

Cedars-Sinai Charcot-Marie-Tooth Patient & Family Conference

February 15, 2014

Cedars-Sinai Medical Center
Harvey Morse Conference Center
South Tower, Plaza Level
8701 Gracie Allen Drive
Los Angeles, CA



**Cedars-Sinai
Charcot-Marie-Tooth
Patient & Family Conference**

February 15, 2014

- 8:00 - 9:00 am: Registration**
- 9:00 - 9:15 am: CMTA: Who We Are and What We Do!**
Patrick A. Livney
Chief Executive Officer
Charcot-Marie-Tooth Association
- 9:15 - 9:30 am: Introduction to the Cedars Clinic**
Richard Lewis, MD, FAAN
Robert H. Baloh, MD, PhD
Cedars-Sinai Medical Center
- 9:30 - 10:00 am: The Clinical Spectrum of CMT**
Richard Lewis, MD, FAAN
Cedars-Sinai Medical Center
- 10:00 - 10:30 am: A Step in the Right Direction**
Glenn B. Pfeffer, MD
Cedars-Sinai Medical Center
- 10:30 - 10:50 am: Break**
- 10:50 - 11:20 am: Physical Therapy and CMT**
Dawn Hageman, DPT, OCS, CSCS
Cedars-Sinai Medical Center
- 11:20- 11:50 am: Bracing Options in CMT**
David F.M. Cooney
Rudy B. Parada
Swiss Balance

11:50 am - 12:15 pm: The Time Is NOW – Get Involved!

Jeana Sweeney
Director of Community Services
Charcot-Marie-Tooth Association

12:15 - 1:30 pm: Lunch

1:30 - 2:00 pm: Tumbling Forward

Bethany Meloche
Director of Social Media
Charcot-Marie-Tooth Association

2:00 - 2:30 pm: Genetics of CMT: New Approaches to Determining the Specific Cause

Tara Funari, MS, CGC
Cedars-Sinai Medical Center

2:30- 3:00 pm: Research Update

Robert H. Baloh, MD, PhD
Cedars-Sinai Medical Center

3:00 - 3:15 pm: Afternoon Break

3:15 - 3:45 pm: Living with CMT: Social/Emotional Aspects

Lynn S. Kuttner, PhD
Psychologist and Psychoanalyst
West Hollywood

3:45 - 4:45 pm: Ask the Experts Panel Discussion

4:45 - 5:00 pm: The Future Is Ours

Patrick A. Livney
Chief Executive Officer
Charcot-Marie-Tooth Association

5:00 pm: Adjourn

Presenters and Experts



Robert H. Baloh, MD, PhD
Director of Neuromuscular Medicine
Cedars-Sinai Medical Center

Dr. Baloh began his research in CMT at Washington University in St. Louis and has an active laboratory-based research program using petri dish and animal models of demyelinating and axonal CMT. He moved to Cedars-Sinai Medical Center in 2011 to found the Neuromuscular Medicine division, to develop active programs in neuromuscular disease research which include a multidisciplinary CMT clinic, and a research laboratory focused on the development of stem cell therapies for CMT.

He has published extensively on inherited disorders of the peripheral nervous system and is a member of the Medical Advisory Board for both the CMTA and the MDA. His research has been supported by the NIH, Burroughs Wellcome Fund, MDA, and the California Institute for Regenerative Medicine, which recently awarded him \$3 million to study the feasibility of stem cell therapies for CMT.



David F.M. Cooney, PT, CPO
Swiss Balance

David F.M. Cooney is an advanced practitioner with clinical experience in lower limb prosthetics and orthotics, spinal orthotics and cranial molding helmets. David has been providing exemplary prosthetic and orthotic care for over 25 years. In addition, he has been a Registered Physical Therapist for 30 years. He holds a Magna Cum Laude Bachelor of Science and a Master of Science degree in Physical Therapy from the USC School of Medicine. He completed the Prosthetic and Orthotics Certificate Education program at UCLA. He is certified in both prosthetics (1983) and orthotics (1984) by the American Board for Certification and maintains a current continuing education

profile as mandated by his profession for said certification.

He is currently certified to provide and fit the Otto Bock C-Leg, Ossur Rheo Knee, and Otto Bock Harmony systems. He has been educated and has significant experience in fitting both the CATCAM and MAS Transfemoral Socket designs. David is also certified to provide the Oregon Orthotic System in addition to a myriad of other advanced lower limb orthotic applications.



Tara Funari, MS, CGC
Department of Neurology
Cedars-Sinai Medical Center

Tara Funari has over 10 years experience working as a genetic counselor in different types of specialty clinics. She began her career at California Pacific Medical Center providing prenatal and cancer genetic counseling services. Tara began working at Cedars-Sinai Medical Center approximately eight years ago in the Skeletal Dysplasia Clinic and served as the research coordinator for the International Skeletal Dysplasia Registry. More recently, Tara assumed the role of genetic counselor for several multi-disciplinary clinics in the Department of Neurology, including the CMT clinic, where she discusses family history, inheritance, and genetic testing with patients and their families.



