



Director of Research
Position Overview

THE BATTEN GROUP
Executive Search & Consulting

The Opportunity

The Charcot-Marie-Tooth Association (CMTA) announces the search for a Director of Research to manage existing research and mission programs while also providing insight and support necessary to develop new care, support, and research programs. This is an opportunity for a research and mission-minded individual to help the largest organization in the CMT industry to continue to pursue the mission of supporting the development of new drugs to treat CMT, to improve the quality of life for people with CMT, and, ultimately, find a cure.

To support the vision of the CMTA, "...a world without CMT", the organization has created the Strategy to Accelerate Research (STAR) program to become a driving force behind CMT research, bringing together best-in-class researchers, biotech companies, and patients to find treatments for CMT. The Director of Research will work closely with the Chief Executive Officer and STAR Advisory Board Chairs to expand the STAR program and support all scientific, translational, and clinical projects.

This is an exciting, opportune time to join the Charcot-Marie-Tooth Association in this newly created position designed to enhance and strengthen the research and clinical programs affecting CMT patients and their families. Since launching STAR, \$17 million has been invested with investments of \$10 million coming in the next few years to accelerate bringing CMT drugs and therapies to the community.

The Director of Research will cultivate and steward relationships with patients, families, industry, academic institutions, government agencies, and research donors to further the mission of the organization and work to expand the STAR network, including the Centers of Excellence (COE) program to develop and maximize impact of care for individuals with CMT.

Compelling candidates for this position will have demonstrated success leading research and mission programs and awarding medical/scientific research grants in a highly complex environment. The ability to serve as a liaison to and partner with the greater research and scientific community will be imperative in this role as the Director will continue to evaluate the national impact and programmatic effectiveness of the organization's research and Centers of Excellence programs.

Organization Overview

The National Foundation for Peroneal Muscular Atrophy (NFPMA) was incorporated in 1983 in Pennsylvania. The original founder, Dr. Howard Shapiro, was, himself, a patient with CMT. Dr. Shapiro hoped to create interest in the disorder within the medical community while also providing support to patients and families dealing with this little-known problem. From its inception, the NFPMA, now the CMTA, has continued that twofold concern by supporting research on the causes and possible cures for CMT and by focusing on patient education and support. With the largest constituency of CMT families around the world, the CMTA actively works with the patient community in the drug development process to ensure patients are involved every step of the way. The CMTA is devoted to:



- Driving the development of new drugs to treat CMT
- Meeting the needs of patients with CMT
- Accelerating research for a cure

The CMTA's overhead and financial management are best in class with more than \$.90 of every dollar raised going directly to support the mission. This is well above the nonprofit average of \$.75 of every dollar going directly to mission support.

The organization is a 4-star designated charity according to Charity Navigator with a perfect 100% score for governance and transparency, indicating the CMTA is in the highest category of rated charities and in the top 3% of all charities evaluated.

About the Chief Executive Officer

Amy Gray, the Chief Executive Officer of CMTA, leads the organization with more than two decades of extensive fundraising and management experience. Her expertise in fundraising, staff development, financial and operational management, strategic planning and community engagement have been shaped by her roles with three voluntary health organizations.

The CMTA has grown substantially since Amy took over as CEO in May 2017. She has worked closely with the board of directors and key stakeholders to establish aggressive fundraising efforts to support new research initiatives and community programs.

Strategy to Accelerate Research (STAR)

Launched in 2008, STAR is the driving force behind CMT research, bringing together best-in-class researchers, biotech companies, and patients to find treatments for CMT. Under the program, there are currently over 50 active research projects with top labs around the world, all vested through the STAR advisory board that is comprised of 30 of the top CMT scientists from around the globe.

- The CMTA is actively working with more than 30 biotech, pharmaceutical, and research labs. They are leaders in the latest genetic and neurological technologies (such as CRISPR, gene therapy, gene silencing, axon and muscle regeneration).

