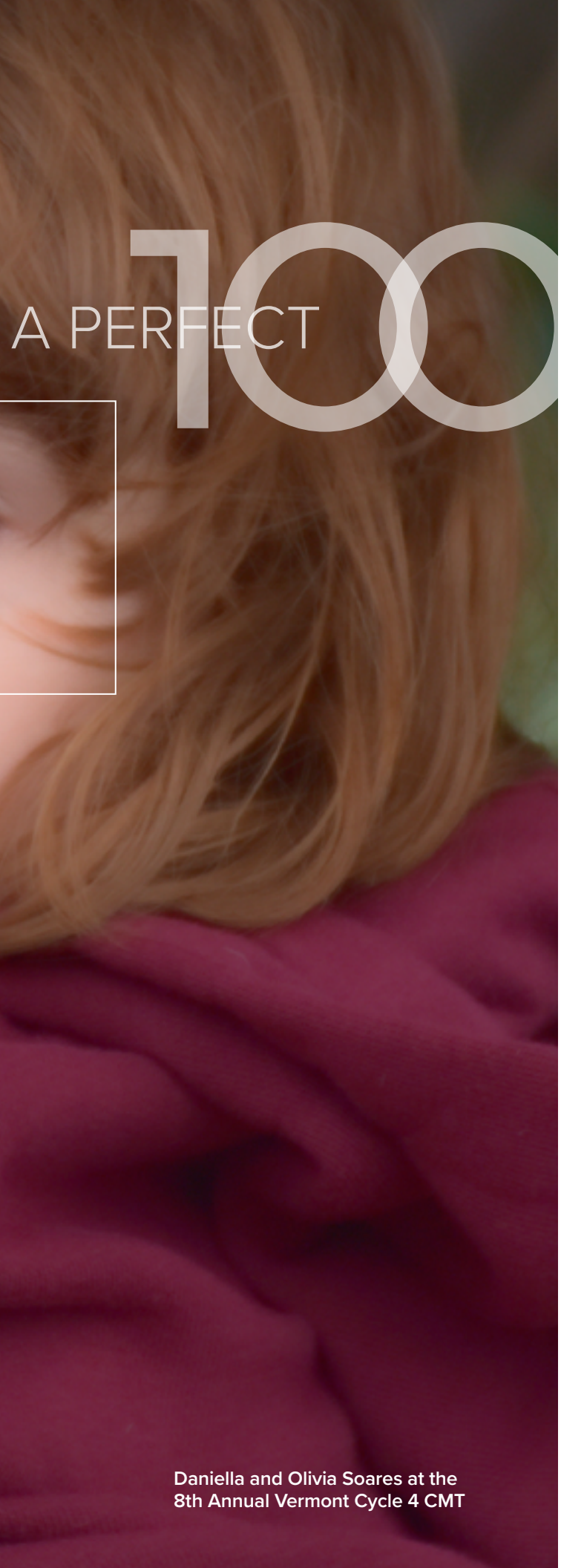

CMTA
Charcot-Marie-Tooth Association
GIVING AND GETTING A PERFECT 100
2021 ANNUAL REPORT

EVERY MEMBER OF OUR CMTA COMMUNITY IS 100% COMMITTED TO OUR MISSION OF A WORLD WITHOUT CMT.




Daniella and Olivia Soares at the 8th Annual Vermont Cycle 4 CMT

Amy Gray
Chief Executive Officer

Gilles Bouchard
Chairman of the Board

Dear Friends,

**Charity Navigator recently awarded the CMTA a "Perfect 100" score** for exceeding industry standards and outperforming other organizations that do similar work. We can think of no better way to sum up the CMTA's record of accomplishments for 2021.

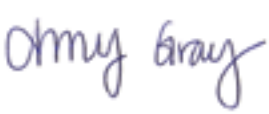
As the nonprofit ranking service said in announcing the awards, "The exceptional charities on this list execute their missions in a fiscally responsible way while adhering to good governance and other best practices that minimize the chance of unethical activities.... Less than 1 percent of the thousands of charities rated by Charity Navigator have earned perfect scores."

We are incredibly honored to be among the 1 percent.
We know, however, that the honor belongs to our community.
**We earned a "Perfect 100" because everyone involved in the organization gives 100 percent.**

Every member of our CMTA community is committed to our mission of a world without CMT. They are all doing their utmost—from the researchers spending long hours in labs around the globe to the branch leaders who keep members engaged and educated to the Camp Footprint counselors, most of whom have CMT, who provide shining examples of how to live with the disease.

The key to the CMTA's Perfect 100 is that our community outreach efforts invigorate and inform our research efforts, with the community providing the energy, excitement and funding for the research. You'll read about all of it in the coming pages.

With best regards,



Amy Gray, Chief Executive Officer

Gilles Bouchard, Chairman of the Board

Since 2008, STAR has invested more than $18.5 million in CMT research.

# DEDICATED RESEARCHERS ACCELERATE PROGRESS

**CMTA-STAR IS THE LARGEST PHILANTHROPIC FUNDER OF CMT RESEARCH,** dedicated to accelerating research to develop drugs and treatments for CMT. Before the Charcot-Marie-Tooth Association launched its Strategy to Accelerate Research (CMTA-STAR) in 2008, researchers worked in silos with very few links among them.

The CMTA recognized that collaboration was vital. With careful planning and funding, we found the best researchers in the world and brought them out of their silos to implement projects that supported our strategy. We also encouraged scientists and clinicians to form partnerships with pharmaceutical companies, universities, biotech companies, nonprofit research organizations, patients and the National Institutes of Health (NIH).

Since 2008, STAR has invested more than $18.5 million in CMT research. Today, the CMTA-STAR portfolio covers therapy approaches for virtually all types of CMT, and we have more than 40 research partners participating in more than 50 research projects.

The CMTA has also established a unique capability to develop new therapies directly with companies and to expertly test those potential therapy candidates. This allows a company interested in positioning a therapy for CMT to access the infrastructure needed to evaluate the therapy without committing significant time and money upfront.

The CMTA's foundational research has put our goal of a world without CMT within reach. With everyone on all of our teams giving 100 percent, we believe we will get there.

**CROSS-TYPE INITIATIVES.** Mutations in more than 100 different genes cause CMT, a progressive disorder of the peripheral nerves that causes people to lose normal use of their hands, arms, feet and legs. It is one of the most commonly inherited genetic disorders, affecting an estimated 150,000 people in the United States and 3 million people worldwide. It occurs in all races and ethnic groups.

Symptoms vary with each individual but commonly include foot deformity (very high arched feet) and foot drop; a "slapping" gait; loss of muscle in the lower legs; numbness in the feet; difficulty with balance and similar symptoms in the arms and hands in later stages

The mutations affect different cellular functions, resulting in many disease mechanisms. Mutations in genes expressed by Schwann cells mostly cause demyelinating CMT, which eventually damages the axons as well. Mutations in genes expressed in nerve cells and their axons mostly cause axonal types of CMT.

***Gene Therapy***

Gene therapy involves the introduction of genetic material (DNA or RNA) into the cells and tissues of an individual. There are several approaches: replacing a faulty (missing or mutated) gene that causes a disease with a healthy copy of the gene; deactivating or "silencing" a mutated gene that is functioning improperly; or editing part of a mutated toxic gene using a "cut-and-paste" method.

The CMTA sponsors gene therapy development for many types of CMT, including CMT1A, CMT1X, CMT2A, CMT2D, CMT2E, CMT2F, CMT2K, CMT4A and CMT4C, utilizing several different technologies, including AAV delivery, gene silencing, gene replacement, genome editing using CRISPR-Cas9 and antisense oligonucleotides (ASOs).

***Biomarkers***
Clinical trials involve large investments of both time and money. Many conversations with CMT pharmaceutical partners about potential therapies focus on how to design clinical trials that will quickly address a new medication's efficacy.

These companies want to see measures that can evaluate signs of success, ideally within three to six months of starting the clinical trial. One of the most urgent needs in the CMT field is to find better ways to assess the dysfunction of the peripheral nerves in patients with CMT. For this reason, CMTA's biomarker efforts extend across multiple subtypes of CMT and include several different studies.

***Gene Discovery***
Gene discovery is another area the CMTA is aggressively pursuing. Fewer than 50 percent of CMT Type 2 patients know their "culprit" gene. Without a known gene, it is very difficult to develop a therapy.

The CMTA supports the Inherited Neuropathy Consortium's most important genomic initiative with the GENESIS project, led by Dr. Stephan Zuchner. The majority of CMT genes have been discovered in the past decade through this collaborative effort.

***Axon Degeneration***
All nerve cells have axons whose proper functioning is essential in signaling muscles to contract. Axons are vulnerable to degeneration due to several destructive injury-induced triggers. There are several genes involved in axon degeneration, including SARM1. In some types of neuropathies, a disease-induced (CMT) injury to the nerves causes inflammation, activating SARM1, which causes axonal degeneration. Inhibiting the activation of SARM1 has the potential of preventing this cascade of events from happening. Several companies are working to develop compounds that inhibit SARM1, and the CMTA has funded efforts led by Drs. Steven Scherer (UPenn), Maurizio D' Antonio (San Raffaele Scientific Institute, Milan), and Robert Burgess (the Jackson Laboratory, Bar Harbor, Maine) to develop successful therapeutics for blocking axonal degeneration pathways.

