



CHARCOT-MARIE-TOOTH ASSOCIATION

FINANCIAL STATEMENTS

DECEMBER 31, 2025

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CHARCOT-MARIE-TOOTH ASSOCIATION

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INDEPENDENT AUDITOR'S REPORT

May 12, 2026

To the Board of Directors
Charcot-Marie-Tooth Association
Glenolden, Pennsylvania

Report on the Audit of the Financial Statements

Opinion

We have audited the financial statements of the Charcot-Marie-Tooth Association, which comprise the statements of financial position as of December 31, 2025, and the related statements of activities, functional expenses, and cash flows for the year then ended, and the related notes to the financial statements.

In our opinion, the accompanying financial statements present, in all material respects, the assets, liabilities, and net assets of the Charcot-Marie-Tooth Association as of December 31, 2025, and the change in their net assets for the year then ended in accordance accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audit in accordance with auditing standards generally accepted in the United States of America ("GAAS"). Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of the Charcot-Marie-Tooth Association and to meet our other ethical responsibilities, in accordance with the relevant ethical requirements relating to our audit. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

To the Board of Directors
Charcot-Marie-Tooth Association

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about the Charcot-Marie-Tooth Association's ability to continue as a going concern for one year after the date that the financial statements are issued.

Auditor's Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and, therefore, is not a guarantee that an audit conducted in accordance with GAAS will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.

Misstatements are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with GAAS, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Charcot-Marie-Tooth Association's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about the Charcot-Marie-Tooth Association's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control-related matters that we identified during the audit.

Barbacane, Thornton & Company LLP

BARBACANE, THORNTON & COMPANY LLP

**CHARCOT-MARIE-TOOTH ASSOCIATION
STATEMENT OF FINANCIAL POSITION
DECEMBER 31, 2025**

ASSETS

CURRENT ASSETS:

Cash and cash equivalents	\$ 638,497
Accounts receivable	47,601
Investments	7,324,463
Prepaid expenses	101,801
TOTAL ASSETS	<u><u>\$ 8,112,362</u></u>

LIABILITIES AND NET ASSETS

LIABILITIES:

Accounts payable	\$ 97,942
Grants payable	1,956,430
Total Liabilities	<u><u>2,054,372</u></u>

NET ASSETS:

Without donor restrictions:

Board-designated	8,878
Undesignated	3,569,586
Total Without Donor Restrictions	<u><u>3,578,464</u></u>
With donor restrictions	<u><u>2,479,526</u></u>
TOTAL NET ASSETS	<u><u>6,057,990</u></u>

TOTAL LIABILITIES AND NET ASSETS	<u><u>\$ 8,112,362</u></u>
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The accompanying notes are an integral part of these financial statements.

**CHARCOT-MARIE-TOOTH ASSOCIATION
STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED DECEMBER 31, 2025**

	Without Donor Restrictions	With Donor Restrictions	Totals
REVENUE AND OTHER SUPPORT:			
Contributions and grants	\$ 2,717,652	\$ 2,494,484	\$ 5,212,136
Bequests	57,021	-	57,021
Research Alliance revenue	810,547	-	810,547
Community events revenue	647,224	-	647,224
Investment income (loss)	287,629	-	287,629
Other revenue	43,538	-	43,538
Net assets released from restrictions	2,055,967	(2,055,967)	-
TOTAL REVENUE AND OTHER SUPPORT	6,619,578	438,517	7,058,095
EXPENSES:			
Program services:			
Research, education, and other	6,867,607	-	6,867,607
Support services:			
Management and general	340,433	-	340,433
Fundraising	341,849	-	341,849
TOTAL EXPENSES	7,549,889	-	7,549,889
CHANGE IN NET ASSETS	(930,311)	438,517	(491,794)
NET ASSETS, BEGINNING OF YEAR	4,508,775	2,041,009	6,549,784
NET ASSETS, END OF YEAR	\$ 3,578,464	\$ 2,479,526	\$ 6,057,990

The accompanying notes are an integral part of these financial statements.

**CHARCOT-MARIE-TOOTH ASSOCIATION
STATEMENT OF FUNCTIONAL EXPENSES
FOR THE YEAR ENDED DECEMBER 31, 2025**

	Research, Education and Other	Management and General	Fundraising	Totals
Salaries and benefits	\$ 1,227,805	\$ 146,046	\$ 192,933	\$ 1,566,784
Advertising and promotion	51,834	5,179	5,226	62,239
Camp fees	426,959	-	-	426,959
Community events cost	590,337	-	44,737	635,074
Research grants	3,342,651	-	-	3,342,651
Information technology	262,966	31,279	41,323	335,568
Meetings and travel	110,957	42,798	4,755	158,510
General and administrative	75,333	10,378	18,013	103,724
Office supplies	211,397	-	-	211,397
Professional fees	557,793	104,586	34,862	697,241
Miscellaneous	9,575	167	-	9,742
TOTAL EXPENSES	<u>\$ 6,867,607</u>	<u>\$ 340,433</u>	<u>\$ 341,849</u>	<u>\$ 7,549,889</u>

The accompanying notes are an integral part of these financial statements.