Dawn Hageman, DPT, OCS, CSCS
Cedars-Sinai Medical Center

Dawn Hageman earned her doctorate in physical therapy at Belmont University in Nashville, Tennessee, in 2004 and joined the Outpatient Rehabilitation team the same year. She completed the Cedars-Sinai Orthopedic Clinical Resident in 2007 and became an Orthopedic Clinical Specialist in 2008. Dawn is also a Certified Strength and Conditioning Specialist. Her areas of expertise include Charcot-Marie-Tooth-Disease, dance medicine, orthopedics and pelvic floor dysfunction.

**Sarah Kesty, MA in Special Education**

Sarah Kesty has worked with individuals with a range of disabilities for over ten years. She has a Masters in Special Education from Sacramento State and two teaching credentials. Sarah is a passionate advocate for people with disabilities. She has experience teaching kindergarten through high school-aged students and coaching Special Olympics. She has received numerous grants, most recently to launch a mentor program and create a disability-awareness and executive functioning curriculum for middle school students.

Sarah has spoken to groups of teachers, parents, and students about disability awareness, advocacy, and maximizing life satisfaction. Her speaking has taken her all the way to Belize, where she taught a seminar on behavior management to a group of 150 teachers. Sarah writes for several publications, including *The Special Edge*, a publication for California's special educators. She shares inspiring stories on her website, sarahkesty.com and has recently written a book for children. Sarah has CMT and can deeply empathize with both students and parents navigating the school support systems. She is honored to help CMTA members make the best of their children's school experiences.

**Lynn S. Kuttner, PhD
Psychologist and Psychoanalyst
West Hollywood**

Lynn Kuttner has worked with both children and adults in psychiatric out-patient, in-patient and day treatment settings over the last three decades. Her interest in the psychological impact of physical illness began while working at the Detroit Medical Center in the Consultation-Liaison Department, providing psychological services to patients coping with medical conditions including cancer and neurological disorders. She has been an invited speaker to physician and patient groups regarding cancer, Guillain Barre Syndrome, chronic inflammatory neuropathies and multiple sclerosis and has taught professional courses on the psychological effects of chronic disorders.

Dr. Kuttner just recently relocated to Los Angeles from Michigan. She has a private practice in West Hollywood where she sees patients for psychotherapy and psychoanalysis, a fair number of whom have had experiences with various disease processes. She also enjoys teaching and supervising students and other professionals within the community.

**Richard A. Lewis, MD, FAAN
Co-Director of the Inherited Neuropathy Clinic
Cedars-Sinai Medical Center**

Richard Lewis is also Director of the EMG Laboratory and of the Clinical Specialty Clinics. Dr. Lewis moved to Los Angeles in November 2012 after 19 years at Wayne State University in Detroit, Michigan, where he helped develop the CMT clinic. He was the Principal

Investigator of the Vitamin C trial in CMT-1A. He has served on the Board of Directors of the Peripheral Nerve Society and is currently on the Steering Committee of the Inflammatory Neuropathy Consortium. He is also on the Medical Advisory Boards of the Guillain Barre-CIDP Foundation International and the Myasthenia Gravis Foundation.

**Patrick A. Livney
Chief Executive Officer
Charcot-Marie-Tooth Association**

Pat assumed the role of Chief Executive Officer (CEO) of the Charcot-Marie-Tooth Association after serving on the Board of Directors for six years. He took office in December, 2011, saying "The CMTA is growing and changing and will continue to aggressively pursue the first treatment for CMT under the STAR initiative."

Pat diligently works to fund this ground breaking research to further the goal of finding a cure for CMT. To this end, he hosts a golf tournament in Chicago that has raised over \$200,000 each year.



Bethany Meloche
Director of Social Media
Charcot-Marie-Tooth Association

Bethany Meloche began working with the CMTA as a volunteer in 2010. As a result of her active participation, she was asked to join the CMTA Advisory Board as a youth liaison. She has worked as an advocate for all youth services within the CMTA. A member of the

Social Media generation, and a student of its trends, Bethany helped edit the book *The Ultimate Guide to Facebook Advertising*, published by the Entrepreneur Press. She has also been spotted on one or two occasions hanging out at Facebook headquarters in Menlo Park. When not working with the CMT community, Bethany may be found feeding squirrels on the UC Berkeley campus, where she is completing a degree in Nutritional Science. Bethany has CMT1A and runs the blog BareYourBrace.com.