***HDAC6 Inhibitors***
While the many genes associated with CMT make it unlikely that a single treatment will work for all forms of the disease, preclinical studies with HDAC6 inhibitors, which have been shown to reduce motor and sensory deficits, have demonstrated promising results in several mouse models of CMT. Based on these promising results, scientists believe that HDAC6 inhibitors might be beneficial in treating a wide array of neurodegenerative conditions including demyelinating (Types 1 and 4) and axonal (Type 2) CMTs. The CMTA is funding work by Dr. Burgess, a member of the CMTA's Scientific Advisory Board, using mouse models of several forms of CMT to determine which types may be candidates for treatment with HDAC6 inhibitors and whether HDAC6 inhibitors may be of therapeutic benefit across a variety of CMT types. The latter will help determine whether patients with genetically undiagnosed cases of CMT are likely to benefit from this therapeutic strategy, or whether only select forms of CMT respond to this treatment.

# CMTA-STAR'S PORTFOLIO FOR DEMYELINATING CMTs: 1A, 1B, 1X (AND SOME 4s)

*The CMTA is taking an aggressive approach to developing treatments for the demyelinating forms of CMT with a multi-pronged and diversified strategy that covers Types 1A, 1X, 1B and some Type 4s and includes some two dozen projects and biotech partners:*

## GENE THERAPY AND GENE EDITING PROJECTS

- In collaboration with Ionis Pharmaceuticals, we are developing antisense oligonucleotides (ASOs), which have shown dramatic results in two rodent models of CMT1A.
- CMTA-funded studies by Dr. Kleopas Kleopa of the Cyprus Institute of Neurology and Genetics have shown positive results in testing gene therapy in rodent models of CMT1X and CMT4C, and the CMTA is actively supporting the efforts of several gene therapy companies to develop new CMT gene therapies.
- Pioneering CMTA-sponsored preclinical gene therapy studies have shown great promise in models of demyelinating CMT. This approach is now being extended to use RNA interference to decrease the PMP22 levels found in CMT1A and to optimize delivery to the affected Schwann cells in demyelinating CMT.
- It is not yet clear if AAV9 will be the optimal vehicle for Schwann cell delivery: The CMTA is still working on a clear pathway for treating CMT1A and other Type 1s. The CMTA is supporting a collaborative relationship to build on Dr. Kleopa's success in fixing Schwann cell deficits in preclinical trials for CMT1X and CMT4C. The partnership of Dr. Kleopa with eminent gene therapy expert Dr. Steven Gray (UT Southwestern), and Dr. John Svaren (University of Wisconsin), an expert in Schwann cell-specific gene expression, will address these challenges by trying multiple AAV subtypes and optimizing the vector engineering to build in necessary safety factors and optimal administration. This will allow us to target Schwann cells more precisely and move to clinical trials for CMT1A. These collaborative efforts will provide the basis for future partnerships as we engage in parallel testing of several strategies to determine which vector designs are most effective.
- We are currently collaborating with ToolGen to use CRISPR (genome editing) to treat demyelinating CMT, and additional collaborations with leading labs are underway.
- Other biotech companies and researchers have expressed an interest in developing gene therapy approaches for CMT1A.

## SMALL MOLECULE AND BIOLOGICAL THERAPY PROJECTS

- Pharnext and the CMTA have been engaged in trial recruitment for the CMT1A Premier Clinical Trial and on a biomarker identification project.
- In collaboration with InFlectis BioScience, we are developing agents to restore myelin protein balance for CMT1A and CMT1B. Phase 1 clinical trials have concluded, and InFlectis is gearing up for Phase 2 trials.
- We are working with partners to develop molecules that regulate the triggers of axon degeneration. We are currently testing this approach in multiple models of CMT, collaborating with several companies to show that candidate drugs can promote axon survival, preserve nerve function and prolong patient mobility in demyelinating Type 1 CMT disorders.
- We are supporting work done by Dr. Maurizio D'Antonio of the San Raffaele Scientific Institute to test new drug classes being developed for stress-related disorders such as stroke, Alzheimer's and retinal degeneration for CMT1B.
- The CMTA has two additional sponsored research agreements to test small molecule therapies in preclinical models of CMT1A and CMT1B, including projects by the Feltri/Wrabetz Lab at the University at Buffalo.
- We are also funding Dr. Luigi Puglielli's work at the University of Wisconsin-Madison to identify new treatment targets.
- The CMTA awarded Esther Wolfs, PhD (Hasselt University in Belgium) a grant to develop a new human stem cell model for CMT1A using stem cells extracted from the pulp of teeth removed during dental procedures. Wolfs' approach will not only provide insight into the molecular pathways involved in CMT1A, but it will also enable the CMTA's preclinical testing alliance to quickly test the effects of a potential therapeutic.

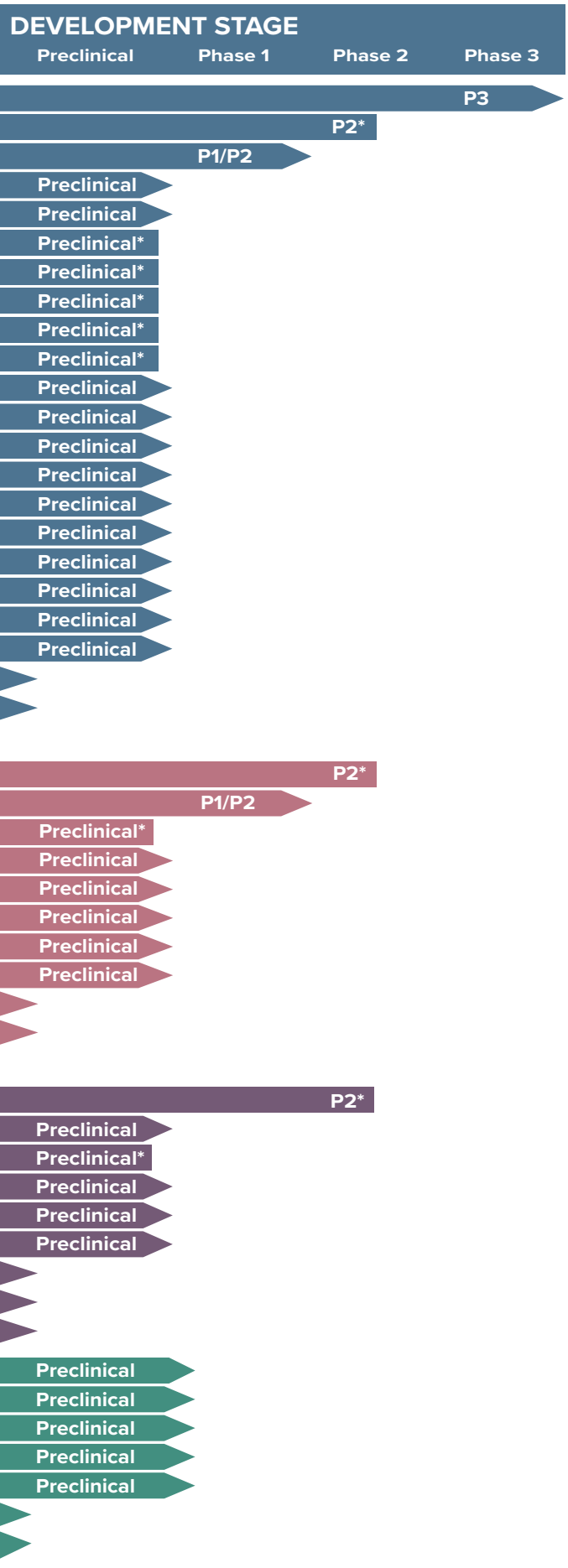
## PREPARING FOR CLINICAL TRIALS

In partnership with the Inherited Neuropathy Consortium and Dr. Michael Shy (University of Iowa), John Svaren, PhD (University of Wisconsin) and Dr. David Herrmann and Kate Eichinger, PhD, DPT (University of Rochester School of Medicine), we are funding the development of new biomarkers and outcome measures in CMT1A, CMT1B and CMT1X to support upcoming clinical trials. The studies are looking at:

- Clinical Outcome Assessments: The CMT Neuropathy Score (CMTNS) and the Examination Score (CMTES), which include assessment of sensory symptoms as well as motor skills and strength of the arms, hands and legs.
- The CMT Health Index (CMT-HI): A patient-reported measure that is unique because it measures patient perspectives on their mobility, foot and ankle strength, hand and finger function, and a series of related symptoms (such as pain, fatigue and numbness).
- The CMT Functional Outcome Measure (CMT-FOM) with performance measures that include strength in hands and feet, lower and upper limb functioning, hand and finger dexterity, balance and mobility.
- Biomarkers such as MRIs, which assess muscle; skin biopsies, which can be used to measure the expression of genes in the nerves found in skin and blood plasma levels of the protein neurofilament light chain, which are a marker of axonal damage as levels are elevated in CMT patients and correlate with disease severity.
- Wearable technology that can be used both in the clinic and at home by patients to measure how a particular treatment helps functions like gait and balance.

