2023 ANNUAL REPORT

American Neuromuscular FOUNDATION®

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The American Neuromuscular Foundation (ANF) is a nonprofit organization dedicated to STRENGTHENING the global effort to CURE neuromuscular disease.

ANF continues to support researchers by allocating 100% of donations to research and educational opportunities for researchers. The foundation is a 501(c) tax-exempt, charitable organization supported by the American Association of Neuromuscular & Electrodiagnostic Medicine (AANEM). AANEM has provided $5.5 million to the ANF over the years and continues to pay for all administrative expenses.

ANF's initiatives include building awareness, funding research, and supporting education through development grants, mid-career grants, and research awards.

Spark the discovery of new treatments and cures by funding ANF research grants. Scientific research for NM and EDX medicine is critical to uncovering treatments and finding a cure. With one hundred percent of all donations to the ANF going directly to funding critical research, education, awards and scholarships, even small donations make an impact. Thanks to generous donors like you, ANF continues to search for a cure for NM diseases.

To join the cause or to learn more, visit:
www.neuromuscularfoundation.org/donate.

ANF continues to ignite awareness and drive progress through new initiatives. On Nov. 5, 2023, five AANEM members from around the country came together to run the TCS New York City Marathon. They raced with ANF's charity team to help raise awareness and funds for NM research and education. Together they raised $27,000.

Fundraising Status

Grand Total Raised: $27,000

Raised
$27,000

The ANF is dedicated to advancing scientific research and medical education through research funding. In 2023, the ANF proudly awarded three Development Grants to support research related to NM diseases. Each of the 2023 Development Grant recipients receives:

Up to $50,000 for up to 2 years. Total award $100,000 including indirect costs.

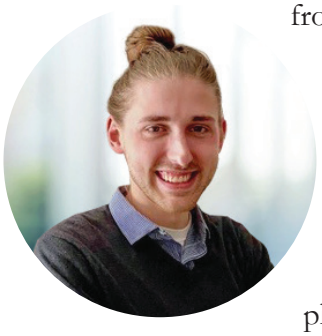
Complimentary AANEM Annual Meeting registration in the year the research is presented. The $1,500 travel award does not need to be included in the grant application. It is paid above in the $50,000 award.

Complimentary AANEM membership during funding.

Development Grant Recipients

Researcher

Tyler Nelson, PhD
New York University Pain Research Center



Project Title

Analysis of a Novel Primary Periodic Paralysis SCN4A Mutation with Pain as a Major Phenotype

Project Summary

With his expertise in neurobiology and personal experience as a patient, Dr. Nelson brings a unique perspective to this field of research. Dr. Nelson plans to generate a mouse model with the same skeletal muscle channelopathy found in himself and his immediate family, which will serve as the basis for most of his research. He will also conduct electrophysiological recordings from cells transfected with normal and pathogenic sodium muscle channels, seeking to understand the functional defects associated with the mutation.

Once the pathophysiology is understood, Dr. Nelson will explore pharmacological therapeutic options for treating the mutant channel. "By unraveling the intricate interplay between skeletal muscle ion-channel genes, myalgia, and pain, my research holds the potential to catalyze a paradigm shift in the approach of healthcare professionals to these conditions," he said. Following completion of the research, Dr. Nelson will present his findings at an AANEM Annual Meeting.

Researcher

Mai Yamakawa, MD
University of California, Los Angelas

Project Title

Causal Genetic Variation and Transcriptomic Signatures of the Peripheral Immune System in the Central Nervous System Pathology of ALS That Are Conserved or Divergent Among ALS Patients and the Animal Models

Project Summary

Dr. Yamakawa's team will build a rigorous data-driven model that describes the role of natural killer cells (NK cells) in amyotrophic lateral sclerosis (ALS)/frontotemporal dementia (FTD), including their cell surface regulators, target cells and predicted molecular drivers. This work will be the basis for future research, performing human-relevant functional validation in cellular and animal models. Dr. Yamakawa explained, "With novel technology of single-cell RNA sequencing of postmortem brain samples, we have higher resolution for pathophysiology in ALS brains. My research will contribute to a new insight into neuroinflammation as a therapeutic target in ALS, and how it is similar or different from the animal model."

Dr. Yamakawa's goal is to characterize neuroinflammation in brain and spinal cord samples from ALS patients, as neuroinflammation is an increasingly attractive therapeutic target with recent exponential discoveries in cancer immunotherapy. Additionally, she aims to systematically describe the difference in neuroinflammation in ALS patients and the most widely used SOD1 mutant mice, as this discrepancy could hinder further drug discovery and repurposing for immunotherapies. Following completion of the research, Dr. Yamakawa will present her findings at an AANEM Annual Meeting.

