

Partner/Sponsor Information

In addition to our presenters and experts, we are pleased to be able to provide you with the opportunity to meet several of our corporate partners and learn more about the products they offer and the contributions they are making to research and to the treatment and management of CMT. (Please note, however, that the CMTA does not endorse the products or services they offer.)



Charcot-Marie-Tooth Association
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www.cmtausa.org



Saturday, October 20, 2018

Grand Hyatt Seattle
721 Pine St
Seattle, WA 98101





- 8:00 - 9:00 am: **REGISTRATION & HOT BREAKFAST WITH CMT EXPERTS**
- 9:00 - 9:05 am: **WELCOME**
Laurel Richardson
CMTA Director of Community Outreach
- 9:05 - 9:30 am: **OUR CENTER AT THE UNIVERSITY OF WASHINGTON - CMT EXAM**
Jane Distad, MD
University of Washington
- 9:30 - 10:00 am: **HISTORY OF CMT RESEARCH AT THE UNIVERSITY OF WASHINGTON**
Thomas Bird, MD
University of Washington

- 10:00 - 10:30 am: **GENETIC COUNSELING AND TESTING FAQs**
Lauren H. Brown, MS, CGC
University of Washington
- 10:30 - 10:45 am: **CMTA RESEARCH UPDATE**
Amy Gray
CMTA Chief Executive Officer
- 10:45 - 10:55 am: **CMT AND ORTHOTICS: PRODUCT OVERVIEW**
Jim King, District Manager
Allard USA
- 10:55 - 11:15 am: **BREAK**
- 11:15 - 11:45 am: **ORTHOTIC MANAGEMENT OF CMT**
Eric Weber, LCPO, FAAOP
Hanger Clinic
- 11:45 am - 12:15 pm: **BRACES VS. SURGERY**
Glenn Pfeffer, MD
Cedars-Sinai Medical Center, Los Angeles
- 12:15 - 12:45 pm: **BREATHING AND CMT**
Ashraf Elsayegh, MD
Cedars-Sinai Medical Center, Los Angeles
- 12:45 - 1:15 pm: **CMT AND PAIN**
Gregory T. Carter, MD
St. Luke's Rehabilitation Institute
University of Washington
- 1:15 - 1:30 pm: **GET INVOLVED WITH THE CMTA**
Jeana Sweeney
CMTA Director of Development
- 1:30 - 2:00 pm: **OPEN Q & A WITH CMT EXPERTS**

Presenters and Experts



Thomas Bird, MD
Director of the Neurogenetics Clinic
University of Washington

Dr. Thomas Bird is one of the founders of the field of clinical neurogenetics in this country, having established the first adult neurogenetics clinic at the University of Washington in 1974. His research career has focused on disease gene identification and genotype/phenotype correlations.

Dr. Bird and his colleagues have identified causative mutations in genes affecting a broad range of neurogenetics disorders including early onset Alzheimer disease (PSEN2), frontotemporal dementia (MAPT), CMT1B (MPZ), HNPP (PMP-22 del), and CMT1C (SIMPLE/LITAF).

Dr. Bird is head of the Division of Neurogenetics in the UW Department of Neurology and an investigator in the Geriatrics Research Education and Clinical Center at the VAPSHCS, the UW Alzheimer's Disease Research Center and the UW Center for Human Development and Disability. He is Emeritus Professor of Neurology and Medical Genetics at the University of Washington.



Lauren H. Brown, MS, CGC
Neurogenetics Counselor
University of Washington

Lauren Brown is a neurogenetic counselor in the Adult Genetics Clinic. She has been at the UW Medical Center since 2014 after receiving her Master's in Genetic Counseling at the University of Pittsburgh. She is certified by the American

Board of Genetic Counseling and licensed by the Washington State Department of Health.

Much of Ms. Brown's clinical time is devoted to serving hereditary neuropathy patients and families - with a focus on those receiving a new diagnosis. She is driven by a desire to help patients process the medical and emotional implications of genetics contribution to disease.



Gregory T. Carter, MD
Chief Medical Officer
St. Luke's Rehabilitation Institute
University of Washington

Dr. Gregory T. Carter is chief medical officer of St. Luke's Rehabilitation Institute and clinical professor at Washington State University's College of Medicine. His clinical and research interests center on rehabilitative and palliative care of neuromuscular disease, with a particular focus on pain, fatigue and quality of life.

An avid researcher and writer, Dr. Carter has co-authored over 200 peer-reviewed publications, including the first studies on longitudinal physical performance, phrenic nerve and pulmonary function, and neuropathic pain in Charcot-Marie-Tooth disease.

Dr. Carter is the recipient of several prestigious research awards from medical societies across the United States, including the Excellence in Research Writing Award from the Association of Academic Physiatrists for his work on exercise in animal models of neuromuscular disease. After graduating from Loyola University Chicago, Dr. Carter began his residency and fellowship at the University of California, Davis, earning a Master's in Physiology along the way and serving as a MayDay Pain fellow at the University of Washington.



Jane Distad, MD
Director of the EMG Lab
University of Washington

Dr. Jane Distad is board certified in neurology and electrodiagnostic medicine in the Neurology Clinic and director of the EMG Lab at UW Medical Center and a UW associate professor of neurology.

Dr. Distad earned her MD at the Medical College of Ohio at Toledo, completed neurology residency at the University of Colorado Health Sciences Center and fellowship through Stanford Medical Center. Her clinical interests include neuromuscular diseases.



