

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



Support for Better Life!



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



The Northwood Club

**6524 Alpha Road
Dallas, TX**

Saturday, March 21, 2015



CMTA STAR RESEARCH UPDATE

March 21, 2015

- 8:00 - 9:00 am:** **Registration/Continental Breakfast**
- 9:00 - 9:10 am:** **Welcome**
Susan Ruediger
Director of Development
Charcot-Marie-Tooth Association
- 9:10 - 9:40 am:** **STAR Overview**
Patrick A. Livney
Chief Executive Officer
Charcot-Marie-Tooth Association
- 9:40 - 10:25 am:** **Overview of CMT;
Updates on CMT 1X, 2E and 4**
Steven S. Scherer, MD, PhD
University of Pennsylvania
- 10:25 - 10:35 am:** **Break**
- 10:35 - 11:20 am:** **Updates on CMT1A, 1B and 2A**
John Svaren, PhD
University of Wisconsin
- 11:20 - 11:45 am:** **Community Involvement**
Jeana Sweeney
Director of Community Services
Charcot-Marie-Tooth Association
- 11:45 am - 12:45 pm:** **Lunch and Question & Answer Panel**
- 12:45 - 1:00 pm:** **Closing**
Susan Ruediger
Director of Development
Charcot-Marie-Tooth Association

Presenters and Experts



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 the CMTA’s groundbreaking research to further the goal of finding a cure for CMT. He personally hosts an annual golf tournament in Chicago that raises more than \$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.



Susan Ruediger
Director of Development
Charcot-Marie-Tooth Association

Susan was diagnosed with CMT when she was 18 months old and can trace CMT back six generations in her mother’s family. She started the Atlanta, GA Branch as a volunteer after the birth of her first child so she could get more information about her genetic disease. Five years later, Susan joined the CMTA staff in January 2010.

As the CMTA’s Director of Development, Susan is responsible for strategic partnerships and fundraising activities. She has developed partnerships with companies focused on products and services that improve the quality of life for those with disabilities. She is continually seeking additional partners to serve the CMT patient and caregiver community, while also seeking funding for research and patient services. Susan has also built a network of physical therapists, occupational therapists and orthotists to create an educational series about the symptoms and treatment of CMT.



Steven Scherer, MD, PhD
Professor of Neurology
University of Pennsylvania

Now Chief of the Neuromuscular Division in the Perelman School of Medicine's Department of Neurology, Dr. Scherer has spent 30 years investigating what causes peripheral neuropathy and what can be done about it. CMT has been his focus for the last 15 years: His students investigate the biological causes of CMT in the laboratory; he sees patients who have CMT in his clinic; and he teaches medical students, graduate students, neurology residents and patients about CMT.

Dr. Scherer has written many papers about CMT for physicians, scientists and patients, developing an ever-larger association with the CMTA. His mission is the same—to unlock the secrets of CMT, to provide patients with treatment and effective therapies, and to ultimately find a cure for CMT—goals that he believes he can help the CMTA accomplish through his participation as a member of the Board of Directors and co-chair of the Scientific Advisory Board.



John Svaren, PhD
Professor, 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 develop and implement a multi-front strategy directed at other forms of CMT.



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

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

Jeana is also the co-leader of the Johnstown, PA CMTA Branch, and she is very enthusiastic when it comes to raising awareness and funds for the CMTA. She has organized many fundraisers, including softball tournaments, the Archy cookbook, a fishing derby and her all-time favorite, "Stepping it up for CMT" in schools.

Notes

Notes