Researcher

Erika Williams, MD, PhD
Massachusetts General Brigham

Project Title

Genetically Decoding Human Afferent and Efferent Autonomic Ganglia

Project Summary

Dr. Williams' research will begin with comparing single-cell sequencing data from human ganglia with existing maps for mice. She explained, "Much foundational work has been done, and is ongoing, to delineate various types of neurons, their anatomy, physiology, and molecular profile in the mouse, yielding critical insights about how the nervous system controls key functions like breathing, circulation, and digestion, among others. At a minimum, I want to know if humans have these same neurons too! The degree of similarity and difference is not only of basic scientific interest but would also provide a very concrete set of molecularly defined tools for future work."

She added, "With this project, we hope to fill the gap and to directly query at single-cell resolution the organization of the human autonomic nervous system, and how that organization changes in disease. I hope this will change how we think about autonomic disorders in our patients. In addition, a data set replete with molecularly defined targets I hope will facilitate novel therapy development for autonomic disorders."

Following completion of the research, Dr. Williams will present her findings at an AANEM Annual Meeting and hopes to eventually see her goals through in her own laboratory and clinical practice over the years to come.

Surinderjit Singh Young Lectureship Award

The Surinderjit Singh Young Lectureship Award, honoring the late, longtime AANEM member Surinderjit Singh, MD, MS, started with a donation from Dr. Singh's wife to honor the late member. This award continues his legacy and allows young physicians the opportunity to advance the NM and EDX field.

The 2023 Surinderjit Singh Young Lectureship Award was received by Mathula Thanarajh, MD, PhD, for her work titled "Making Visible the Invisible: Cognitive Disability in DMD," which highlights the whole spectrum of disability in Duchenne muscular dystrophy (DMD), aligning with the 2023 plenary meeting topic "Disability and NMDs: The Whole Enchilada." Her unique perspective toward inclusivity and disabilities in DMD brought attention to often overlooked areas in the field.

The ANF celebrates outstanding research in NM and EDX medicine. Each year, 200+ research abstracts are submitted for presentation at the AANEM Annual Meeting. Select abstracts receive awards as recommended by the Abstract Review Committee.

Golseth Young Investigator Award

The Golseth Young Investigator Award, named in honor of AANEM founding member James Golseth, MD, is awarded annually for original research in NM and EDX medicine. The research is judged based on scientific merit, methodology, manuscript form, and the candidate's contribution to the project.

Winner: Eleanor Thomas, MD, PhD
COVID-19 Infection in Myasthenia Gravis: Clinical Course and Outcomes

Runner-up: Leah Liu, BSc
Damaged Neurons Secrete Factors That Influence Myogenic Differentiation

Best Abstract Award

The Best Abstract Award is given to the best abstract submitted to the AANEM Annual Meeting. All abstracts are considered for this award unless authors decline participation.

Winner: Jerry Mendell, MD
Long-Term Safety and Efficacy in Patients With Duchenne Muscular Dystrophy 4 Years Post-Treatment With Delandistrogene Moxeparvovec in a Phone 1/2a Study.

Runner-up: Oksana Haiko, MD, PhD
The Role of Ultrasound in Diagnosis of Nerve Injury After Gunshot Wounds and Blast Injuries

Technologist Best Abstract Award

The Technologist Best Abstract Award is given to the best research paper submitted by a technologist who has conducted and shared research to advance the science of NM and MSK diseases.

Stephanie Harvey: **A Survey of Nerve Conduction Technologist's Role in EMG Labs**

Presidents Research Award

The President's Research Initiative Award is given to up to 10 individuals who submit the best abstracts related to the annual meeting plenary topic chosen by the AANEM President each year.

Mosen Ahmed: **Are Neuromuscular Diseases Associated With a Greater Level of Neuro-Psychiatric Conditions?**

Abdullah Al Qahtani, MD, MPH: P**atient Reported Impact of Symptoms in Spinal Bulbar Muscular Atrophy**

Hala Elhabashy, MD: **Transcranial Direct Current Stimulation in Multiple Sclerosis: Exporing Novel Routes**

Ryan Floresca: **Impact of Edaravone on the Amyotrophic Lateral Sclerosis Course at TTUHSC El Paso Clinic: A Prospective Cohort Study**

Naglaa Gadallah, MD: **Objective Prognostic Parameters for Management of Spasticity: Clinical, Electrodiagnostic, and Surgical Study**

