, incorporating movement, play, yoga and sensory activities into her therapy sessions with great therapeutic benefits**.** Hughes has been practicing yoga for 30 years and is certified as a children's yoga teacher through the Budding Yogis program. She received her 200-hour training certification from Nimaste Yoga in Kensington, Md. A mother of two teenagers, Hughes began teaching them yoga in the womb and has continued bonding with them by getting into silly or challenging yoga poses and listening to nature and animal meditations together. She is co-founder of Talk Yoga™, which combines speech and language with the movement of yoga to strengthen communication. She believes yoga can build self-esteem, strength, and inner beauty. When Hughes isn't doing yoga, you can find her in the garden or walking in the woods. She lives in Kensington with her husband, two children, and dog, Mojo.

Luke M. Judge, MD, PhD

Neonatologist and Genome Genetic Surgery Researcher/University of California San Francisco Health

Dr. Luke Judge is a pediatrician who specializes in caring for infants in the intensive care nursery. He also resuscitates newborns when needed during high-risk deliveries. At the Fetal Treatment Center, he provides prenatal counseling to women with complicated pregnancies. Judge's research focuses on genetic diseases of the heart and skeletal muscle. He employs an approach called "disease modeling in a dish," which involves growing human cell types and tissues in the laboratory. Judge earned his undergraduate degree from Pomona College. He earned his doctoral and medical degrees from the University of Washington, then completed a residency in pediatrics and a fellowship in neonatal-perinatal medicine at UCSF. Judge is a member of the American Academy of Pediatrics and the International Society for Stem Cell Research.

Dr. Kleopas A. Kleopa, MD, FAAN

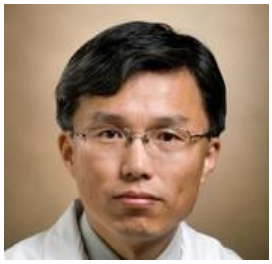
Neurology, Cyprus Institute of Neurology and Genetics

Dr. Kleopas Kleopa holds a medical and a doctoral degree from the University of Wuerzburg in Germany. He trained as a neurologist at Drexel University in Philadelphia, followed by a fellowship in neuromuscular disorders and electromyography at the University of Pennsylvania. He is currently a consultant neurologist at the Cyprus Institute of Neurology and Genetics, where he coordinates the Center for Neuromuscular Disorders. He is also head of the Neuroscience Department and a professor at the Cyprus School of Molecular Medicine, where he coordinates the neuroscience graduate program. His research group has used international competitive funding to make significant contributions to the understanding of neurological disease mechanisms and the development of cell-targeted gene therapies for inherited demyelinating neuropathies and leukodystrophies. He has received many prestigious awards for his academic achievements, including the 2015 European Academy of Neurology Investigator Award for his research on gene therapy for inherited neuropathies and the 2017 National Distinguished Researcher Award from the Research Promotion Foundation of Cyprus. He is an elected board member of the Charcot-Marie-Tooth and Related Disorders (CMTR) Consortium and a member of the CMTA's Scientific Advisory Board.

Jaeyoung Lee

R&D Therapeutics and Business Development at ToolGen Inc.

Jaeyoung Lee is a director of R&D therapeutics and business development at ToolGen Inc., a gene editing-based company, where he builds external partnerships, establishes strategic decisions/plans, and develops CRISPR/Cas9-based therapy. He received his BEng (first class honors) from the University of Melbourne and his PhD in medicine from Monash University, graduating with a dean's award for doctoral thesis excellence.



Jun Li, MD, PhD, FANA, FAAN

Chair of the Stanley H. Appel Department of Neurology at the Houston Methodist Neurological Institute.

Dr. Jun Li is the chairman of the Stanley H. Appel Department of Neurology at the Houston Methodist Neurological Institute. Li most recently served as the chairman of the Department of Neurology, the scientific director of Translational Neuroscience Initiatives at Wayne State University (WSU) and the specialist-in-chief of neurology at the Detroit Medical Center. Li spent nine years of his junior faculty career at WSU and another nine years at Vanderbilt University before taking on the chairman position at WSU.

Li received his medical degree from Anhui Medical University in the People's Republic of China in 1985. He received his doctoral degree in neurosciences in 1995 from the Drexel University College of Medicine. He completed a neurology residency in 1999 at Ohio State University; and an EMG/neuromuscular fellowship at the Department of Neurology at the University of Utah in 2000.

