Stanford
Charcot-Marie-Tooth
Patient & Family Conference

September 27, 2014

Stanford University
McCaw Hall
Frances C. Arrillaga Alumni Center
326 Galvez Street
Stanford, CA 94305

CMTA
Charcot-Marie-Tooth Association

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September 27, 2014

8:00 - 9:00 am:	**Registration**
9:00 - 9:15 am:	**Welcome** *Patrick A. Livney* *Chief Executive Officer* *Charcot-Marie-Tooth Association*
9:15 - 9:45 am:	**CMT: The Basics** *John Day, MD, PhD* *Neuromuscular Program* *Stanford Hospital and Clinics*
9:45 - 10:15 am:	**Genetics and CMT** *Carly Siskind, MS, LCGC* *Neuromuscular Program* *Stanford Hospital and Clinics*
10:15 - 10:45 am:	**STAR: Treatments for CMT** *Michael E. Shy, MD* *University of Iowa Hospitals and Clinics*
10:45 - 11:00 am:	**Morning Break**
11:00 - 11:15 am:	**The Time Is NOW – Get Involved!** *Jeana Sweeney* *Director of Community Services* *Charcot-Marie-Tooth Association*
11:15 - 12:00 pm:	**Q & A with Speakers from AM Sessions**
12:00 - 1:15 pm:	**Lunch**

1:15 - 1:45 pm:	**Breakout Session One (Select 1, 2 or 3)**
Option 1:	**The Joys of CMT; Choosing Life on the Bright Side** *Jonah Berger, CMTA Advisory Board*
Option 2:	**A Stepping Stone or Stumbling Block ... Raising Kids with CMT** *Sarah Kesty, CMTA Advisory Board*
Option 3:	**H.E.A.L. Program - IEP and 504 Plans** *Jeanne Kane, H.E.A.L. Program Coordinator and Educational Specialist &* *Michileen Oberst, LCSW* *Lucile Packard Children's Hospital*
1:45 - 2:15 pm:	**Breakout Session Two (Select 1, 2 or 3)**
2:15 - 2:30 pm:	**Afternoon Break**
2:30 - 3:00 pm:	**Genetically Handicapped Persons Program (GHPP)** *Peggy Peter, Health Program Manager*
3:00 - 3:30 pm:	**A Little Help Goes a Long Way - Aids for Living Independently** *Janis Kitsuwa-Lowe, OTR/L* *Lucile Packard Children's Hospital*
3:30 - 4:00 pm:	**CMT and Breathing** *Kristina Zekos-Ortiz, RRT, AE-C* *Neuromuscular Program* *Stanford Hospital and Clinics*
4:00 - 4:15 pm:	**Q & A with Janis Kitsuwa-Lowe and Kristina Zekos-Ortiz**
4:15 - 4:30 pm:	**Closing** *Susan Ruediger, Director of Development* *Charcot-Marie-Tooth Association*

Presenters and Experts

Jonah Berger
CMTA Advisory Board Member

Jonah Berger is 42 years old and lives in Colorful 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 Advisory Board, and believes in the challenge and the wisdom that come from CMT!

Herbert Beron
Board Chairman and President
Charcot-Marie-Tooth Association

When his daughter Julia was diagnosed with CMT 2E, Herb and his wife Rachael decided that they needed to become actively involved with the CMTA. In 2007, Rachael participated in a one-mile swim to raise funds for the CMTA. Eight years later, "TeamJulia & the Swim for the Cure" has raised in excess of $600,000 in total donations for the STAR program. Herb has been on the Board of Directors for the past seven years, and he welcomes the opportunity and challenge to lead the Board in taking the CMTA to even greater heights.

Herb received a BBA in Finance from Emory University in 1986 and is currently a Director for Morgan Stanley Smith Barney. It is his heartfelt goal that the CMTA achieve its stated mission: "to find a cure, to create awareness, and to improve the quality of life for those affected by Charcot-Marie Tooth."

John W. Day, MD, PhD
Director of the Neuromuscular Program
Stanford Hospital and Clinics

Dr. Day has over 25 years of experience in diagnosing, treating and supporting patients with neuromuscular diseases. He is involved in ongoing research defining causes, diagnosis and novel treatments of genetic neuromuscular disorders. Prior to his arrival at Stanford in 2011, Dr. Day directed the Paul and Sheila Wellstone Muscular Dystrophy Center at University of Minnesota. Dr. Day graduated from the Albert Einstein College of Medicine and completed his Residency and Fellowship at University of California Medical School in San Francisco. Dr. Day is Board Certified in Neurology by the American Board of Psychiatry and Neurology and serves as an advisor to many scientific committees researching neuromuscular diseases, including NIH's Advisory Committees on Muscular Dystrophy and Muscular Dystrophy research. His areas of interest include most areas of nerve and muscle diseases, in particular, muscular dystrophies, motor neuron diseases, Ataxia and Myasthenia Gravis.