# DEMYELINATING CMTs

| | STAR ALLIANCE PARTNERS | THERAPY TYPE | DRUG Discovery | DRUG Research Tools |
|---|---|---|---|---|
| 1A | Pharnext | Small Molecule | | |
| | Acceleron | Biological | | |
| | InFlectis BioScience | Small Molecule | | |
| | Cyprus + University of Wisconsin + University of Texas, SW | Gene Therapy | | |
| | Ionis | Gene Therapy | | |
| | National Institutes of Health | Assays/Small Molecule | | |
| | Regenacy Pharmaceuticals | Small Molecule | | |
| | Sanofi | Small Molecule/Biomarkers | | |
| | Star Biotech Partner A | Small Molecule | | |
| | Star Biotech Partner B | Small Molecule | | |
| | Star Biotech Partner C | Small Molecule | | |
| | Toolgen | Gene Therapy | | |
| | Orthogonal | Biological | | |
| | University of Wisconsin | Small Molecule | | |
| | University of Wisconsin | Target Validation | | |
| | Jackson Laboratory | SARM1/Target Validation | | |
| | Jackson Laboratory | HDAC6/Target Validation | | |
| | University of Rochester, NY | Biomarkers (Wearables) | | |
| | University of Buffalo, NY | Small Molecule | | |
| | Addex | Small Molecule | | |
| | Hasselt University, Belgium | New Cell Model | | Laboratory |
| | New York Stem Cell Foundation | New Cell Lines | | Laboratory |
| | University of Wisconsin + Memorial Sloan Kettering | Target Discovery | Discovery* | |
| 1B | Acceleron | Biological | | |
| | InFlectis BioScience | Small Molecule | | |
| | National Institutes of Health | Assays/Small Molecule | | |
| | San Raffaele Scientific Institute | Small Molecule | | |
| | University of Buffalo, NY | Small Molecule | | |
| | Universities of Iowa and Wisconsin | Biomarkers | | |
| | University of Wisconsin | Target Validation | | |
| | University of Iowa | Target Validation | | |
| | University at Buffalo, NY | Animal Model/Target Validation | | Laboratory |
| | New York Stem Cell Foundation | New Cell Lines | | Laboratory |
| | University at Buffalo, NY | Target Discovery | Discovery | |
| 1X | Acceleron | Biological | | |
| | Cyprus Institute | Gene Therapy | | |
| | University of Pennsylvania | Target Validation | | |
| | Jackson Laboratory | SARM1/Target Validation | | |
| | Universities of Iowa & Wisconsin | Biomarkers | | |
| | University of Wisconsin + Jackson Laboratory | Small Molecule | | |
| | University of Illinois (Chicago) | Animal Model | | Laboratory |
| | New York Stem Cell Foundation | New Cell Lines | | Laboratory |
| | The Jackson Laboratory | Animal Model | | Laboratory |
| ALL TYPES | Psychogenics + Cleveland Clinic + Charles River | Preclinical Testing Partners | | |
| | Inherited Neuropathies Consortium | Research & Clinical Tools | | |
| | ARQ Genetics | Gene Expression | | |
| | WuXi | Chemical Analysis | | |
| | Frontage Laboratories | Chemical Analysis | | |
| | New York Stem Cell Foundation | Stem Cell Lines | | Laboratory |
| | Jackson Laboratories | Animal Models | | Laboratory |




# STAR ALLIANCE PARTNERS

40+ Research Partners
50+ Research Projects
$18.5M+ in Research Funding

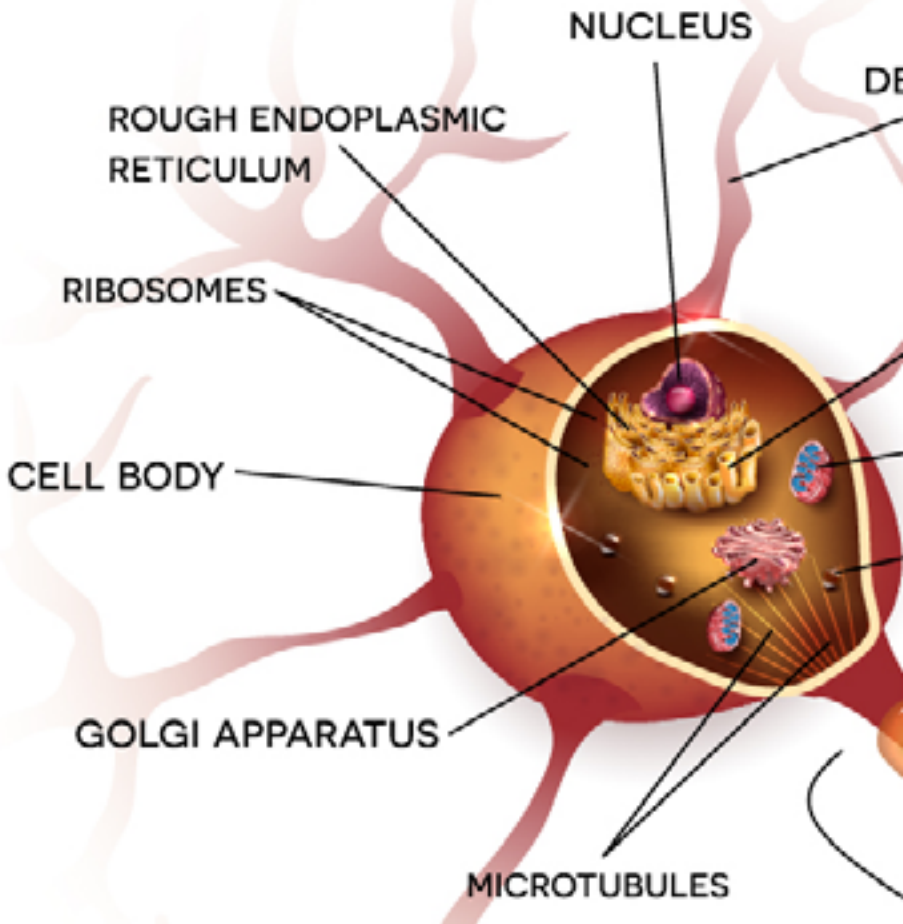
* Project Completed

## GENE THERAPY AND GENE EDITING PROJECTS

- The CMTA is supporting pilot studies of gene therapy in CMT mouse models following a gene therapy trial for one peripheral neuropathy (GAN) at the NIH.
- We are partnering with Dr. James Wilson at the University of Pennsylvania and Passage Bio to use gene therapy to treat CMT2A.
- We are funding work with two eminent experts, Drs. Bruce Conklin and Luke Judge of the Gladstone Institutes and UCSF Departments of Medicine and Pediatrics, to explore the therapeutic application of genome editing technology (CRISPR) to CMT2A, CMT2E and CMT2F. They recently received follow-on funding from the NIH to extend their work.
- We awarded a grant to two researchers who believe that CMT4A is an ideal candidate for gene therapy approaches. he innovative project may lead to the development of clinically translatable gene replacement therapy for patients with GDAP1 (ganglioside-induced differentiation-associated protein 1) mutations. Principal investigators Steven Gray, PhD, and Xin Chen, PhD, of the University of Texas Southwestern Medical Center hypothesize that broad central nervous system (CNS) -directed delivery of GDAP1 gene with adeno-associated viral 9 (AAV9) during early life can ameliorate CMT4A disease symptoms in GDAP1 mutant mice, using an approach amenable to human translation.
- The CMTA is also supporting Dr. Kathrin Meyer's project, along with a leading gene therapy group at Nationwide Children's Hospital in Cincinnati, to bring gene therapy to CMT2E.