**CHARCOT-MARIE-TOOTH ASSOCIATION
STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED DECEMBER 31, 2025**

CASH FLOWS FROM OPERATING ACTIVITIES:	
Change in net assets	\$ (491,794)
Adjustments to reconcile change in net assets to net cash provided (used) by operating activities:	
Unrealized (gain)/loss on investments	(141,427)
Increase (Decrease) in accounts receivable	5,442
Increase (Decrease) in prepaid expenses	(101,801)
Increase (Decrease) in accounts payable	71,169
Increase (Decrease) in grants payable	(1,398,444)
NET CASH PROVIDED (USED) BY OPERATING ACTIVITIES	<u>(2,056,855)</u>
CASH FLOWS FROM INVESTING ACTIVITIES:	
Sale of investments	1,969,479
Purchase of programmatic investment	<u>(470,788)</u>
NET CASH PROVIDED (USED) BY INVESTING ACTIVITIES	<u>1,498,691</u>
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS	(558,164)
CASH AND CASH EQUIVALENTS, BEGINNING OF YEAR	<u>1,196,661</u>
CASH AND CASH EQUIVALENTS, END OF YEAR	<u><u>\$ 638,497</u></u>
SUPPLEMENTAL INFORMATION:	
Interest paid	<u>\$ -</u>
Income taxes paid	<u><u>\$ -</u></u>

The accompanying notes are an integral part of these financial statements.

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

NOTE A PURPOSE OF THE ASSOCIATION

The Charcot-Marie-Tooth Association (“the Association”) is a nonprofit Association founded in 1983. The Association is the largest philanthropic funder of Charcot-Marie-Tooth (“CMT”) disease research globally. They provide funding initiatives for CMT researchers, clinicians, and experts. They work actively to improve the quality of life for CMT-affected families.

NOTE B SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Basis of Accounting

The financial statements of the Association have been prepared on the accrual basis of accounting in accordance with accounting principles generally accepted in the United States of America (“U.S. GAAP”).

Effective for the year ended December 31, 2025, the Association transitioned its financial reporting from the modified cash basis of accounting to U.S. GAAP. This transition provides additional information to readers of the financial statements on outstanding funds due to the Association as well as on its long-term mission commitments, and ensures compliance with evolving state charitable registration guidelines. As a result of this transition, prior year comparative financial information has not been included in this year’s financial statements. It is the intention of the Association to resume inclusion of prior year comparative information with its December 31, 2026 financial statements.

Financial Statement Presentation

The Association is required to report information regarding its financial position and activities according to two classes of net assets:

Without Donor Restrictions

Net assets that are not subject to donor-imposed restrictions.

With Donor Restrictions

Net assets that are subject to donor-imposed restrictions that will be satisfied by actions of the Association and/or the passage of time. When a restriction is satisfied, net assets with donor restrictions are reclassified to net assets with donor restrictions and reported in the statements of activities as net assets released from restrictions.

Also included in this category are net assets subject to donor-imposed restrictions that require the net assets be maintained indefinitely while permitting the Association to expend the income generated in accordance with the provisions of the contribution. The Association had no net assets required to be maintained indefinitely at December 31, 2025.

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

NOTE B SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (cont'd)

Fair Value Measurements of Assets and Liabilities

Fair value is defined as the price that would be received to sell an asset or paid to transfer a liability (i.e., the "exit price") in orderly transaction between market participants at the measurement date. Accounting standards establish a fair value hierarchy for inputs used in measuring fair value that maximized the use of observable inputs and minimized the use of unobservable inputs by requiring that the most observable inputs be used when available. Observable inputs are those that market participants would use in pricing the asset or liability based on market data obtained from sources independent of the Association. Unobservable inputs reflect the Association's assumptions about the inputs market participants would use in pricing the assets or liability based on the best information available in the circumstances. The fair value hierarchy is categorized into three levels based on the inputs as follows:

Level 1 – Valuations based on quoted prices in active markets for identical assets or liabilities that the Association has the ability to access. Since valuations are based on quoted priced that are readily and regularly available in active market, valuation of these assets and liabilities does not require a significant degree of judgement.

Level 2 – Valuations based on quoted prices in markets that are not active or for which all significant inputs are observable, either directly or indirectly.

Level 3 – Valuations based on inputs that are unobservable, that is, inputs that reflect the Association's own assumptions.

Contributions

Contributions received are recorded as with or without donor restrictions, depending on the existence and/or nature of any donor restrictions. Such contributions are required to be reported as support with donor restrictions and are then reclassified to net assets without donor restrictions upon expiration of the time restriction. All contributions are considered to be available for unrestricted use unless specifically restricted by the donor.

Cash and Cash Equivalents

For purposes of the financial statements, the Association considers all highly liquid investments without donor restrictions with an initial maturity of three months or less to be cash equivalents.

Allocation of Functional Expenses

The costs of providing the various programs and other activities have been summarized on a functional basis in the statement of activities. Accordingly, certain costs have been allocated among the programs and supporting services benefited based on activity as determined by management.