Bob DeRosa
Member, CMTA Board of Directors

With over 35 years of marketing and creative experience, Bob DeRosa is currently the Director of Marketing/ Creative at Aetrex Worldwide, Inc., a family-owned health and wellness footwear company located in Teaneck, NJ. In 2012, Aetrex became a corporate sponsor of the CMTA, but their commitment goes far beyond your typical corporate sponsorship. With Bob's graphic and design work, he has provided a fresh and engaging approach to the CMTA's goals and objectives—all successful and effective in raising awareness, education and funding. The Time Is Now brochure, the Awareness Month Website, the Survivor's Guide, and even the "Shark-O Marie Tooth" t-shirts were all collaborations between the CMTA team and Bob.

Jennifer Fisher
Community Liaison
Neuromuscular Program
Stanford Hospitals and Clinics

Prior to joining the Stanford Hospital and Clinics neuromuscular team in 2012, Ms. Fisher worked for the Muscular Dystrophy Association (MDA), helping patients and their loved ones access resources and services to improve independence and quality of life. She's worked in the palliative care field when she was the communications coordinator at the pediatric hospice, George Mark Children's House. With a broad knowledge base in community resources, Ms. Fisher is dedicated to building relationships with community partners, patients and their families. She will develop new avenues of patient support (like support groups, teen transitional support, educational seminars, webinars etc.) and will connect patients and their loved ones with resources and support services, help recruit for clinical trials, as well as oversee the neuromuscular program's social media presence.

Jeanne Kane, MA
Program Coordinator and Educational Specialist
Hospital Educational Advocacy Program (H.E.A.L.)
Lucile Packard Children's Hospital

Jeanne Kane has been a credentialed Special Education Teacher and Educational Specialist for 37 years. Jeanne brought her unique expertise about medically fragile children to LPCH in 2003 when she created the H.E.A.L. School Re-entry Program. HEAL helps schools understand how a child's medical condition and treatment can affect their cognition, learning and psycho/social growth which may impact their performance in school and help schools devise a plan for student success. Since that time, the HEAL Program has provided advocacy, assessment and educational planning for hundreds of Packard children. Jeanne has been a speaker at many conferences over the past 11 years. They include: Leukemia & Lymphoma Back to School Workshops, the Association for Child Neurology Nurses, planner and presenter at the AECMN Conference at LPCH and two years ago she presented at the Council of Exceptional Children's National Conference in Denver. Her advanced degree includes a Masters in Exceptional Children. This past year, Jeanne was selected as the recipient for The Grace Award for the Employee of the Year 2013 at Lucile Packard Children's Hospital.

Sarah Kesty, MA in Special Education
CMTA Advisory Board Member

Sarah Kesty is an educator, author, and speaker from Sacramento, California. She was named Twin Rivers School District's 2014-15 Teacher of the Year. Sarah writes for several publications, including *The Special EDucator*, a publication for California's special educators. She shares inspiring stories on her website, sarahkesty.com, and has recently written a book for children, *Everyone Has Something. Together We Can*. 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.

Sarah has a Masters in Special Education from Sacramento State and two teaching credentials, and she has worked with individuals with a range of disabilities for over ten years. 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.

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.

Janis Kitsuwa-Lowe, MA, OTR/L
Occupational Therapist
Neuromuscular Program
Stanford Hospitals and Clinics

Janis joined the Pediatric Neuromuscular Team at Stanford Children's Health in 2011 after working for more than 30 years in settings across a range of care, including hospitals, outpatient rehabilitation, and community-based programs. Besides serving as a consultant in the pediatric MDA Clinic, she is involved in multidisciplinary clinics for high-risk infants and children with Down Syndrome, and provides clinical care for outpatients. She received her Master's degree in occupational therapy and holds advanced certifications in Neuro-Developmental Treatment and swallowing. She is interested in helping individuals with chronic conditions live productive and meaningful lives as they transition through the developmental continuum.

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.

Michileen Oberst, LCSW
Advanced Licensed Clinical Social Worker
Lucile Packard Children's Hospital

Michileen Oberst is an advanced licensed clinical social worker, providing patient and family support services for over twenty years at Stanford Hospital and Lucile Packard Children's Hospital. She has a Masters in Social Work from University of Michigan. Her role on the neuromuscular multi-disciplinary team is to educate families regarding supportive services, assist them in accessing programs that enhance their independence and quality of life, and provide patients and families supportive counseling and advocacy.

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.