As a physician-scientist, Li subspecializes in peripheral nerve diseases and myelin biology. His laboratory has been continuously funded by NIH since 2004. He has published more than 90 articles in peer-reviewed journals and book chapters and earned a Wolfe Research Prize from the American Neurological Association (ANA) in 2014. He is a current member of the ANA Board of Directors and a member of the Scientific Advisory Board for the Muscular Dystrophy Association, the CMTA and the scientific committee of the Peripheral Nerve Society. He has been a member of NIH study sections for more than a decade.

Bethany Meloche

CMTA Advisory Board Member

Bethany Meloche is the author of "How a Body Should Be?", a coming-of-age story about growing up in Michigan, falling in love and learning to live with CMT. Bethany is a professional storyteller who speaks internationally on the topics of facing fears, having a vision, and embracing one's differences. Her story has been featured in the Daily Cal, the Mercury News, Mountain View Voice, Lower Extremity Review and Neurology Now.

Bethany worked for the CMTA for five years as director of social media and director of digital strategy. She pioneered the growth of the CMTA's online communities and remains a powerful patient advocate in her role on the Advisory Board.

Raised in Ann Arbor, Mich., Bethany has a degree in nutritional science from UC Berkeley and currently lives in London, where she writes and goes for long walks with her husband.

Kathrin C. Meyer, PhD

Principal Investigator, Nationwide Children's Hospital, and Assistant Professor, Ohio State University

Kathrin C. Meyer, PhD, studied cellular and molecular biology at the Institute of Cell Biology in Berne, Switzerland, with post-doctoral research at Brian Kaspar's laboratory at the Center for Gene Therapy, Nationwide Children's Hospital in Columbus, Ohio. She established a fast new reprogramming method for in vitro modeling of neurodegenerative diseases and worked on multiple AAV gene therapy programs, including Zolgensma. In 2018, Meyer became a principal investigator at the Center for Gene Therapy and an assistant professor at Ohio State University. Her team develops gene therapy programs and other novel therapeutics for neurodegenerative and neurological disorders. To date, she has helped to advance five AAV gene therapies to clinic, including spinal muscular atrophy, Batten diseases and SMARD1/CMT2S.

David B. Misener, B.Sc. (HK), CPO, MBA

Clinical Prosthetics & Orthotics, LLC.

David B. Misener, BSc (HK), CPO, MBA, is an American board-certified prosthetist and orthotist who has been practicing in Albany, NY, since 1998. He is one of three owners of Clinical Prosthetics and Orthotics, which has office locations ranging from Saratoga Springs to Poughkeepsie, NY. Originally from Guelph, Ontario, he received his BS in human kinetics from the University of Guelph. He then went on to post-graduate work in orthotics and prosthetics at George Brown College, Toronto, Ontario. Misener was born with CMT1B, as was his son Ethan. David's maternal grandfather was the first known family member with CMT, and David assisted his family in determining the genetic source by working with the Lupski Laboratory at Baylor College of Medicine. He serves on the CMTA Advisory Board.

John Nixon

Body Builder and CMTA Community Member

John is a 42-year-old father to twin girls, partner to Kelly, and stepfather to two more children. He works as a branch manager for a DIY and trade retailer in the United Kingdom. After many early years of suffering with balance and pain, John was diagnosed with CMT at 12 years of age in 1991, when not much was known about the disease. He has remained active throughout his life, refusing to let CMT beat him. His latest personal success was winning a bodybuilding competition. He intends to compete again and use his platform to create CMT awareness.

Riccardo Perfetti, MD, PhD

Chief Medical Officer, Applied Therapeutics

Dr. Riccardo Perfetti has served as chief medical officer of Applied Therapeutics since August 2018. Before that, he served as a senior medical officer, vice president and head of Global Medical Affairs, Diabetes and Cardiovascular Business Unit at Sanofi S.A., a publicly traded pharmaceutical company. Before joining Sanofi, Perfetti served in various roles at Amgen Inc., a publicly traded biopharmaceutical company, including director and global development leader in diabetes, obesity, metabolism, and endocrinology He was previously an associate professor of medicine at the University of California in Los Angeles and a professor of medicine at NIH. Perfetti practiced as an endocrinologist at Cedars-Sinai Medical Center and served as director of the Diabetes Research Laboratory and director of the Outpatient Diabetes Program. He received his MD and PhD in endocrinology from University La Sapienza in Rome, Italy, and did post-graduate training in endocrinology and molecular biology at NIH.