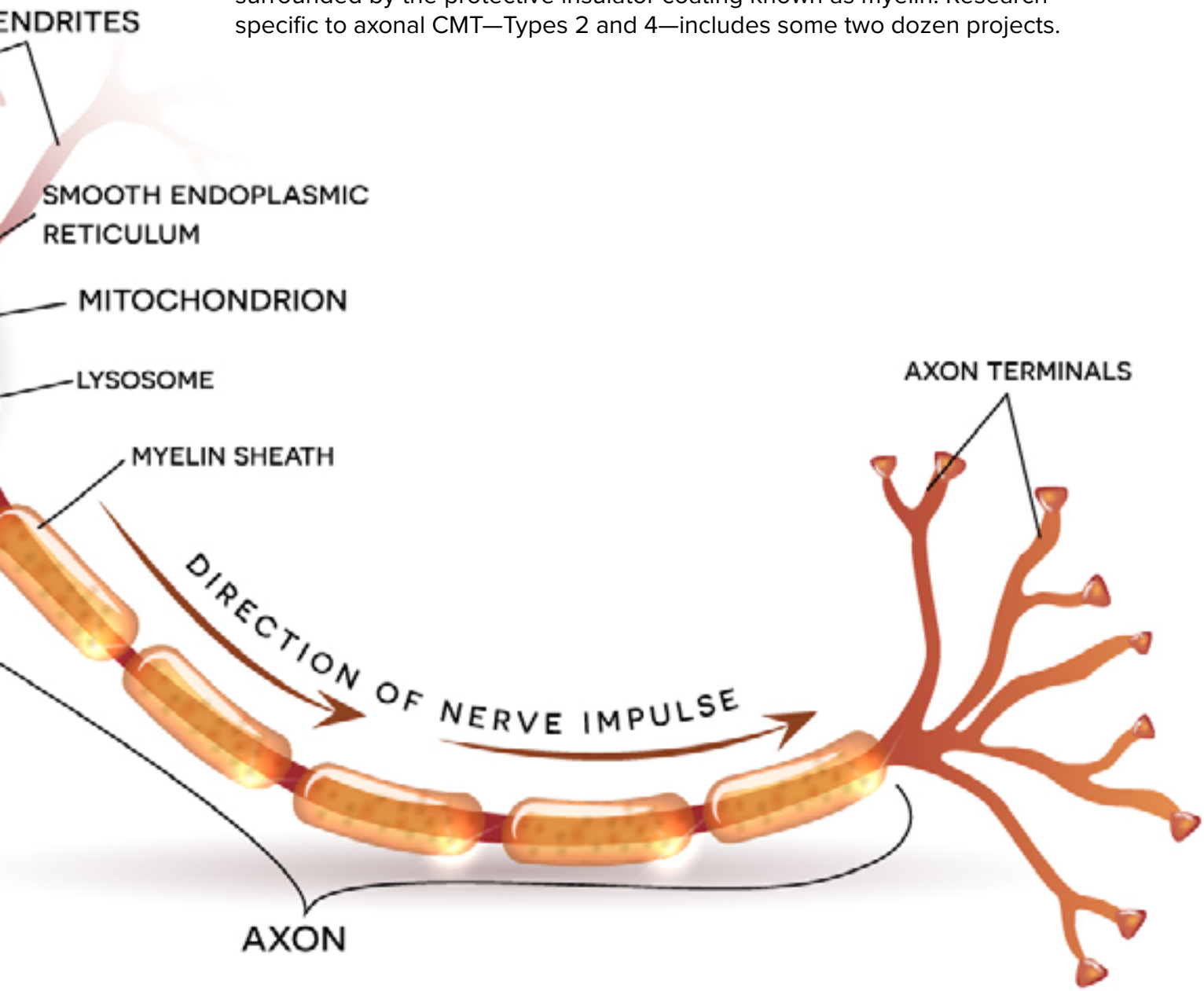
## SMALL MOLECULE AND BIOLOGICAL THERAPY PROJECTS

- CMTA partners are working on developing molecules for several types of CMT, including 2A, 2E and others, that regulate recently identified biochemical triggers of axon degeneration.
- CMT2E is caused by mutations in the neurofilament light (NEFL) gene. The CMTA has a diverse portfolio of approaches for 2E.
- We are funding Dr. Mario Saporta's work at the University of Miami using human stemcells to develop assays and test additional libraries of drugs for treatment in CMT2E.
- In addition, we supported a screen of FDA-approved compounds in Dr. Ron Liem's lab at Columbia University.



# CMTA-STAR'S PORTFOLIO FOR AXONAL CMTs: TYPE 2s (AND SOME 4s)

Axonal forms of CMT affect the "electrical wire" that is the nerve, which is surrounded by the protective insulator coating known as myelin. Research specific to axonal CMT—Types 2 and 4—includes some two dozen projects.



# AXONAL CMT's

| | STAR ALLIANCE PARTNERS | THERAPY TYPE | DRUG Discovery | DRUG Research Tools |
|---|---|---|---|---|
| 2A | Passage Bio + University of Pennsylvania | Gene Therapy | | |
| | Regenacy Pharmaceuticals | Small Molecule | | |
| | Star Biotech Partner D | Stem Cell Licensing | | |
| | Star Biotech Partner A | Small Molecule | | |
| | Star Biotech Partner C | Small Molecule | | |
| | Star Biotech Partner G | Small Molecule | | |
| | Star Biotech Partner H | Small Molecule | | |
| | Star Biotech Partner I | Small Molecule | | |
| | Star Biotech Partner J | Small Molecule | | |
| | Star Biotech Partner K | Small Molecule | | |
| | Star Biotech Partner L | Small Molecule | | |
| | Star Biotech Partner M | Small Molecule | | |
| | Star Biotech Partner N | Biological | | |
| | Universities of Iowa & Wisconsin | Biomarkers | | |
| | Gladstone Institute (University of California, SF) | Gene Therapy (CRISPR) | | |
| | University of Iowa | Respiratory Study | | |
| | University of Pennsylvania | Animal Models | | Laboratory |
| | New York Stem Cell Foundation | New Cell Lines | | Laboratory |
| | Star Partner O (Recursion) | Stem Cell Licensing | | |
| | Washington University | Small Molecule | Research Interest | |
| 2D | Jackson Laboratory | SARM1/Target Validation | | |
| | Jackson Laboratory | HDAC6/Target Validation | | |
| | Jackson Laboratory | Target Discovery | Discovery | |
| 2E | Regenacy Pharmaceuticals | Small Molecule | | |
| | Orthogonal | Biological | | |
| | Nationwide Children's Hospital + Ohio State University | Gene Therapy | | |
| | Columbia University | Small Molecule | | |
| | University of Miami | Small Molecule | | |
| | Gladstone Institute (University of California, San Francisco) | Gene Therapy (CRISPR) | | |
| | Jackson Laboratory | SARM1/Target Validation | | |
| | Jackson Laboratory | HDAC6/Target Validation | | |
| | Columbia University | Animal Model | | Laboratory |
| | New York Stem Cell Foundation | New Cell Line | | Laboratory |
| 2F | Gladstone Institute (University of California, San Francisco) | Gene Therapy (CRISPR) | | |
| | Universities of Iowa & Wisconsin | Biomarkers | | |
| 2S | Jackson Laboratory | SARM1/Target Validation | | |
| | Jackson Laboratory | HDAC6/Target Validation | | |
| UNKNOWN TYPE 2 VUS | University of Miami | Gene Identification | Discovery | |
| | Genesis Foundation | Gene Identification | Discovery | |
| 4 | 4A – University of Texas Southwestern | Gene Therapy | | |
| | 4B – San Raffaele Scientific Institute | Small Molecule | | |
| | 4C – Cyprus Institute | Gene Therapy | | |
| | 4J – Neurogene | Gene Therapy | | |
| | 4A – Envigo | Animal Models | | |
| SORD | Applied Therapeutics | Small Molecule | | |

## DEVELOPMENT STAGE

Preclinical | Phase 1 | Phase 2

- Preclinical*
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- Preclinical

* Project Completed


### UNDIAGNOSED TYPE 2s

Approximately 50 percent of CMT2 patients do not yet have a definitive genetic diagnosis. Dr. Stephan Zuchner at the University of Miami is spearheading an ambitious project to identify new disease-causing mutations in patients seen in Centers of Excellence affiliated with the Inherited Neuropathy Consortium (INC). In addition, the CMTA is funding the Distant Cousin Project, thanks to the financial support of a patient and donor who is a research advocate. The Distant Cousin Project will enroll 10 sets of distant cousins in seeking to identify more culprit genes that cause CMT.

### PREPARING FOR CLINICAL TRIALS

In partnership with INC, we are supporting efforts to extend development and testing of critical biomarkers for CMT2A and CMT2F for upcoming clinical trials. Several academic centers and companies have reached out to INC to develop clinical trials for CMT2A, which will likely be instituted within the next few years. However, disease biomarkers for CMT2A and other Type 2s are needed to demonstrate the biological effects of candidate therapies and to provide additional sensitive natural history data of disease progression.

Led by CMTA Board Members Dr. Michael Shy of the University of Iowa and John Svaren, PhD of the University of Wisconsin, the study will examine several different biomarkers, including protein biomarkers identified in blood samples, such as neurofilament light, which can be used to measure axonal damage; RNA biomarkers identified from skin biopsies and MRI imaging of patients' legs because the accumulation of fat within muscles damaged by neuropathy can be measured very precisely.

# STAR ADVISORY BOARD

The CMTA's STAR Advisory Board comprises a Scientific Advisory Board (SAB), a Therapy Expert Board (TEB) and a Clinical Expert Board (CEB), bringing together the world's top CMT specialists.

