

Orlando
Charcot-Marie-Tooth
Patient & Family Conference

November 9, 2013

Holiday Inn Lake Buena Vista Downtown
1805 Hotel Plaza Blvd
Lake Buena Vista, FL



**Orlando
Charcot-Marie-Tooth
Patient & Family Conference**

November 9, 2013

- 8:00 - 9:00 am: Registration and Exhibits**
- 9:00 - 9:10 am: Welcome**
Elizabeth Ouellette, Board Member
Charcot-Marie-Tooth Association
- 9:10 - 9:30 am: Who We Are and What We Do!**
Patrick A. Livney, CEO
Charcot-Marie-Tooth Association
- 9:30 - 10:15 am: Pediatric Aspects of CMT**
Richard S. Finkel, MD
Nemours Children's Hospital
- 10:15 - 10:30 am: Break and Exhibits**
- 10:30 - 11:15 am: Orthopedic Options for Treating CMT**
Steven L. Frick, MD
Nemours Children's Hospital

11:15 am - 12:00 pm: Orthotic Management of Patients with CMT

Sean McKale, CO, LO
Midwest Orthotic and
Technology Center

David B. Misener, CPO
Clinical Prosthetics and Orthotics

12:00 - 1:15 pm: Lunch with the Experts
(See pages 14 & 15 for seating chart.)

1:15 - 1:30 pm: The Time Is NOW – Get Involved!

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

1:30 - 2:15 pm: Genome Analysis in CMT Patients

Stephan Züchner, MD, PhD
University of Miami

2:15 - 2:30 pm: Afternoon Break

2:30 - 3:45 pm: Diagnosing and Managing CMT

Michael E. Shy, MD
University of Iowa

3:45 - 4:00 pm: Heading Toward the Future...

Patrick A. Livney, CEO
Charcot-Marie-Tooth Association

The CMTA Youth Outing November 9, 2013



- 8:00 am: Meet in Hotel Lobby - Holiday Inn, Lake Buena Vista Downtown
- 8:15 am: Depart from Holiday Inn
- 8:45 am: Arrive at Magic Kingdom for A MAGICAL DAY AT THE PARK!!!
- 4:00 pm: Pick Up at Magic Kingdom
- 4:00-6:45 pm: Back to Holiday Inn for a Poolside Pizza Party
- 6:45 pm: Meet in Holiday Inn Lobby
- 7:00 pm: Depart from Holiday Inn
- 7:30 pm: Arrive at Magic Kingdom
- 10:00 pm: Pick Up from Park & Return to Holiday Inn

Presenters and Experts



**Roy Behlke, Facilitator
Naples, FL CMT Support and Action Group**

Roy is a 75-year-old active senior who facilitates the Naples, Florida Support and Action Group. In addition, he has started another Support and Action Group in Hartford, CT. Roy was diagnosed with CMT1A at age 55 and currently wears AFOs but can still play golf, the game he loves. He has been married to his wife Diana for 45 years and has a daughter and a son.

Roy has a BS in Aero Engineering from U of Maryland and an MS from RPI. He worked for Pratt and Whitney Aircraft in CT for 45 years designing compressors for jet engines. He spends winters in Naples and summers in Manchester, CT. His hobbies are model railroading and spending time with his four grandchildren.



**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.

Seven years later, "TeamJulia & the Swim for the Cure" has raised in excess of \$550,000 in total donations for the STAR program. Herb has been on the Board of Directors for the past four 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."



**Robert DeRosa, Marketing and Creative Director
Aetrex Worldwide, Inc.**

Bob has been involved in the development of marketing and creative design for multi-national companies for over thirty years. Bob has been with Aetrex Worldwide, a health conscious footwear company, for the last eight years and is personally involved with all aspects of the company, including marketing, creative design, product development, public relations, social media, media planning, trade show development and retail store build-outs.

Aetrex became a proud sponsor of the CMTA in August of 2012. Bob's commitment to helping the CMTA goes beyond what he had intended and we had hoped for. He has developed and created the CMTA's most recent Annual Report, Awareness Month Web Initiative, Endowment Brochure and our Year End Campaign. In Bob's own words, "The courage and strength that the CMTA community lives by on a daily basis makes my commitment to their cause a very personal and inspirational one—one that will continue to be a part of my life for years to come.