Glenn B. Pfeffer, MD

Director, Foot, and Ankle Surgery Program, Cedars-Sinai Medical Center

Dr. Glenn Pfeffer is the director of the Foot and Ankle Center at Cedars-Sinai Medical Center. He is also a co-director of the Hereditary Neuropathy Program and co-director of the Cedars-Sinai/USC Gloria Kaufman Dance Medicine Center. Pfeffer has written numerous scientific articles on orthopedics and has edited seven academic textbooks on the foot and ankle. He has been treating foot and ankle problems in patients with CMT for 25 years. He is a past president of the American Orthopedic Foot and Ankle Society and recently served as president of the California Orthopedic Association. Pfeffer is frequently interviewed on foot and ankle topics and has been featured on CNN, Dancing with the Stars, Dateline NBC, Good Morning America and in The New York Times. He serves on the CMTA Advisory Board.

Suyash Prasad, MBBS, M.SC., MRCP, MRCPCH, FFPM

Chief Medical Officer and Head of Research and Development, Taysha Gene Therapies

Dr. Prasad is a pediatrician, clinical development physician, translational scientist, and executive leader with 20 years in the biopharmaceutical industry. He currently serves as the chief medical officer and head of research and development at Taysha Gene Therapies, an organization dedicated to developing AAV gene therapy approaches for treating children and adults with severe neurological disease. Dr. Prasad graduated in medicine at the University of Newcastle upon Tyne, UK, where he received commendations for pediatrics, obstetrics and gynecology and medical ethics. He completed his pediatric training at recognized centers of excellence in the UK and Australia before moving to industry. His industry career progressed at Eli Lilly, Genzyme and BioMarin, and more recently he was chief medical officer at the gene therapy company Audentes Therapeutics (now Astellas Gene Therapies), before moving to Taysha. He is a UK board-certified physician and is a member of the Royal College of Physicians (MRCP) and the Royal College of Pediatrics and Child Health (MRCPCH). Dr. Prasad received his diploma in pharmaceutical medicine from the Royal College of Physicians of the UK, and his master's in translation science with distinction from Kings College, London. He is a fellow of the faculty of Pharmaceutical Medicine and is a past recipient of its outstanding contribution award. Dr. Prasad has dedicated his career to the well-being and advocacy of children who are afflicted by rare and severe diseases.

Laurel Richardson

CMTA Director of Community Outreach

As the CMTA director of community outreach, Laurel is responsible for the national branch system, the CMT Patient & Research Summit, CMT Clinical Summit and Camp Footprint. She also acts as liaison to the CMTA Centers of Excellence and oversees the CMTA's educational materials and website. Laurel earned a degree in journalism with an advertising emphasis from San Diego State University. Before joining the CMTA, she worked as a media account executive for Cox Media and WECT and as a client relations manager/regional media buyer for Right Point Media.

As a stay-at-home mother for 10 years, Laurel held many volunteer leadership positions, including leader of the Wilmington, NC CMTA Branch, communications chair at her church, Parent Teacher Student Organization hospitality chair and command team advisor for the 1st Maintenance Battalion at Camp Pendleton. Laurel lives in Wilmington, N.C. with her husband and two teenagers.

Zarife Sahenk, MD, PhD

Professor, Pediatrics and Neurology, Abigail Wexner Research Institute, Nationwide Children's Hospital, Center for Gene Therapy, Neuromuscular Program

Dr. Zarife Sahenk is a professor of pediatrics and neurology and the director of Experimental and Clinical Neuromuscular Laboratories at Abigail Wexner Research Institute at Nationwide Children's Hospital. Her laboratory plays an integral part in the preclinical studies and gene therapy clinical trials that take place in the Center for Gene Therapy at Nationwide Children's Hospital. Her research program's primary goal is to gain a detailed understanding of the anatomical and molecular basis of nerve degeneration and impaired regeneration in hereditary peripheral neuropathies. The role of neurotrophin-3 (NT-3) in impaired nerve and muscle function in animal models of CMT subtypes is currently being investigated and gene therapy paradigms are being developed. In addition, her laboratory works on projects involving the development of therapeutics and novel methods to target impaired cellular mechanisms in neurodegenerative and myodegenerative disorders. The results of her research on CMT and other neuromuscular diseases have been published in more than 100 peer-reviewed articles and her most recent contributions on the topic of CMT include articles in Brain Research, Molecular Therapy Methods & Clinical Development, Gene Therapy and Brain Communications.