***John Svaren, PhD, SAB Chair***
University of Wisconsin

***Mark Scheideler, PhD, TEB Chair***
HumanFirst Therapeutics LLC

***Mike Shy, MD, CEB Chair***
University of Iowa

***Mary Reilly, MD, CEB Co-Chair***
National Hospital for Neurology, London, UK

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

***Robert Burgess, PhD, SAB***
The Jackson Laboratory, Bar Harbor, Maine

***Joshua Burns, PhD, CEB***
University of Sydney, Australia

***Maurizio D'Antonio, PhD, SAB***

San Raffaele Scientific Institute, DIBIT, Milan

***Laura Feltri, MD, SAB***
University at Buffalo

***Richard Finkel, MD, CEB***
St. Jude Children's Research Hospital, Memphis, Tennessee

***Steven Gray, PhD, SAB***
University of Texas Southwestern Medical Center

***Scott Harper, PhD, SAB***
The Ohio State University School of Medicine

***David Herrmann, MD, CEB, TEB***
University of Rochester

***Tage Honore, PhD, TEB***
Aestus Therapeutics Inc.

***Christopher Klein, MD, CEB, TEB***
Mayo Clinic, Rochester, Minnesota

***Kleopa Kleopas, MD, SAB***
Cyprus Institute of Neurology & Genetics

***Lars J. Knutsen, PhD, TEB***
Discovery Pharma Consulting LLC, Cambridge, UK

***Jun Li, MD, PhD, SAB***
Houston Methodist Hospital and Weill Cornell Medical College

***Rudolf Martini, PhD, SAB***
University of Würzburg, Germany

***Michael McDermott, PhD, CEB Consultant***
University of Rochester Medical Center, New York

***Klaus-Armin Nave, PhD, SAB***
Max Planck Institute of Experimental Medicine, Germany

***Davide Pareyson, MD, CEB***
Besta Institute, Milan, Italy

***Brian Popko, MD, SAB***
University of Chicago

***Mario Saporta, MD, PhD, SAB***
University of Miami

***Steven Scherer, MD, PhD, CEB, SAB***
University of Pennsylvania

***Claes Wahlestedt, MD, PhD, TEB***
University of Miami

***Lawrence Warbetz, MD, SAB***
University at Buffalo

***Stephan Zuchner, MD, PhD, SAB***
University of Miami

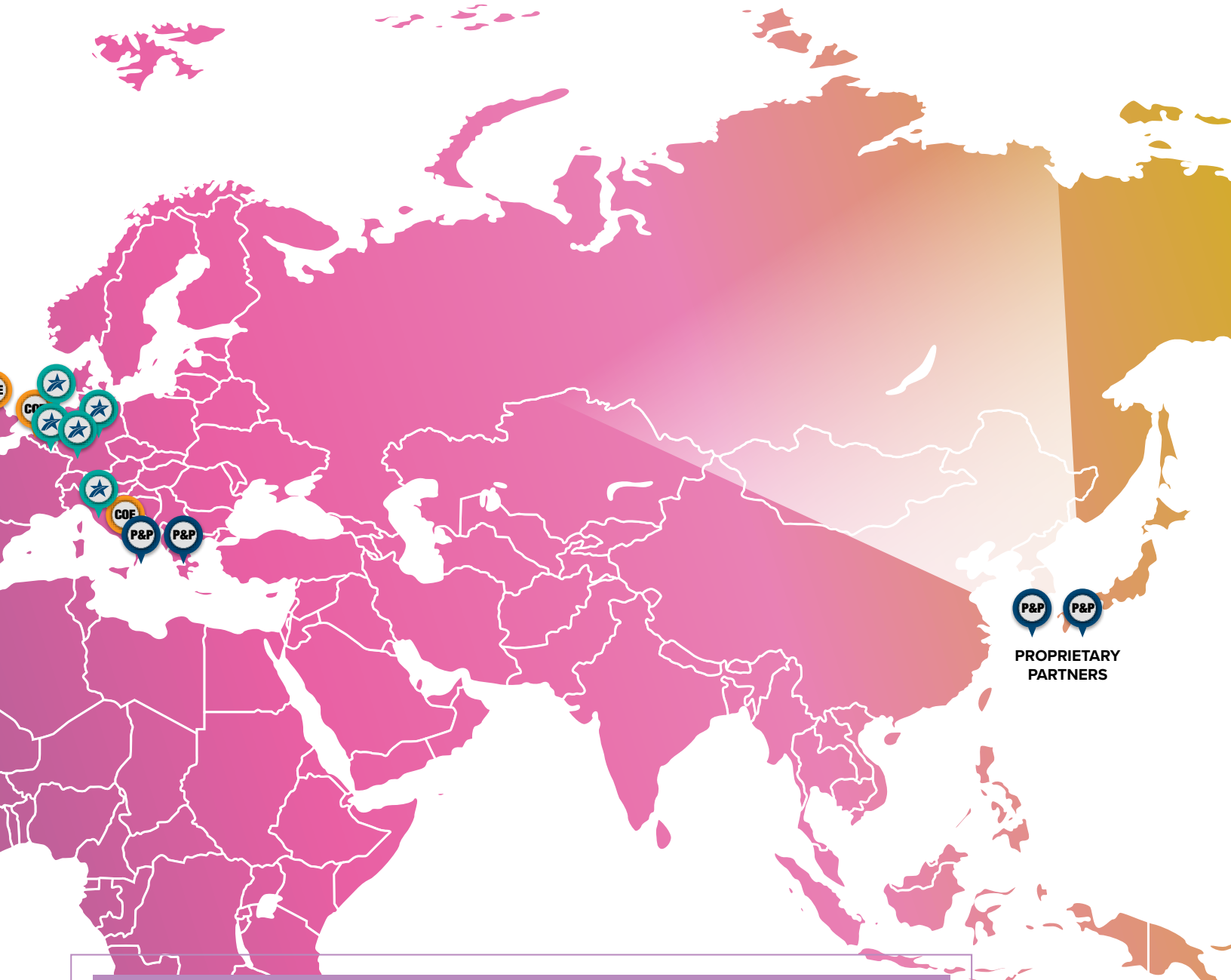
# CMTA-STAR'S **GLOBAL REACH**


**CMTA CENTERS OF EXCELLENCE**
48 CENTERS

Scan this code with your camera phone for a complete listing of the CMTA Centers of Excellence

**PROJECTS & PARTNERS**
40+ PARTNERS/50+ PROJECTS

**CMTA-STAR ADVISORS**
28 ADVISORS




## THE CMTA ADDED SEVEN NEW CENTERS OF EXCELLENCE (COEs) IN 2021, EXPANDING THE NETWORK'S REACH AND GIVING MORE CMT PATIENTS ACCESS TO A CENTER.

COEs are patient-centric, multidisciplinary CMT clinics where children, adults and families affected by CMT receive comprehensive care from a team of CMT experts. In addition to neuromuscular clinicians with clinical and research experience in CMT, teams can include nurse specialists, social workers, genetic counselors, physical therapists, podiatrists and orthotists. The new centers are located at the University of Louisville, Ky., Atrium Health Neuroscience Institute in Charlotte, N.C., Austin Neuromuscular Center in Austin, Texas, Arkansas Children's Hospital, the Mayo Clinic in Florida, St. Elizabeth's Hospital in Illinois and Creighton University in Nebraska.

While all the Centers of Excellence have multi-disciplinary teams of CMT specialists, the ones affiliated with the Inherited Neuropathy Consortium (INC) go a step further by collecting and recording genetic, biological and other data from people with the disease.


CMTA BOARD MEMBER DAN CHAMBY WITH HIS WIFE ETSUKO, DAUGHTERS ANNA AND AIKO AND LIANA MATHIAS AT THE CYCLE 4 CMT EVENT IN CHARLOTTE, VERMONT

# A DEDICATED COMMUNITY

The CMTA is not only the world's largest funder of CMT research; it is also the leading provider of community services aimed at connecting and educating patients.

The CMTA has empowered community members to provide many of those services. They hold walks and fundraisers, moderate online groups and teach campers how to take care of their feet, chair-dance and support each other. They write stories for the newsletter, staff our help desk and provide graphic design. They also provide crucial information to the researchers trying to cure CMT, taking part in clinical trials, filling out surveys and signing up for our Patients as Partners in Research initiative.

Volunteers also help the CMTA by helping each other. By sharing tips, comfort, understanding, resources and referrals, they help the CMTA fulfill its mission of improving the quality of life for everyone affected by CMT.

# INHERITED NEUROPATHY CONSORTIUM (INC)

INC is an integrated group of academic medical centers, patient support organizations and clinical research resources dedicated to conducting clinical research in different forms of CMT and improving the care of patients. Funded by the National Institutes of Health (NIH), INC is part of the Rare Diseases Clinical Research Network.

Over the past few years, INC has carried out studies; identified multiple genetic causes of CMT; begun testing possible markers for CMT; enrolled thousands of patients in its studies; trained young scientists in CMT research; and created a website that provides information about CMT to patients, families and researchers. Future goals include conducting further natural history studies to enable clinical trials, continuing the search for biological features (biomarkers) of disease; continuing to identify novel genetic causes and modifiers of CMT, and maintaining and updating its website to continue providing information to patients, their families, doctors and researchers.

As the CMTA begins clinical trials for candidate therapies, data derived from these ongoing studies will become even more important. The success of these trials will largely depend on how much we know about the “natural history” of CMT—how different types of CMT progress over time and whether novel medications are slowing the course of the disease—and much of that information will be supplied by the Centers of Excellence.


John Svaren, PhD at a CMTA branch meeting

# CMTA BRANCHES

Branch Leader Tim Nightingale and family

The CMTA's 93 branch leaders and co-leaders spent 2021 connecting virtually with their members to provide support, education and resource information. While COVID forced most meetings onto Zoom, there was a silver lining—the ease and accessibility of online meetings. Members enjoyed connecting from the comfort of their own homes and could participate from anywhere in the world. Zoom allowed us to welcome many new faces to branch meetings in the United States, Canada and Mexico.

The CMTA's 71 branches are the main touchpoint between the national organization and patients: The CMTA provides education and support, and members raise funds and awareness for the parent organization.

Branch leaders organize and facilitate regularly scheduled meetings where individuals share their experiences face to face, creating a haven of understanding and camaraderie. In these structured forums, individuals can help and be helped by others, lifting the burden of isolation. Speakers often include CMT-savvy experts willing to donate their time and knowledge to educate members about their specialties. Branch members, whose lived experience gives them their own expertise, often enlighten presenters about their symptoms and the challenges of living with CMT.

***The CMTA added five new branches in 2021, located in:***

- Orange County, Calif.
- Central Michigan
- Northern Alabama
- Manitowoc, Wis.
- Guadalajara, Mexico

***Tim Nightingale, who leads the Jacksonville, Fla., Branch along with co-leader Stephanie Burkhalter,*** exemplifies the dedication and selflessness of all CMTA branch leaders. He grew up in Kingsland, Ga., and graduated from Tuskegee University in Tuskegee, Ala. He worked for Blue Cross and Blue Shield of Florida for 20 years. Tim, who was diagnosed with CMT in 2008, and his wife have been married for 32 years and raised two sons.

Tim plans regular branch meetings on relevant and important topics and spearheads a T-shirt fundraiser to help raise vital funds for STAR research. He sits on the Steering Committee for the Patient & Research Summit, making sure that the patients' interests are represented. He is also working with the CMTA on implementing a pilot diversity, equity and inclusion (DEI) program that will reach out to underserved community members in Jacksonville.