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

NOTE B SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (cont'd)

Income Taxes

The Association is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code. However, income from certain activities is not directly related to the Association's tax-exempt purpose may be subject to taxation as unrelated business income.

Accounting principles generally accepted in the United States of America prescribe rules for the recognition, measurement, classification, and disclosure in the financial statements of uncertain tax positions taken or expected to be taken in the Association's tax returns. Management has determined that the Association does not have any uncertain tax positions or associated unrecognized benefits that materially impact the financial statements or related disclosures. Since tax matters are subject to some degree of uncertainty, there can be no assurance that the Association's tax returns will not be challenged by the taxing authorities and that the Association will not be subject to additional tax, penalties, and interest as a result of such challenge.

Concentration of Credit Risk

The Association maintains two cash accounts. At December 31, 2025, these accounts are covered under the Federal Deposit Insurance Corporation ("FDIC") and are insured by the FDIC up to \$250,000. At December 31, 2025, \$250,000 was covered under FDIC insured and \$254,306 was uninsured. The Association had \$6,572,634 in an investment account with Morgan Stanley, a \$253,066 investment in Armatus Bio 1A, \$150,000 promissory note in Elpida Therapeutics, a \$248,763 investment in the Shark tooth Biotech, and a \$100,000 investment in a Shark-Intervene Ever tree Bio account.

NOTE C INVESTMENTS

Investments at December 31, 2025 consisted of the following:

Money market funds	\$ 6,572,634
Promissory note	150,000
Private company stock (a)	253,066
Private company stock (b)	100,000
Private company stock (c)	<u>248,763</u>
	<u>\$ 7,324,463</u>

(a) Investment in private company stock represent programmatic investments, which consist of preferred stock.

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

NOTE C INVESTMENTS (cont'd)

Investments are measured at fair value using Level 1 (quoted priced in active markets) valuation inputs, except for promissory note and private company stock which is measured using Level 3 valuation inputs.

Investment income (loss) consisted of the following:

Interest, dividends, and capital gains	\$ 146,202
Net realized and unrealized gain (loss) on investments	<u>141,427</u>
	<u>\$ 287,629</u>

NOTE D NET ASSETS WITHOUT DONOR RESTRICTIONS – BOARD DESIGNATED

At December 31, 2025, the Board designated \$8,878 of its net assets without donor restrictions to support the Association's Strategy to Accelerate Research (STAR) initiative.

NOTE E NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions are restricted for the following purposes:

	<u>Balance</u> <u>12/31/2024</u>	<u>Additions</u>	<u>Releases</u>	<u>Balance</u> <u>12/31/2025</u>
Subject to expenditure for specific purposes:				
Strategy to Accelerate Research (STAR) initiative	<u>\$2,041,009</u>	<u>\$2,494,484</u>	<u>\$2,055,967</u>	<u>\$2,479,526</u>

NOTE F RETIREMENT PLAN

The Association participates in a 403(b) plan that covers substantially of all employees. Employees can contribute any percentage of their income to the internal Revenue Service limit for the year. The Association can make a discretionary 3% matching contribution. The Association made contributions to the plan of \$32,144 for the year ending December 31, 2025.

NOTE G LIQUIDITY AND AVAILABILITY OF RESOURCES

The following table reflects the Association's financial assets as of December 31, 2025, which has been reduced by financial assets not available within one year.

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

NOTE G LIQUIDITY AND AVAILABILITY OF RESOURCES (cont'd)

Cash	\$ 638,497
Accounts receivable	47,601
Investments	7,324,463
Total financial assets	<u>8,010,561</u>
Less: financial assets not available for general operations within one year	
Restricted by donors for specific purposes	(2,479,526)
Designated by Board of Directors	<u>(8,878)</u>
Total financial assets available within one year	<u>\$ 5,522,157</u>

Liquidity Management

As part of the Association's liquidity management, it invests its cash in excess of daily requirements in short-term investments, typically money market funds and U.S. Treasury securities and obligations of U.S. Government Agencies.

NOTE H RELATED PARTY TRANSACTION – MISSION-RELATED INVESTMENT

During 2025, the Association entered into an alliance agreement with Shark Tooth Biotech, a privately held biotechnology company conducting research related to CMT1A therapies. A member of the Association's Board of Directors is an owner of Shark Tooth Biotech. The board member recused himself from the Association's consideration and approval of the arrangement. Under the agreement, donations directed by donors to support Shark Tooth Biotech research are allocated 90% to an investment in Shark Tooth Biotech through a Simple Agreement for Future Equity and 10% to support the Association's general mission and administrative support. During the year ended December 31, 2025, the Association received \$162,940 of such directed donations, invested \$146,646 in Shark Tooth Biotech, and retained \$16,294 for general mission support. At December 31, 2025, the Association's investment in Shark Tooth Biotech had a carrying value of \$248,763, which also includes investments made in 2025 for donations received in 2024. At December 31, 2025, \$8,878 was payable to Shark Tooth Biotech.

NOTE I SUBSEQUENT EVENTS

The Association has evaluated all subsequent events through May 12, 2026, the date the financial statements were available to be issued.