**Richard S. Finkel, MD, Chief
Division of Neurology, Department of Pediatrics
Nemours Children's Hospital, Orlando, FL**

Dr. Finkel's clinical practice and research focuses on pediatric neuromuscular disorders and metabolic diseases affecting the nervous system. He also performs pediatric electromyography and provides consultation in fetal neurology. Dr. Finkel conducts research in the natural history, optimal care and new treatments of pediatric neuromuscular disorders. He has participated in efforts to develop new outcome measures and design clinical trials for spinal muscular atrophy, Duchenne muscular dystrophy, inherited neuropathies and glycogen storage diseases.

Dr. Finkel received his medical degree from Washington University School of Medicine. He completed both his residency in pediatrics and a fellowship in child neurology at Boston Children's Hospital and Harvard Medical School. He is board certified in pediatrics, child neurology,

electrodiagnostic medicine and neuromuscular medicine, and is a fellow of the American Neurological Association. Dr. Finkel has published over 70 peer-reviewed papers. He serves on the editorial board of Neuromuscular Disorders and the advisory boards of the Muscular Dystrophy Association, Families of SMA, SMA Foundation, and Parent Project MD. Dr. Finkel is Professor of Neurology at the University of Central Florida School of Medicine.



**Steven L. Frick, MD, Chairman
Department of Orthopedic Surgery
Nemours Children's Hospital, Orlando, FL**

Dr. Frick is a pediatric orthopedic surgeon who became the Chairman of the Department of Orthopedic Surgery at Nemours Children's Hospital in July 2013, where he also serves as the Director of Medical Education. He is a Professor of Orthopedic Surgery and the Assistant Dean at the University of Central Florida College of Medicine, and Clinical Professor of Orthopedic Surgery at the University of Florida. Previously, he was the residency program director for the Department of Orthopedic Surgery at Carolinas Medical Center in Charlotte, NC. His main interests are clubfoot, pediatric trauma, hip dysplasia, growth, leadership, professionalism, and graduate medical education. He is active in many orthopedic professional societies.



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 dis-

ability 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, available in July 2013. 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.



Alan Korowitz
Member, CMTA Board of Directors

Alan is the Executive Vice President of Sales at Premiere Radio Networks. He and his wife Ruth became involved with the CMTA shortly after their son Zachary was diagnosed in 2008 with a still-to-be identified form of CMT. Ruth immediately became active as a support group leader on Long Island. They have committed themselves to finding a cure for a disease that affects over 2.6 million people.

Alan's hope in joining the board is simple: to assist in increasing awareness of the disease and the Association so the CMTA can raise the necessary funds to finance the important research being done today. By working to grow our base of support in the New York area, Alan hopes to further the Association's ongoing efforts to achieve a cure in the not-so-distant future.



Phil Lewis, Facilitator
South Florida CMT Support and Action Group

With his support and action group, Phil hopes to create an extended family for patients so that they can truly believe they have others to talk to and share with. Phil's interests are Japanese culture, Zen, yoga, nutrition, sports cars and muscle cars.



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. His overriding goal is to give back to society and to make a difference despite his busy personal and business life.



Eileen Martinez, Co-facilitator
South Florida CMT Support and Action Group

Although Eileen does not have CMT, she became involved with the South Florida Support and Action Group as co-facilitator through her friend Phil Lewis. Eileen lives in Boynton Beach, FL and has a 28-year-old son living in Indiana.

She's been in the medical field for 25 years and currently works as Office Manager for a psychotherapy/memory center. Her interests include fishing, bowling and cooking. She was also an active member of a prize-winning BBQ Cook Team in Katy, Texas.



Sean McKale, CO, LO, Practice Manager
Midwest Orthotic and Technology Center
Chicago, IL

Sean began as an athletic trainer who decided his love of working with his hands would lead him to making furniture. Fortunately a mentor of his told him about the field of orthotics. He has worked in various clinical settings, but through his time spent at the Rehabilitation Institute of Michigan and his relationship with Dr Michael Shy, he

has become increasingly passionate about helping patients with neuromuscular involvement.