***Raleigh, N.C. (RTP) Branch Leader Jeanne Boehlecke,*** a retired rehabilitation counselor with Type 2, says branch meetings "offer sound, helpful suggestions for CMT management and reassurance to people newly diagnosed." Jeanne's work taught her that groups show members that they are not alone in living with CMT challenges, a real stress reducer. In addition, she says, the CMTA's Strategy to Accelerate Research (STAR) gives her confidence that serious efforts are being made to find a cure for CMT. She shares that hope for the future by updating branch members with the latest research findings through branch meetings and CMTA webinars.

# ONLINE COMMUNITY

The CMTA's online community also provides information, resources and support. At the close of 2021, the CMTA had a total of 50,378 fans across our various social media platforms. During the year, we had a net growth of 607 followers on Facebook, bringing our total to 38,851. On Instagram, we gained 858 net followers, raising that audience to 6,591. Our LinkedIn audience grew by 54 percent to 1,310. Our Instagram engagement grew from 5,052 in 2020 to 31,262 in 2021.

All of the CMTA's branches have Facebook pages. The CMTA also hosts five Facebook groups with an international reach: The CMTA Discussion Group is the largest with almost 19,000 members; CMTActive has 1,523 members; CMTA Parents has 1,359 members; the CMTA Youth Group has 253 members and the Cycle 4 CMT Group has some 150 members.

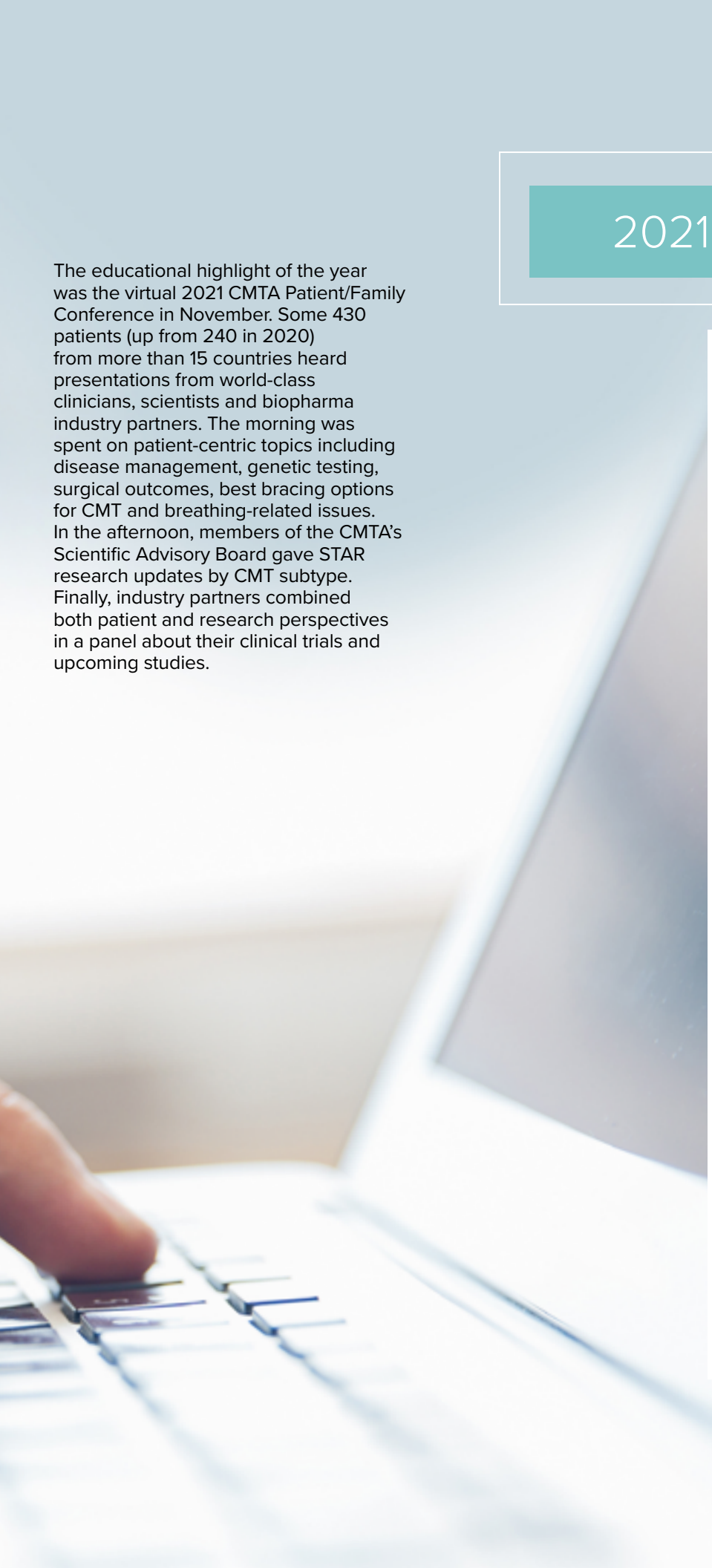
The CMTA's Emotional Support Group, which has 1,206 members, lives on the CMTA website (cmtausa.org/emotional-support-group/). Moderated by CMTA Advisory Board member and psychotherapist David Tannenbaum, the group provides a place for members to vent the feelings that come with a chronic condition and share coping techniques.

The number of new users on the CMTA website increased to 416,400 users in 2021. The What is CMT? webpage (cmtausa.org/understanding-cmt/what-is-cmt/) had 193,874 unique page views in 2021 compared to 60,074 in 2020.

Educational meetings are another important component of the CMTA's online strategy and the CMTA experienced record-breaking attendance at monthly education meetings in 2021, almost doubling from 670 attendees in 2020 to 1,297 in 2021. Virtual meetings were offered on topics such as occupational therapy, nutrition, parenting kids with CMT, surgical outcomes, bracing, foot care, disability/SSDI and more. Most of the monthly education meetings are led by CMTA Advisory Board members and neuromuscular specialists.

# 2021 ONLINE HIGHLIGHTS

The educational highlight of the year was the virtual 2021 CMTA Patient/Family Conference in November. Some 430 patients (up from 240 in 2020) from more than 15 countries heard presentations from world-class clinicians, scientists and biopharma industry partners. The morning was spent on patient-centric topics including disease management, genetic testing, surgical outcomes, best bracing options for CMT and breathing-related issues. In the afternoon, members of the CMTA's Scientific Advisory Board gave STAR research updates by CMT subtype. Finally, industry partners combined both patient and research perspectives in a panel about their clinical trials and upcoming studies.



**50,378**
SOCIAL MEDIA FOLLOWERS

**38,851**
FACEBOOK FOLLOWERS

**GIVING TUESDAY**
RAISED $56,928 WITH 18,891 VIDEO VIEWS

**5,990**
FOLLOWERS ON INSTAGRAM

**430**
ATTENDEES AT VIRTUAL PATIENT/FAMILY CONFERENCE

**1,297**
ATTENDEES AT MONTHLY EDUCATION SESSIONS

# WALKS 4 CMT


BAILEY'S
Beat the Bite
5K
Walk 4 CMT
YOU'VE BEEN
FLOCKED!
JOIN THE FUN AND FLOCK A FRIEND
FOR A SMALL DONATION TO:
BAILEY'S
Beat the Bite
5K
Contact Kristen (520) 304-7711


Boston Walk 4 CMT

The CMTA is one of the few national nonprofit organizations with a walk campaign organized and led solely by volunteers. Those volunteers hosted 28 Walks 4 CMT in 2021, raising more than $190,000 for STAR research despite the disruptions and restrictions caused by the pandemic.

Adapting to the constant changes, walk leaders stayed flexible. Some hosted in-person walks at a set time and place. Others had virtual walks on a set day, with participants walking on their own time at various locations. There were also several statewide walks, with walkers participating from their own neighborhoods statewide on a prescribed date, then reporting their results online.

The DC Metro Walk, typically held on the National Mall, had to find another location due to National Park COVID restrictions. ***Walk Leaders Steve Weiss and Kim Hughes*** adapted quickly and switched the location to a park near their home. According to Steve and Kim, "When you attend a Walk 4 CMT, you experience the vibrant spirit of the people and families living with this disease. Whether in-person or virtual, in a metropolitan area or a neighborhood park, Walk 4 CMT sends the strong message that together, the CMT community can overcome any challenge the disease throws at us."

***In Ohio, walk leaders Jill Stuhlmueller and Jo Koenig from Cincinnati and Jessica Diamond of Columbus*** worked together for an in-person walk that took place across the state. According to Jessica, "The All-Ohio Walk was such a success because we were able to combine all our branch resources together, and in doing so, created a fun event for everyone. Bringing together different members from each Ohio CMTA branch and advertising to all of Ohio, we were able to meet so many new people with CMT in our state who we wouldn't have met if it weren't for this walk! We will continue to do our walks as a statewide event, and we hope to grow more each year and continue to meet new faces of CMT!"

***More than 30 people came out for Bailey's Beat the Bite 5K in Tucson, Ariz.***, in 2021, raising a total of $17,000for CMT and bringing their five-year total to more than $50,000.