Peggy Peter
Health Program Manager
Genetically Handicapped Persons Program

Peggy Peter emigrated from Germany with her husband, Hans, in 1972. They raised two sons, Shawn and Mario, while living in Sacramento. Peggy worked for 23 years in California State service as an auditor in various state departments, auditing medical hospitals, regional centers, and other health care entities.

She moved on as the audit appeals officer for the 2100 vendors contracted through the 21 regional centers located in Northern and Southern California providing services to the mentally disabled clients living there. She came to the Department of Health Care Services as the Health Program Manager for the Genetically Handicapped Persons Program in May 2013.

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.

Michael Shy, MD
Co-Director of the Inherited Neuropathy Clinic
University of Iowa Hospitals and Clinics

Scientifically, Dr. Shy is interested in understanding the biology of neurodegenerative diseases so that rational treatments can be developed for these devastating disorders. It is his belief that when we understand the biological cause of degenerative diseases like CMT, ALS or Parkinson's Disease then treatments for many other neurological diseases can be developed as well. He believes that CMT provides the best group of disorders to achieve these aims because the genetic cause of many forms is already known. Therefore, it is possible to discover how mutations in these specific genes cause nerve degeneration and then develop treatments to reverse the degeneration.

Dr. Shy, who says he has grown to respect and admire the many patients he sees that live with CMT, has recently moved his multidisciplinary CMT clinic to the University of Iowa, in Iowa City. His Center of Excellence combines patient care, genetic counseling, physical therapy, occupational therapy and orthopedic expertise.

Carly Siskind, MS, LCGC
Senior Genetic Counselor /Assistant Clinical Professor
Neuromuscular Program
Stanford Hospitals and Clinics

Before joining the neuromuscular team in 2011, Carly Siskind worked in neurogenetics at Wayne State University in Detroit. She sees patients both at Stanford Hospital and Clinics and Lucile Packard Children's Hospital. Ms. Siskind is a Clinical Assistant Professor of Neurology (Affiliated), with her main research focus being Charcot-Marie-Tooth disease. Ms. Siskind obtained her Bachelor's degree from the University of Michigan with a major in Biology. She obtained her Master's degree from Northwestern University in Chicago. She was board certified by the National Society of Genetic Counselors in 2009 and licensed by the state of California in 2011.

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

Jeana is the Co-faciltator 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!

Brittany Wright, PhD
CMTA Research Associate
National Center for Advancing Translational Sciences
Bethesda, MD

In 2009, Brittany Wright graduated with a Bachelor of Science degree in chemistry from Eckerd College in St. Petersburg, Florida, and started the PhD program in Pharmaceutical Sciences at the Eshelman School of Pharmacy at the University of North Carolina at Chapel Hill. Her graduate research was focused on neuroscience drug discovery where she identified a new molecular therapeutic target for chronic pain. She graduated from UNC with a PhD in Pharmaceutical Sciences with a concentration in chemical biology and medicinal chemistry in December of 2013.

Brittany joined the laboratory of Dr. James Inglese at the National Center for Advancing Translational Science, the newest institute at the National Institutes of Health, in April 2014 where she is focused on assay design and development for CMT1B. Brittany is excited to join the CMTA STAR program and enjoys being part of an organization committed to research for CMT.

Kristina Zekos-Ortiz, RRT, AE-C
Respiratory Therapist
Neuromuscular Program
Stanford Hospitals and Clinics

Kristina Zekos-Ortiz, respiratory therapist for the adult neuromuscular program, joined the team in 2013. She received her degree in Respiratory Care in 2007 and belongs to the National Board of Respiratory Care and the California Society of Respiratory Care.

She enjoys working with the neuromuscular team because of the collaborative team approach to patient care. She enjoys seeing patients in the clinic; answering questions and helping them find solutions that are in line with their goals of care. Ms. Zekos-Ortiz also works throughout the main hospital and provides coverage in the Intensive Care Unit, Emergency Department, Cathangio lab, and Cystic Fibrosis Clinic.

The CMTA Youth Outing
September 27, 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 will be CMTA Advisory Board Members Bethany Meloche and Jonah Berger.

The Youth Outing will be held after the Patient Family Conference. We'll meet at 4:30 pm at McCaw Hall at the Frances C. Arrillaga Alumni Center.

After introductions, the group will head straight to Golfland USA in Sunnyvale for a game of mini-golf. Once everyone has worked up an appetite, we will head over to a nearby restaurant for good conversation over dinner. The night will end back at the Alumni Center.

Bring on the pizza!

Orthotist Sean McKale (far left), CMTA Advisory Board Member Jonah Berger (second from left), and teens at the CMT Youth Outing in Chicago.

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

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