Elizabeth Ouellette
Member, CMTA Board of Directors

When her son was diagnosed with CMT1A 13 years ago, Elizabeth made a conscious decision to become an active participant in the CMTA, with the goal of making a significant difference in the lives of her son and others affected by this disorder. Upon moving to California, she obtained an MA in Counseling Psychology, a course of study and training proving invaluable in the understanding of herself and others, especially in the realm of pain disorders and disabilities. Although she does not have CMT, she has dealt with chronic neuropathic and disabling foot pain for the past 20 years, a condition that has not only helped her to relate to, and empathize with, her son and his CMT, but also to all those who have to manage chronic pain.

As a CMTA Board Member, Elizabeth is making a difference not only in her son's life, but in the lives of all those with CMT. Through her writing, school-based presentations, work with the CMTA's Support and Action Groups and various fund-raising events, she continues to build CMT awareness and raise funds needed for research via the STAR initiative.

As a CMTA Board Member, Elizabeth is making a difference not only in her son's life, but in the lives of all those with CMT. Through her writing, school-based presentations, work with the CMTA's Support and Action Groups and various fund-raising events, she continues to build CMT awareness and raise funds needed for research via the STAR initiative.



Rudy B. Parada, CPO
Swiss Balance

Rudy is a Certified Prosthetist Orthotist with the American Board for Certification in Orthotics, Prosthetics & Pedorthics, Inc. (ABC). He joined the team as a volunteer in 1996, while simultaneously obtaining his Bachelor of Science Degree in Prosthetics and Orthotics from California State University Dominguez

Hills (CSUDH). During his ten years as a practitioner, Rudy has provided excellent clinical care to his patients and distinguished his career with the necessary skills and experience to provide appropriate and functional orthotic and prosthetic devices. Rudy stays in the forefront of technological innovation, and he is certified in the WALKAIDE Functional Electrical Stimulation (FES) system, Stance Control Knee Ankle Foot Orthosis (KAFO) and E-Knee™ computer controlled knee joint. He has also received certification in the FLEX-FOOT Prosthetic Foot System and the Boston Brace Spinal Management. He maintains good standing in his mandatory continuing education with ABC. Rudy is a member of ABC, and the American Academy of Orthotists and Prosthetists.



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 The New York Times.



Susan Ruediger
Director of Development
Charcot-Marie-Tooth Association

Susan is developing two initiatives: creating and producing an educational series designed for PT, OT and orthotic clinicians to learn more about CMT and treat those with CMT more effectively and appropriately initiating fundraising efforts through grant research and writing. She continues to seek and manage corporate relationships in efforts to continue to build awareness for CMT and the CMTA. Susan collaborates with the team at the CMTA to strategically position the organization for success.

Susan started the Atlanta Support and Action Group in 2008 and really enjoys the fellowship and support she gets from the group. Susan has CMT, as do 18 people in five generations in her family.



Jeana Sweeney
Director of Community Services
Charcot-Marie-Tooth Association

Jeana is the Co-facilitator of the Johnstown, PA, CMT Support and Action Group, and she is very enthusiastic when it comes to raising awareness and funds for the CMTA. She has done many things including softball tournaments, the Archy cookbook, a fishing derby and her all-time favorite, "Stepping it up for CMT" in schools.

Jeana is the main point of contact for everything related to being a Support and Action Group facilitator. She helps with any questions related to the website, materials and marketing for support groups, and any plans or ideas people may have concerning fundraising. Jeana also visits Support and Action Groups and speaks about the STAR Program, getting members excited about fundraising and interested in what the CMTA is doing for them!

The CMTA Youth Outing

February 15, 2014

It's time to celebrate being young, so members of the CMTA have planned an evening of fun for teens between the ages of 13 and 19. Leading the event are CMTA volunteer Yohan Bouchard and Advisory Board Members Bethany Meloche* and Jonah Berger. After introductions, the group will head straight to the bowling alley Lucky Strike by way of the famous Walk of Fame and then on to dinner at a nearby restaurant before returning to Cedars-Sinai.



Yohan Bouchard is currently a student at Pitzer College in Claremont, California. He began working as a volunteer for the CMTA when he was diagnosed with CMT at age seven. Yohan enjoys sharing and discussing the ways in which he has learned to cope with his CMT over the years. When not studying psychology, Yohan spends his time organizing events for the Mage Club, practicing archery and playing various computer games with his friends.



Jonah Berger is 41 years old and lives in Colorado. He runs a business called The Rhythm Within, working with kids and adults with special needs. He has been diagnosed with CMTX and has enjoyed an interesting journey of challenge and wisdom. He is the author of *He Walks Like A Cowboy*, a book detailing the life and lessons of the CMT path. He is a proud member of the CMTA community!

*Bethany's profile appears in the Presenters and Experts section.

Our thanks to our sponsors, Aetrex,
Allard, GeneDx, and Dynamic Bracing Solutions, whose
generosity helped make this conference possible.



allard|USA

Support for Better Life!



Charcot-Marie-Tooth Association
PO Box 105
Glenolden, PA 19036
800-606-2682
www.cmtausa.org