Ashraf Elsayegh, MD
Pulmonary Medicine
Cedars-Sinai Medical Center, Los Angeles

Dr. Ashraf Elsayegh, is a distinguished physician and researcher based in Los Angeles, California. With fifteen years of experience, Dr. Elsayegh is a foremost expert in the field of pulmonary medicine. He currently practices at Cedars-

Sinai where his interest and research centers around neuromuscular disorders, specifically amyotrophic lateral sclerosis (ALS), as well as diaphragm dysfunction and disorders.



Amy J. Gray
Chief Executive Officer
Charcot-Marie-Tooth Association

Amy brings to the CMTA more than 17 years of management experience in national voluntary health agencies, combined with a strong understanding of mission-driven organizations. Her experiences working for three major

non-profit health care organizations have shaped her expertise in fundraising, staff development, financial and operational management, strategic planning and community engagement.

Amy was most recently the senior vice president of constituent and community relations for the National Parkinson Foundation (NPF), responsible for providing the overall leadership, strategy and vision for the foundation's fundraising efforts, planned giving legacy society and network of chapters. She joined the NPF in 2013 in the role of vice president of chapter relations and community partnerships, providing guidance to its nationwide network of affiliates in organizational, mission, board and fund development activities. In 2014, she led the foundation and its affiliate chapters through a process of unification, integrating the chapters and foundation into one organization.

Before joining the NPF, Amy served in executive roles at the Crohn's and Colitis Foundation of America and the Muscular Dystrophy Association, where she successfully built strong chapters and robust relationships with donors, volunteer leaders, and key stakeholders.



Jim King, MS
District Manager
Allard USA

Jim King received his MS in Exercise Physiology from the University of Illinois at Chicago. He has worked as a territory manager for medical products companies in the cardiovascular, orthopedic and podiatric specialties for over

20 years. While a graduate student, he taught anatomy lab to pre-med students. He has been with Allard USA for five years.



Glenn Pfeffer, MD
Director of the Foot and Ankle Center
Cedars-Sinai Medical Center

Dr. Pfeffer is also a Co-Director of the Hereditary Neuropathy Program and Co-Director of the Cedars-Sinai/USC Gloria Kaufman Dance Medicine Center. Dr. Pfeffer has written numerous scientific articles on orthopaedics and has edited

seven academic textbooks on the foot and ankle. He has been treating foot and ankle problems in patients with Charcot-Marie-Tooth disease for 25 years. He is a past president of the American Orthopaedic Foot and Ankle Society, and recently served as president of the California Orthopaedic Association. Dr. 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.



Laurel Richardson
Director of Community Outreach
Charcot-Marie-Tooth Association

Laurel Richardson organizes patient and family engagement events and creates and manages education and community outreach programs. She also oversees the national CMTA branch system and is a co-director of CMTA Camp

Footprint. With over 15 years of experience working in communications and marketing and a lifelong commitment to volunteerism, Laurel brings with her a passion for finding a cure for CMT and a dedication to providing support to those living with CMT. Laurel graduated from San Diego State University with a degree in journalism. She lives in Wilmington, North Carolina with her husband and two children.



Jeana Sweeney
Director of Development
Charcot-Marie-Tooth Association

Jeana is a dedicated, passionate leader and communicator with a solid background in community services and years of experience working with a highly diverse clientele. She is adept at planning and executing multiple, simultaneous events with significant fundraising success. Jeana began working for the CMTA in an official capacity in January 2011, after a significant period as a volunteer that included stints as a branch leader, fundraiser, advocate and promoter of awareness about CMT.

Jeana facilitates communications between CMTA branches and volunteers nationwide to increase awareness of Charcot-Marie-Tooth disease and raise funds for research. She also creates educational programs in communities and schools, implements an annual Awareness Month campaign and participates in national fundraising events.



Eric Weber, LCPO, FAAOP
Clinical Research Associate
& National Orthotics Specialist
Hanger Clinic

Eric Weber is a graduate of the University of Washington's prosthetics and orthotics program. He completed a residency in both orthotics and prosthetics at Northwest Prosthetics and Orthotics in Washington State. He has managed the clinical operations of multiple prosthetic and orthotic clinic locations, overseeing the evaluation, design and fabrication of prosthetic and orthotic interventions. He actively participates in education, research and development of orthotic and prosthetic technologies.

Eric currently resides in Seattle and divides his time between patient care and his role as a member of Hanger's Clinical and Scientific Affairs Department acting as a Clinical Research Associate. His focus is on outcomes, clinical practice guidelines and product development. He is an active presenter, educator, and clinical support specialist participating in product development and clinical research nationwide.

Notes



CMTA Branches in Washington, Oregon & California



Seattle, WA CMTA Branch

Branch Leader: Denise Snow
denisesnow@comcast.net / 206-321-1261
Branch Co-Leader: Emily Osborne
emily4cmt@gmail.com / 425-220-4225
www.cmtausa.org/branch/se/



Grants Pass, OR CMTA Branch

Branch Leader: Jessica Barton
gp4cmt@gmail.com / 541-846-8525
www.cmtausa.org/branch/gp/

Portland, OR CMTA Branch

Branch Leader: Debbie McHugh
mchugh6847@gmail.com / 503-543-2637
www.cmtausa.org/branch/pd/



Antelope Valley, CA CMTA Branch

Branch Leader: Donna Murphy
madondala@gmail.com / 661-317-6332
Branch Co-Leader: Danielle Metzger
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CMTA Branches in Washington, Oregon & California



Los Angeles, CA CMTA Branch

Branch Leader: Alani Price
alani.price@fulbrightmail.org / 310-710-2376
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Sacramento, CA CMTA Branch

Branch Leader: Holly Stevens
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San Diego, CA CMTA Branch

Branch Leader: Annette Van Veen
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San Francisco Bay Area, CA CMTA Branch

Branch Leader: Ori Bash
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