Sean has spoken at numerous national orthotic and prosthetic conferences about dynamic AFOs, CMT, unique case presentations, and the management of pediatric patients. He enjoys working with CMT patients because he knows he is really helping improve someone's daily life.



**David B. Misener, BSc (HK), CPO, MBA
Clinical Prosthetics and Orthotics, Albany, NY**

David 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 Bachelor of Science

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.

Not only does David provide services to people with CMT, he has CMT, as does 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 looks forward to contributing to the CMT Association and is excited to be part of a great team.



**Elizabeth Ouellette
Member, CMTA Board of Directors**

When her son was diagnosed with CMT 1A 13 years ago at the age of seven, 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 understand-

ing 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 daily.

As a CMTA Board Member, Elizabeth wants to make 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 knows that she can not only build continued CMT awareness, but also participate in raising the funds needed for continued CMT research via the STAR initiative. Her efforts will not cease until treatments are found and available to all.



**Victoria Pollyea, OTR/L and Facilitator
Tampa Bay Area CMT Support and Action Group**

Vicki is a graduate of the Bachelor of Health Science Occupational Therapy program at the University of Florida. Early in her career, she worked primarily with children and families focusing on neuro-developmental problems, and emotional counseling. Vicki developed community outreach programs focusing on child development and parenting issues, and she has had articles published regarding OT, issues of disability, and CMT in professional and peer-support periodicals.



**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 also serves at the Atlanta Support and Action Group Facilitator. She started the group in 2008. She 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 E. Shy, MD
Director of the CMT Clinic and Co-Director of the Neuromuscular Program and MDA Program University of Iowa

Dr. Shy joined the University of Iowa Health Care team in the beginning of 2012, moving from Wayne State University, where he developed and ran a CMT clinic for 17 years. He has published extensively on inherited disorders of the peripheral nervous system, and he is the Chairman of the CMTA's Medical Advisory Board. He has also served on the Board of Directors of the Peripheral Nerve Society (PNS) and has been on the Medical Advisory Board for the MDA since 2002 because of his expertise in neuromuscular disease. He is also President-Elect for the Peripheral Nerve Society because of his work with inherited peripheral neuropathies.



John Svaren, PhD, Associate Professor
Department of Comparative Biosciences
University of Wisconsin

Dr. Svaren also serves as 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.

Dr. Svaren is working with the CMTA to lead one arm of the collaborative STAR project, which is focused on understanding the regulation of the PMP22 gene in order to develop novel assays for drug screening at the NIH. Although his primary focus has been on CMT1A, he welcomes the opportunity to help in the development and implementation of a multi-front strategy directed at other forms of CMT



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

Even before Jeana became employed by the CMTA in 2011, she was very much involved with the CMTA and its efforts. She is the co-facilitator for the Johnstown, PA, 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!



Chrissy Thomas, Manager
Education & ToeOFF Family Product Team
Allard, USA

Chrissy represents Allard, USA, a worldwide leader in the creation of innovative orthotic devices for over 50 years. Allard's partnership with the CMTA embodies the philanthropic spirit of the Allard companies, while achieving the CMTA's mission of improving the quality of life for those affected by CMT.



Stephan Züchner MD, PhD
University of Miami

Dr. Züchner is the Interim Chair at the Dr. John T. Macdonald Foundation, Department of Human Genetics. He is also a Professor of human genetics and neurology at the John P. Hussman Institute for Human Genomics, located in the University of Miami's Miller School of Medicine Biomedical Research Building.