Centers of Excellence (COE)

As the only organization with a national network of branches dedicated to supporting the CMT community and with the largest network of CMT Centers of Excellence and a partnership with the Inherited Neuropathy Consortium (INC), the CMTA is best positioned to help patient registries and outcome measure for pharmaceutical and biotech partners to aid fast and effective clinical trials. There are 41 CMT Centers of Excellence in the US and abroad that provide multidisciplinary medical care and treatment to CMT patients.

CMTA Community

The CMTA provides education, resources, and support to more than 70,000 patients via print publications, social media platforms, and virtual meetings. With 70+ volunteer-led Branches bringing CMT patients together to connect and to share resources in their local communities. The CMTA has a camp for kids (ages 10-18) called Camp Footprint, the only camp in the US just for kids with CMT.

CMTA Fundraising

The CMTA is funded solely through private donations and grassroots fundraising. Last year, despite the pandemic, the CMTA community came together and collectively raised and/or donated over \$5.3 million. The CMTA's Board of Directors contribute or raise over \$1 million to support the mission and the volunteer-led National Walk & Cycle 4 CMT program saw 1,000 participants come together and collectively raise over \$500,000.

STAR Advisory Board

John Svaren, PhD
STAR Advisory Board Chair
University of Wisconsin

Frank Baas, MD, PhD
University of Amsterdam, The Netherlands

Robert Burgess, PhD
The Jackson Laboratory

Maurizio D'Antonio, PhD
San Raffaele Scientific Institute, Milan

M. Laura Feltri, MD
University at Buffalo

Steven Gray, PhD
University of Texas Southwestern Medical
Center

Scott Harper, PhD
The Ohio State University School of Medicine

Kleopas Kleopa, MD
Cyprus Institute of Neurology & Genetics

Jun Li, MD, PhD
Wayne State University

Rudolph Martini, PhD
University of Würzburg, Germany

Klaus-Armin Nave, PhD
Max Planck Institute for Experimental
Medicine, University of Göttingen

Brian Popko, MD
University of Chicago

Mario Saporta, MD, PhD
University of Miami

Steven S. Scherer, MD, PhD
University of Pennsylvania

Lawrence Wrabetz, MD
University at Buffalo

Stephan Züchner, MD, PhD
University of Miami

Mark Scheideler, PhD
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HumanFirst Therapeutics LLC

David Herrmann, MD
University of Rochester

Tage Honore, PhD
Aestus Therapeutics Inc.

Christopher Klein, MD
Mayo Clinic, Rochester, Minnesota

Lars J.S. Knutsen, PhD
Discovery Pharma Consulting LLC

Claes Wahlestedt, MD, PhD
University of Miami

Michael E. Shy, MD
Clinical Expert Board Chair
University of Iowa

Mary Reilly, MD
Clinical Expert Board Co-Chair
National Hospital, London, England

Richard Finkel, MD
Nemour's Children's Hospital, Orlando

Davide Pareyson, MD
Besta Institute, Milan

Joshua Burns, PhD
University of Sydney

Michael McDermott, PhD, Consultant
University of Rochester Medical Center

Position Summary

The Director of Research will work closely with the CEO and STAR Advisory Board Chairs to manage existing research and mission programs while also providing the insight and support necessary to develop new care, support and research programs. The Director of Research provides program support for all scientific, translational and clinical projects and corresponding relationships with patients, families, industry, academic institutions, government agencies, and research donors to further the mission of the organization; manages the existing network of scientists in basic, translational and clinical science to enable them to advance new treatments; and works with the Centers of Excellence (COE) to develop and maximize impact of care for individuals with CMT. The Director of Research will work from a home-based office.

The Director of Research position is critical to the success of both the mission and strategic plan goals that include:

- Strengthening and building research partnerships with industry, academia, and government agencies
- Ensuring a robust pipeline of new CMTA researchers
- Expanding CMTA's research portfolio
- Fueling clinical research by ensuring active enrollment in clinical studies
- Striving to improve the standards for clinical care and disease management
- Expanding the Centers of Excellence program

Position Duties and Responsibilities

Scientific

- Manage research agreements.
- Support the implementation of the CMTA's STAR Research Program, including the request for proposal (RFP) process, grant review summaries, oversight of process reports and related administrative functions.
- Develop and maintain library of relevant clinical and scientific articles.
- Monitor science landscape and support ongoing evaluation of research impact.
- Contribute regular scientific updates to CMTA website and publications for research donors that integrates information from published literature, scientific meetings, and CMTA specific meetings summarizing current state of knowledge in the field.
- Develop and track metrics and KPIs for STAR program.
- Identify areas of synergy with other research foundations.