Mark Scheideler, PhD

Founder, HumanFirst Therapeutics

Mark Scheideler founded HumanFirst Therapeutics LLC (HFT) in 2011 with the goal of accelerating new therapies toward clinical development by providing the expertise needed to form, fund, and operationally manage life science projects. HFT provides managing partner expertise to public-private alliances for drug development, including research direction, path-to-clinic planning, medicinal chemistry, project and consortium management, agreement support and patenting and public funding. Clients have included universities and disease foundations seeking to advance therapeutic opportunities and companies pursuing drug development via public sector collaboration. He advises the CMTA on its research strategy and alliances, directs its preclinical evaluation network and chairs the STAR Therapy Experts Board.

Scheideler previously held leadership roles in the pharmaceutical and biotechnology sector, including posts as managing director-Europe and SVP at MDS Proteomics, head of neurobiology research at SmithKline Beecham and GSK and principal scientist at Novo Nordisk Healthcare. In addition, he served as a senior scientific officer at NIH, working across institutes to shape and direct collaborative translational research initiatives and small business programs. Before joining the private sector, he held academic positions as a research assistant professor at Albert Einstein College of Medicine and a research fellow at Duke University Medical Center. Mark completed a PhD in biochemistry at the University of Chicago, a BA in biochemistry and molecular biology at Northwestern University and a graduate certificate in finance and accounting from the Wharton School of Business.

Michael Shy, MD

Director, Division of Neuromuscular Medicine, Neurology, University of Iowa

Dr. Shy is the clinical director of the CMTA Center of Excellence at the University of Iowa. He also serves on the CMTA-STAR Scientific Advisory Board as chair of the Clinical Expert Board. Dr. Shy is interested in understanding the biology of neurodegenerative diseases so that rational treatments can be developed for these devasting disorders. He believes that understanding the biological cause of degenerative diseases like CMT, ALS, and Parkinson's disease will lead to the development of treatments for other neurological diseases and that CMT is the best path to achieve these aims because the genetic cause of many forms is already known. This knowledge makes it possible to discover how mutations in these specific genes cause nerve degeneration and how to reverse the degeneration.

Reza Seyedsadjadi, MD

Massachusetts General Hospital, Harvard Medical School

Dr. Reza Seyedsadjadi is a neuromuscular neurologist at MGH and an assistant professor in neurology at MGH. He is the director of the CMTA Center of Excellence at MGH and part of the Inherited Neuropathy Consortium. His clinical and research focus is on disease outcome measures and clinical trial readiness.

Shoshana Shendelman, PhD

CEO and Founder, Applied Therapeutics

Shoshana Shendelman founded Applied Therapeutics in 2016 and now serves as president and CEO as well as chair of the Board of Directors. Before founding Applied Therapeutics, she founded Clearpoint Strategy Group LLC, a boutique life sciences consulting firm, where she served as the managing director from July 2012 to December 2016 and a senior advisor from January 2017 to December 2018. Shendelman received her PhD in cellular, molecular and biophysical studies from Columbia University Vagelos College of Physicians and Surgeons. She is also a member of the Clinical Advisory Board of Columbia University Medical Center and Columbia University Vagelos College of Physicians & Surgeons, where she serves on the Nominations Committee and the Committee on Innovation and Entrepreneurship.

David Horn Solomon, MD, PhD

Chief Executive Officer, Pharnext

Dr. David Horn Solomon is a leader in the life sciences industry with a 30+ year track record. Before joining Pharnext, he served as the CEO of Silence Therapeutics, Akari Therapeutics, Bionor Pharma and Zealand Pharma, guiding Zealand through approval of Adlixin for Type II Diabetes. He was managing partner at Sund Capital in Denmark and headed healthcare investments at Carrot Capital Healthcare Ventures in New York City. A former board member of TxCell, Onxeo, Promosome and Ixaka, Solomon is currently chairman of the board for Advicenne Pharma in Paris. He was also a professor of pharmacology and neurology at Columbia University's College of Physicians and Surgeons in New York City.

Hannah Spencer

Camper at CMTA Camp Footprint

Hannah joined the CMTA youth community after enjoying her first year at Camp Footprint last summer. Her nickname is "Hannah-Banana," but her mom calls her "Butterfly" because she is a free spirit. Hannah is 14 years old and a sophomore in high school. She likes school but mostly likes to hang with friends and family and make TikTok videos. She was diagnosed with CMT in January 2022, after two hip surgeries. Hannah says Camp Footprint has made her feel like she is not different and that it is okay to walk with a limp. She believes that CMT has made her a stronger person and increased her compassion for others.