Brendan McNeish, MD: **Chemotherapy-Induced Peripheral Neuropathy is Associated with Decreased Executive Functioning in Cancer Survivors**

Julia Shah, MD: **Assessing Rehab Needs in Children With Spial Muscular Atrophy Status Post Onasemnogene Abeparvovec-Xioi**

Hallie Walsh: **Virtual Exercise Group Programs for Rehabilitation of Veterans With Amyotrophic Lateral Sclerosis**

Adeel Zubair, MD: **Evaluation of Neuromuscular Provider Perceptions and Office Setup for Evaluating Patients With Disabilities**

Medical Student Research Award

The Medical Student Research Award encourages medical students to conduct research in NM and EDX medicine. In 2023, 16 awards were given to medical students who were the first author and designated presenter on abstracts presented at the AANEM Annual Meeting.

Residency and Fellowship Member Awards

The Residency and Fellowship Member Award encourages young physician members to conduct research in NM and EDX medicine. Awards are given to residency and fellowship members who are first author and designated presenter on abstracts presented at the AANEM Annual Meeting. ANF proudly granted 59 Residency and Fellowship Member Awards in 2023!

Late-Onset Neuromuscular Disease Consortium (LONDC) Launches Groundbreaking Project

ANF unites the best advocacy organizations and medical professionals to drive progress in the field. In 2023, ANF's LONDC began its groundbreaking initiative to decrease wait times between diagnosing and treating late-onset neuromuscular diseases (LONDs). To inspire continued education and heighten professional standards for healthcare professionals serving those with NM disease, it began its first project - the Common Experience Research and Awareness Campaign. This campaign has three main goals:

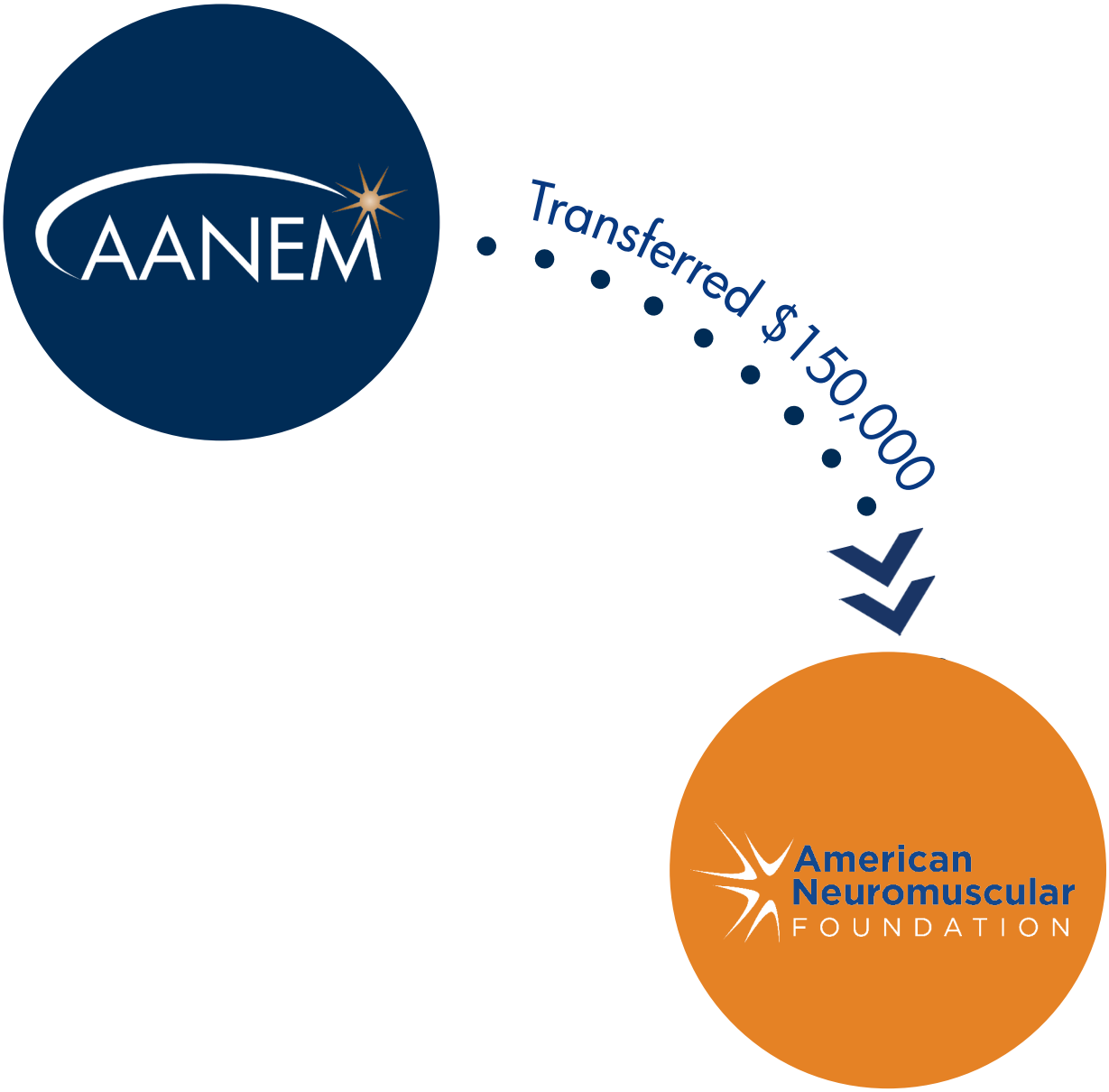
- Improve awareness, understanding, and identification of LONDs.
- Increase access to resources and support services.
- Enhance collaboration and coordination among healthcare providers, advocacy organizations, and the LOND community.