Bailey began showing signs of CMT at the age of 3 and was wearing AFOs full-time by the age of 4. In 2017, she and her family launched a 5K walk to raise money for medical research. Since then, they have not only organized and implemented a 5K walk every year, but they have also come up with other creative ways to fundraise and raise awareness about CMT. Every year, Bailey (now 12), challenges her Aunt Kristen Oaxaca to a Facebook Live duel: They throw pies in each other's faces or pour food on each other's heads for donations. In a game called "Bail or Jail," they gathered some of their biggest supporters and threw them in "jail," making them raise their own bail money to be released. Family members traveled all over Tucson planting pink flamingoes in yards to get some buzz for their virtual event.

The first year, they had no idea what they were doing, Kristen said, and had to grasp the concept that "We just ask people for money and donations?" By the time the 2021 event rolled around though, they knew exactly what they were doing. "We started out doing this for Bailey, but we come back every year to raise money for everyone with CMT," Kristen says.

WALK 4 CMT

The Weinstein family at the Colorado WALK 4 CMT

# 2021 WALK 4 CMT HIGHLIGHTS

$192,451 raised for CMT research

28 Walk 4 CMT events

526 participants

9 in-person walks

6 virtual area/city walks

13 virtual all-state walks

4 sites raised more than $15,000

7 sites raised more than $10,000

DC walk raised $38,711 overall

Top DC team “The Mighty Quinn” raised $20,655

*Cousins Paul Kang and Steven Lee*

# FUNDRAISERS AND CHALLENGE MATCHES

***Missy and Seth Warfield***

While the CMTA walks raise both awareness and funds, they aren't the only volunteer-run fundraisers. Some volunteers hold wine and chocolate tastings, kids construct lemonade stands and hold bake sales and others cycle and swim for CMT.

***Paul Kang and his cousin Steven Lee formed one of the satellite teams that joined in the Vermont Cycle (and Walk!) 4 CMT in 2021.*** The two grew up in Seattle with "a bunch of cousins," including Michelle Yuri, whose daughter Julianna was diagnosed with an aggressive form of CMT at the age of 2.

As Paul recounted, "I remember seeing Julianna grow up and miss milestone after milestone. She was never able to walk, and she died at the age of 5 from a severe form of CMT that not only affected her arms and legs but her breathing, too."

Bringing some members of the Vermont afterparty to tears, Paul paid tribute to Julianna: "In a world where hate is so easy and prevalent, Juliana was a bright star in a dark sky. In a world where people are so focused on money and power, Julianna is a reminder that life's greatest currency is love. In a world where we compare ourselves to others, Julianna showed us we are all human. Julianna was special to our family, and we want to do everything we can on this earth to make a difference for those with CMT." Riding under the team name "Love is a Super Power," Paul and Steven raised $7,870 for STAR research.

## The Challengers

The CMTA has been fortunate throughout its almost 40-year history to have had a number of generous benefactors who challenged the community to match their donations. 2021 was no exception.

***Missy and Seth Warfield, not for the first time, issued a $500,000 challenge for CMT1A***. Three generations of the Warfield family live with the disease—Missy, Missy and Seth's two adult children and two of their six grandchildren. Those grandkids are the reason the Warfields issued their latest challenge. They were also inspired to give by CMTA-STAR, the CMTA's 40-plus Alliance partners, our 4-Star Charity Navigator rating and the wide range of services the CMTA offers the patient community. Together, more than 400 donors raised over $1.1 million for CMT1A research.

As Missy said, "With five people with CMT1A in our immediate family of 12, it seemed only right to help push research to the goal line of a cure." She urged others to "make any gift a 'matching' challenge. It does not need to be a large amount, simply a challenge that invites others to help."


# CMTA YOUTH PROGRAM

The CMTA's Youth Program has grown exponentially in the three years since it was formalized.

Young people with CMT experience physical limitations daily. For many, walking is difficult, and running impossible. Even something as mundane as picking a coin up off a table can be challenging. Kids with CMT are often excluded from PE at school, after-school sports and neighborhood pick-up games. They are almost always chosen last for team sports.

That all changes at Camp Footprint, the highlight of the Youth Program year, the only camp in the country just for kids with CMT. For one week a year, campers who have never met another kid with CMT find each other in what they soon came to call The Tribe of the Funky Feet. Camp Footprint (motto: One Step at a Time) gives campers the chance to master their environment, participate in activities planned just for them and celebrate their abilities.

COVID forced Camp Footprint online for the second year in a row in 2021, but the energy, excitement and empowerment were all there, even through a computer screen. Sixteen Camp Footprint counselors and staff gathered at a hotel in downtown Pittsburgh to lead campers on the hunt for "Queen Corona," who stole the keys to the real Camp Footprint and locked them out. In an elaborate real-life/video game hybrid, some 93 campers spent the week looking for clues to the keys' whereabouts so they could return to sleepaway camp in Pennsylvania in 2022.



***Laurie Palermo, mother of campers Adam, 14, and Sam, 13, explained Camp Footprint's effects on her sons.*** "From day one, I saw smiles on their faces that I had not seen since the pandemic began in March 2020.

Finally, they were with a group of kids who could relate to them, as fellow teens, dealing with similar struggles.

There were no explanations necessary, no fear of being discovered and no fear of being left out."

Laurie has CMT and tries to be a positive role model for her sons but says, "Being with peers was something they were missing. For the very first time, Adam and Sean were sharing and talking to other kids about their thoughts and feelings about CMT. They were empowered to share and were taught skills that will help them to talk with others and not be afraid of being discovered."

Before camp started, one of Laurie's sons had noticed an increase in symptoms and was struggling to remain positive. At Camp Footprint, "He learned that he is not alone, and he learned from campers and peers that you can face your challenges with a positive attitude. In fact, Camp provided him with the confidence to put AFOs on for the very first time—in public and in shorts!!" Camp Footprint wasn't the only item on the Youth Program agenda. Members raised more than $11,000 with the Second Annual Fund the Stars Venmo Bingo and hosted three Youth Zoom hangouts where youth came together from around the world to check in and stay connected. They played games and talked about life and remembered how much love and understanding there is whenever The Tribe of the Funky Feet gets together. "One of the good things to come out of COVID has been our ability to connect online," National Youth Program Manager Jonah Berger noted.

The group also launched a Discord Server for gaming, raised more than $28,000 with the first-ever Dance 4 CMT and published a quarterly Youth Newsletter written by young people, for young people.

Finally, in December 2021, members of the Youth Program published "Walk a Mile in My Braces," charting the experience of 75 youth from around the world with CMT. The book has sold hundreds of copies with all proceeds going to the CMTA.


CYCLE 4


CYCLE 4CMT


WALK 4 CMT

# BOARD OF DIRECTORS

The entrepreneurs, executives, doctors and lawyers who serve on the CMTA Board of Directors are all dedicated to making the CMTA's vision of a world without CMT a reality. Their backgrounds and experience give them the expertise to oversee the organization's operations and strategy, including STAR, the CMTA's signature research initiative.

What makes the CMTA board stand out is that each member is directly impacted by the disease. This gives them an intimate understanding of what will enhance the lives of people with CMT. In addition to overseeing the CMTA's research efforts, our dedicated Board of Directors raises funds to pay for them, contributing $1,106,692 to STAR in 2021.

Board members hosted several high-profile events to raise funds for STAR in 2021. ***Chris and Elizabeth Ouellette (shown) organized the Eighth Annual Vermont Cycle (and Walk!) 4 CMT,*** which raised over $300,000 for an eight-year total of more than $1,291,300. Thanks to a break in the pandemic, the Vermont event was able to return to the charming Old Lantern Inn in Shelburne, Vt., with rides and walks through the lush countryside. A virtual component allowed anyone, anywhere to take part.

***After a virtual event in 2020, Steve O'Donnell (shown) and his crew got back in the pool and on the trail for his Seventh Annual FunAthlon in 2021,*** raising more than $73,000. Swimmers gathered at the Meadowbrook Swim Club in Baltimore at 7 a.m. for the first leg of the FunAthlon. Spurred by Steve and Sherri O'Donnell's challenge match of $5 per lap, participants free-styled, breast-stroked and back-stroked with added intensity. Bikers were up next, taking to the North Central Rail Trail in Baltimore County to meet a second challenge match of $5 per mile biked. A gaggle of walkers shared the bucolic trail. Everyone then moved to Camp Puh-Tok in the Pines for a picnic and awards ceremony.

***Board member Dave Coldiron and his wife Christina (shown) raised more than $55,000 for the CMTA with a Kentucky Derby party*** in Nashville, Tenn. The outdoor, tented fundraiser featured live music, fabulous bites, mint juleps, Derby viewing, live and silent auctions and a bourbon tasting. Eighty-five people came out in their finest Derby attire and hats.

While the pandemic prevented ***Board Member Phyllis Sanders*** from holding her long-running Essex House fundraiser in New York City, she pivoted to a letter-writing campaign that raised more than $68,400 for STAR, up from $44,513 in 2020.

As Phyllis put it in her letter, "In recent years, the acceleration promised by STAR has gained even more momentum, like a snowball rolling downhill. But we need to continue the momentum. That means that research funds are more critical than ever."

***Board Member Herb Beron (shown) and his family have raised over $1 million for research in the past 15 years as TeamJulia.*** For many years, members of TeamJulia swam to raise money. In 2021, they switched things up and held a walk in their neighborhood, inviting others to join them by participating in their own virtual swim/walk to help spread awareness of CMT. They raised $60,997 for 2E research.