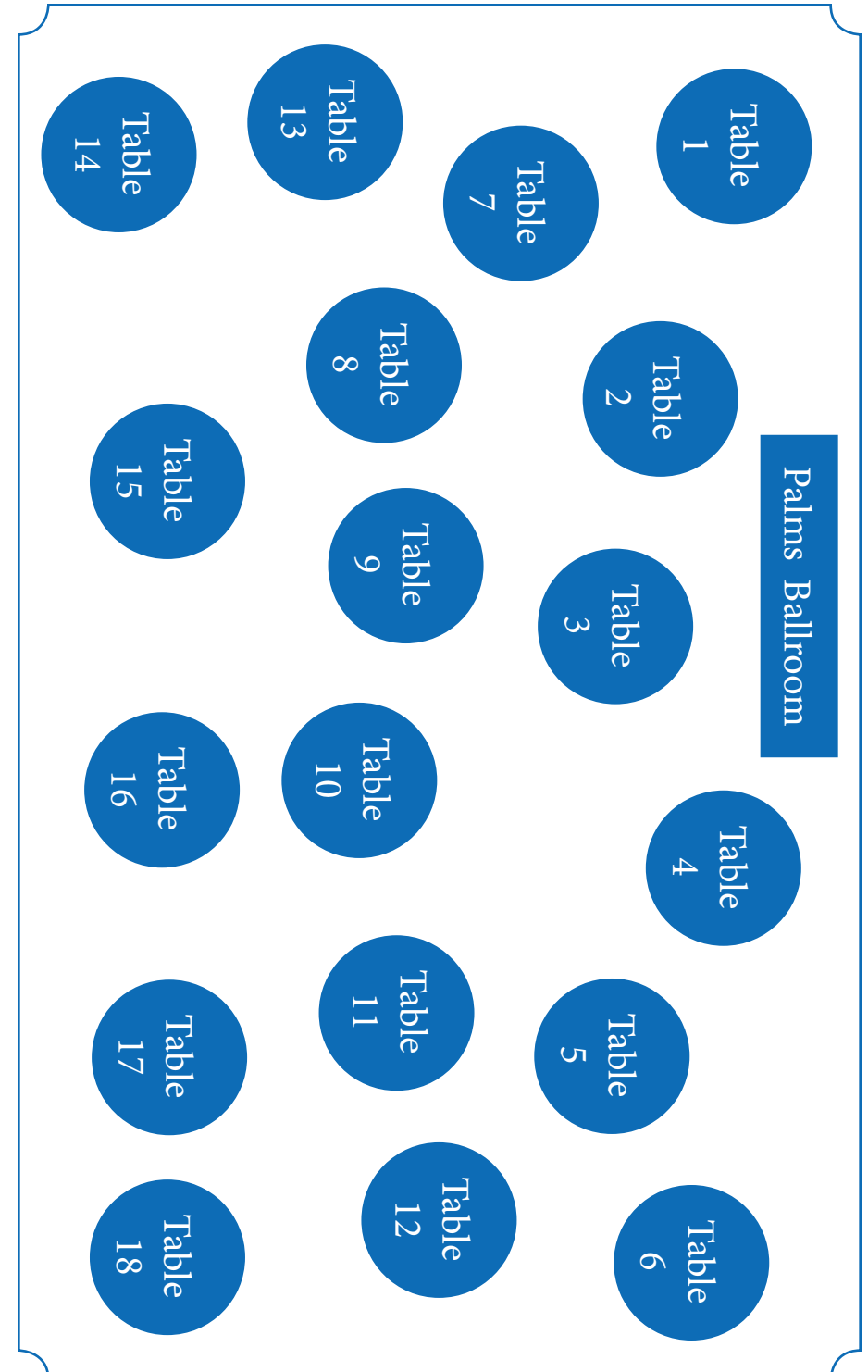
Lunch with the Experts

We invite you to join us for “Lunch with the Experts.”

The list of experts by table is below, and the diagram on the facing page shows the position of the tables.

- Table 1 – Roy Behlke
- Table 2 – Herb Beron
- Table 3 – Robert DeRosa
- Table 4 – Dr. Richard Finkel
- Table 5 – Dr. Steven Frick
- Table 6 – Sarah Kesty
- Table 7 – Alan Korowitz
- Table 8 – Phil Lewis
- Table 9 – Patrick A. Livney
- Table 10 – Eileen Martinez
- Table 11 – Sean McKale
- Table 12 – David B. Misener
- Table 13 – Vicki Pollyea
- Table 14 – Susan Ruediger
- Table 15 – Dr. Michael E. Shy
- Table 16 – Dr. John Svaren
- Table 17 – Chrissy Thomas
- Table 18 – Dr. Stephan Züchner

Seating is on a first-come, first-seated basis, and more information about the experts may be found in the “Presenters and Experts” section of your program.



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



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Support for Better Life!

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