Translational

- Support CMTA's STAR biotech partners, including work study plans, patient programs, and liaising with key opinion leaders and the CMT community.
- Attend and coordinate participation in scientific and industry meetings to keep up to date on latest research, present CMTA's STAR program, and recruit potential partners.
- Grow CMTA's STAR biotech partnerships as well as STAR's unique offerings to industry partners.
- Act as liaison with National Institutes of Health (NIH) and Federal Drug Administration (FDA), with targeted outreach on initiatives that would further Strategy to Accelerate Research (STAR) research priorities and support the efforts of STAR biotech partners.

Clinical

- Build and execute strategies to continue the development of the Centers of Excellence program.
- Support clinical research participation in the CMTA community through direct management of programs.
- Attend Inherited Neuropathy Consortium (INC) monthly meetings and serve as liaison to INC.
- Participate in Rare Diseases Clinical Research Network (RDCRN) meetings and committees.
- Oversee and train network of volunteers and speak at Branch meetings as needed.

Budgeting and Reporting

- Oversee research budget, track research commitments and expenditures.
- Create updates on research projects and research budget for CMTA board meetings.

Mission Programs

- Assist in the drafting of grant proposals and cooperative agreements to support the CMTA mission programs and participate in additional funding initiatives as assigned.
- Coordinate with STAR Chairs and oversee management of STAR Advisory Board meetings, including recruitment of new STAR advisors.
- Identify and recruit new researchers to submit targeted projects that support CMTA's strategy.
- Oversee COE review and approval processes, including measuring impact of care at COEs.
- Manage COE Annual Meeting.

Other

- Assist in the development and fulfillment of educational materials to local volunteers and clinics.
- Contribute to enhancing diversity in advisory boards, branch participation, outreach and patient recruitment.
- Organize researcher and clinician articles for newsletter and website.
- Maintain extensive awareness of CMTA constituencies, programs, features, and benefits.
- Meet and speak with donors about CMTA STAR and Center of Excellence programs.
- Draft biannual donor update for CMTA constituencies.

Candidate Qualifications

- Passion for CMTA's mission and demonstrated commitment to the nonprofit sector and patient population.
- An advanced degree (MS, Ph.D., or PharmD) in neurology, neuroscience, neurobiology, public health, healthcare administration or related field is desired.
- 7+ years of experience in managing the awarding of medical/scientific research grants.
- Knowledge of CMT disease and/or other neurodegenerative disorders preferred.
- Experience translating and communicating complex scientific and medical information in understandable language to lay constituencies.
- Strong leader and energetic team player who will fit seamlessly into a small organization that is driven to accomplish its mission.
- Ability to function as a dependable leader and work cross-functionally as a collaborator and team player in a virtual environment.
- Superb oral and written communication skills, strong interpersonal abilities, and a collaborative style.
- Willingness to travel up to 25%.
- Demonstrated strategic planning and visioning experience in a nonprofit environment, including significant financial experience and aptitude.
- Ability to evaluate national impact, programmatic effectiveness, analyze trends, and integrate evaluation results into future planning.
- Must demonstrate a positive outlook, enthusiasm, high energy, and be self-motivated.
- Strong collaboration skills and innovate research programming, with a high degree of creativity and initiative.
- Demonstrated ability to serve as a liaison to the greater research community.
- Strong ethics and capacity to carry out responsibilities in an ethical, professional, and objective manner.
- High proficiency with Word, Excel, PowerPoint, E-technologies, web analytics, and grant software experience.

Contact Information

To speak to one of the members of The Batten Group team to learn more information about this opportunity and how to apply, please use the contact information below:

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