The project, set to take place over two years, consists of two phases. The first phase focuses on identifying common symptoms across various LONDs, securing consensus among physicians and patients, and creating crucial tools to assist physicians and individuals in identifying LONDs so they may seek a referral to a NM specialist. The second phase will build on the foundation set in phase one and aims to increase awareness of these tools.

The success of the Common Experience Research and Awareness Campaign relies on support from individuals and organizations who have a passion for improving the lives of those impacted by LONDs. Thank you to our sponsors, argenx, Catalyst Pharmaceuticals, Horizon, and UCB for their Champion Level support, and J&J Innovative Medicine for being a Contributor Level sponsor.

Visit **londc.neuromuscularfoundation.org** to learn more and stay up to date on LONDC news.

In 2023, the foundation received more than $90 thousand in donations. AANEM also transferred $150 thousand to the foundation and continues to pay all administrative costs so 100% of donations directly fund research and education.



"There are not many awards available to support early career physicians or scientists in the fields of NM and EDX medicine. Therefore, the ANF plays an important role in championing research into the conditions affecting the patients we care for, many of which by themselves are rare or under recognized by other agencies. In cooperation with the AANEM, the ANF is developing the next generation of leaders for our discipline."

-Colin Franz, MD, PhD

The ANF thanks the following donors for their support. Your contributions are vital to growing the foundation's impact on strengthening the global effort to cure neuromuscular disease!

Titanium Level $10,000+

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Platinum Level ($2,500 - $9,999)

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Gold Level ($1,000 - $2,499)

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Visit www.neuromuscularfoundation.org/donate
to support the ANF.

STATEMENT OF FINANCIAL POSITION - AMERICAN NEUROMUSCULAR FOUNDATION

For years ending 12/31/2023 and 12/31/2022

	2023	2022
ASSETS		
Current Assets	$ 291,458	$ 261,248
Investments	6,983,383	6,357,279
Total Assets	**$ 7,274,841**	**$ 6,618,527**
LIABILITIES & NET ASSETS		
Current Liabilities	$ 59,382	$ 109,114
Total Liabilities	**$ 59,382**	**$ 109,114**
Net Assets		
Board Designated Funds	6,918,122	6,360,261
Undesignated Funds	297,337	149,152
Total Net Assets	**7,215,459**	**6,509,413**
Total Liabilities and Net Assets	**$ 7,274,841**	**$ 6,618,527**

SUMMARY STATEMENT OF ACTIVITIES - AMERICAN NEUROMUSCULAR FOUNDATION

For periods ending 12/31/2023 and 12/31/2022

	2023	2022
TOTAL REVENUES	**$ 307,328**	**$ 191,716**
TOTAL EXPENSES	**$ 382,298**	**$ 402,018**
Operating Surplus	**$ (74,971)**	**$ (210,303)**
Net Investment Income	631,017	(1,023,008)
Transfer from AANEM	150,000	150,000
CHANGE IN NET ASSETS	**$ 706,046**	**$ (1,083,311)**

Donate

Even a small donation can help meet research funding goals, which is crucial in improving the lives of patients. The more scientific research conducted on NM diseases, the closer we will get to finding a cure. Donate online at www.neuromuscularfoundation.org/donate.

Apply

If you are conducting research related to NM diseases, apply for funding through the ANF. Learn more about various research funding opportunities at www.neuromuscularfoundation.org/research.

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