John Svaren, PhD

Director, IDD Models Core/University of Wisconsin Waisman Center

John Svaren is a professor in the Department of Comparative Biosciences at the University of Wisconsin and director of the Cellular and Molecular Neuroscience core at the UW Waisman Center, where his laboratory is located. Since 2000, he has focused his research program on the genetic basis of peripheral myelination and the disruptions found in peripheral neuropathies such as CMT. He began working with the CMTA to lead one arm of the collaborative STAR project, which investigated PMP22 regulation to develop assays for drug screening for CMT1A. As the scope of CMTA's mission expanded, he became a member of the CMTA Board of Directors and chair of its Scientific Advisory Board, working with scientists and neurologists in the development and implementation of a multi-front strategy to develop new therapies for the common forms of CMT.

Jeana Sweeney

CMTA Chief Engagement and Gift Officer

Jeana was diagnosed with CMT at the age of 14 and has dedicated her professional life to the CMTA community and finding treatments for her daughter and all those who live with CMT. She started as a volunteer in 2001 and in 2008 she became the director of community services, a position she held for nine years. During that time, she expanded the national branch system, developed Patient/Family conferences, created the successful Walk 4 CMT fundraising program, helped start Camp Footprint, led Awareness Month initiatives, and built out a grassroots fundraising campaign for community/branch leaders.

Sweeney was named development director in June 2018 and chief engagement and gift officer in 2022. In this role, she spearheads numerous opportunities for donors, board members, corporate sponsors, and pharmaceutical companies to support the CMTA's mission. She also created the Legacy Society and expanded the Innervators Monthly Giving program. In her spare time, Sweeney loves to put on her waders, grab her fishing rod and hit the river to fish for smallmouth bass. The Zara Puppy is her favorite lure.

David Walk, MD, FAAN

Division Head of Neuromuscular Disease at the University of Minnesota Medical Center and the Clinical Director CMTA Center of Excellence

Dr. David Walk is the division head of neuromuscular disease at the University of Minnesota Medical Center and the clinical director of the CMTA Center of Excellence at Fairview Maple Grove Medical Center. His clinical and research interests include motor neuron disorders, CMT and other neuropathies. His career focus has been on the diagnosis and management of neuropathy, including small fiber neuropathy, inflammatory neuropathy, and inherited neuropathy, as well as ALS and other motor neuron disorders. His clinics emphasize multidisciplinary management, utilizing interdisciplinary teams of content and disease-state experts. Walk completed his residencies in neurology at New York University and the University of Chicago.

Amy Warfield, PT, DPT

Physical Therapist

Amy Warfield, PT, DPT, is a physical therapist with Montgomery County Public Schools in Maryland. She received her master's degree in physical therapy from Ithaca College in New York and her doctorate in physical therapy from A.T. Still University in Arizona. She was certified by the American Physical Therapy Board of Specialties as a Neurologic Certified Specialist (NCS) from 2005-2015.

Amy previously worked as adjunct faculty for physical therapy programs at Marymount University and The University of Maryland. She practiced clinically at Medstar National Rehabilitation Hospital in Washington, the Kennedy Krieger Institute in Maryland, and the University of Rochester in New York. In each setting, she enjoyed working with pediatric and adult neurologic rehabilitation patients at different stages of care. Amy's husband and two of her three children have CMT1A. Watching her kids and husband struggle with the everyday challenges of CMT motivates Amy to make a positive difference in understanding the optimal management of CMT across the lifespan.

Stephan Züchner, MD, PhD

Professor and Chair, Department for Human Genetics/University of Miami School of Medicine

Dr. Stephan Züchner is a professor of human genetics and neurology at the University of Miami Miller School of Medicine. He is also the chairman of the Dr. John T. Macdonald Foundation Department of Human Genetics and the co-director of the Hussman Institute for Human Genomics. Züchner's research interests focus on identifying genetic variants associated with disease. His lab is internationally renowned for its success in identifying several dozen genes for Mendelian disorders, especially axonal neuropathies, ataxia, and spastic paraplegia, and for evaluating risk factors for complex genetic conditions, including Alzheimer's disease, Parkinson's disease, and obsessive-compulsive disorder. Every day, hundreds of patients around the world get tested and diagnosed for the genes identified in his lab. His pioneering group has promoted genome sequencing methods for disease gene identification in humans, mice, worms, and fruit flies. Utilizing in-house software solutions, such as the widely used GENESIS platform, he is currently pursuing large-scale exome and genome analysis in multiple Mendelian neurodegenerative disorders to map their complex genetic architecture, including modifier genes. His group is also developing therapeutic applications based on genetic approaches.