# THE TEAM

## STAFF

Amy Gray
Chief Executive Officer

Jonah Berger
*National Youth Programs Manager*

Sarah Gentry
*Technology Manager*

Sarah Kaider
*Digital Marketing Manager*

Kim Magee
*Director of Finance and Administration*

Laurel Richardson
*Director of Community Outreach*

Jeana Sweeney
*Chief Engagement and Gifts Officer*

Elizabeth Ouellette
*CMTA Board Member/ Staff Volunteer*

## ADVISORY BOARD

Teresa Carroll, MS, PhD
Gregory Carter, MD, MS
Ken Cornell, CO
Bob DeRosa
Katy Eichinger, PT, DPT, NCS
Ashraf Elsayegh, MD, FCCP
Tim Estilow, OTR/L
Shawna Feely, MS, CGC
Valery Hanks, OTR/L, C/NDT
Sarah Kesty
Kate Lair
Bethany Noelle Meloche
Tom Meloche
David Misener, BSc (HK), CPO, MBA
Elizabeth Misener, PhD, LMSW
Christine Murray, MD
James Nussbaum, PT, PhD, SCS, EMT
Sabrina Paganoni, MD, PhD
Glenn Pfeffer, MD
Kenneth Raymond
Clark Semmes
Carly Siskind, MS, CGC
Greg Stilwell, DPM
David Tannenbaum, LCSW
Amy Warfield, PT, DPT

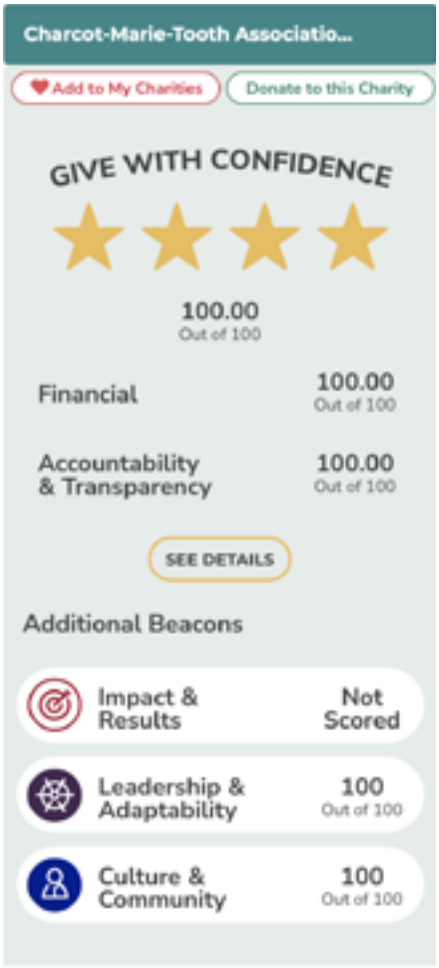
## YOUTH COUNCIL

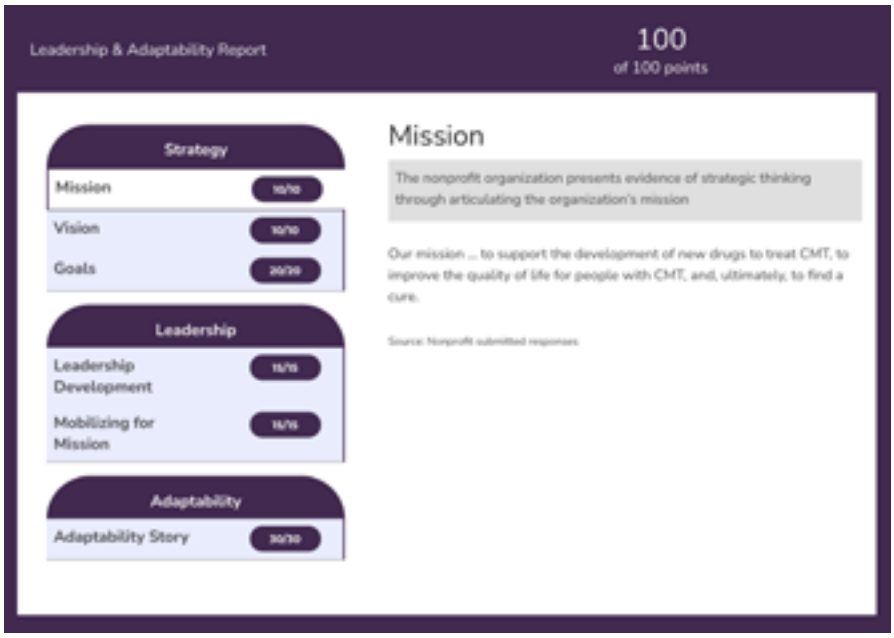
Julia Beron
Erin Black
Season Ciriello
Sam Docker
Jaden Ellman
Rai Ganesan
Ashlyn Montisanti
Elisheva Landau Pope
Hannah Roberts
Emmily Stufflet
Abby Thompson
Elijah Tolz
Riley Williams
Evan Zeltsar

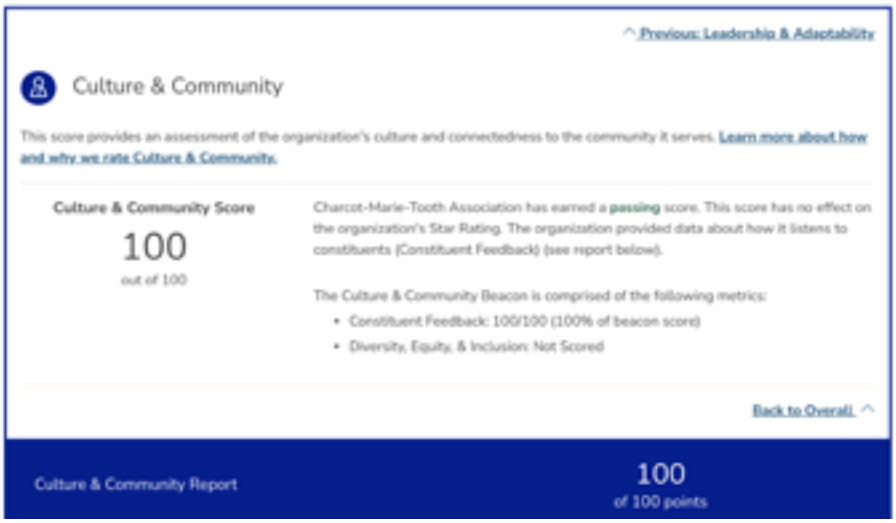
## Charity Navigator
# A PERFECT 100

## 4 STARS, THE HIGHEST POSSIBLE RATING

The CMTA received a **4-Star ranking and a "Perfect 100"** score from independent nonprofit evaluator Charity Navigator, **one of just 15 health-related charities to earn a perfect score** and the only CMT-related organizations to earn four stars.



# 2021 BY THE NUMBERS

PERFECT 100
★★★★ Charity Navigator 4-Star ranking

**$3.47 Million** Spent on STAR

**86%** of every dollar donated spent on mission

**$1.1 Million** raised by the CMTA Board of Directors

**50+** **STAR** partner initiatives

**28** WALKS 4 CMT

**70+** BRANCHES

**99% of CMT** patients covered by an active research project

**1** International Patient/Family Conference

**430** ATTENDEES AT Patient/Family Conference

93 CAMP FOOTPRINT CAMPERS

44 CAMP FOOTPRINT COUNSELORS

**416,400** NEW USERS ON CMTAUSA

**96** BRANCH MEETINGS

**$192,451** raised by WALKS 4 CMT

**50+** Research Projects

**40+** Research Partners

**$18.5M+** in Research Funding

**3,976 VIEWS** of Patient/Family Conference session recordings

# CONSOLIDATED STATEMENT OF FINANCIAL POSITION DECEMBER 31, 2021

## MISSION EXPENSES

### TOTAL MISSION EXPENSES $4,277,563

RESEARCH
81% - $3,467,123

EDUCATION & AWARENESS
19% - $810,440

## TOTAL REVENUE $5,297,364

0% OTHER REVENUE
$0

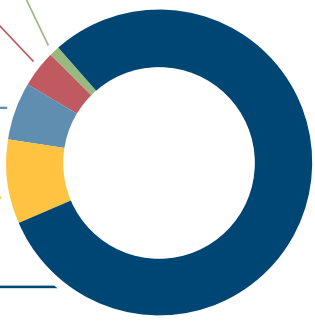
1% INVESTMENT INCOME
$19,834

6% GRANTS RECEIVED
$339,445

6% BRANCH REVENUE
$295,341

10% SPECIAL EVENTS
$523,431

77% CONTRIBUTIONS
$4,119,313



## TOTAL EXPENSES $4,955,319

10% GENERAL MANAGEMENT
$477,640

4% FUNDRAISING
$200,116

86% MISSION SERVICES
$4,277,563

## OUR 100 PERCENT PLEDGE FOR 2022 AND BEYOND

We pledge to our community that we will continue to give 100 percent in everything we do, from funding the cutting-edge research that will translate to potential treatments to partnering with companies on their preclinical testing and clinical trial development efforts. We will continue to work to identify new genes that cause CMT and the development of biomarkers that will help with fast and reliable clinical trials. We'll be pushing hard on the research, but we'll also work to ensure that we provide community members the support they need, including our first-ever CMT Clinical Summit, which will educate health care providers on caring for CMT patients. We'll also be expanding our Youth Program with a new Young Adults Group in 2022 and a second Camp Footprint location in 2023.

CMTA
Charcot-Marie-Tooth Association

P.O. Box 105 • Glenolden, PA 19036 • 800-606-2682

CMTAUSA.ORG

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