

Charcot-Marie-Tooth Association

Financial Statements

Years Ended December 31, 2021 and 2020



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CHARCOT-MARIE-TOOTH ASSOCIATION

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INDEPENDENT AUDITOR'S REPORT

**Board of Directors
Charcot-Marie-Tooth Association
Glenolden, Pennsylvania**

Opinion

We have audited the accompanying financial statements of the Charcot-Marie-Tooth Association (a nonprofit organization), which comprise the statements of assets, liabilities and net assets – modified cash basis as of December 31, 2021 and 2020, and the related statements of revenues, support and expenses – modified cash basis and functional expenses – modified cash basis for the years then ended, and the related notes to the financial statements.

In our opinion, the financial statements referred to above present fairly, in all material respects, the assets, liabilities and net assets of the Charcot-Marie-Tooth Association as of December 31, 2021 and 2020, and its revenues, support and expenses for the year then ended in accordance with the modified cash basis of accounting as described in Note 2.

Basis for Opinion

We conducted our audits in accordance with U.S. generally accepted auditing standards. 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 audits. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Basis of Accounting

We draw attention to Note 2 of the financial statements, which describes the basis of accounting. The financial statements are prepared on the modified cash basis of accounting, which is a basis of accounting other than U.S. generally accepted accounting principles. Our opinion is not modified with respect to this matter.

Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with the modified cash basis of accounting as described in Note 2; and for determining that the modified cash basis of accounting is an acceptable basis for the preparation of the financial statements in the circumstances. Management is also responsible 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.

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 generally accepted auditing standards 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 generally accepted auditing standards, 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.

BBO, LLP.

Philadelphia, Pennsylvania
July 12, 2022

CHARCOT-MARIE-TOOTH ASSOCIATION

STATEMENTS OF ASSETS, LIABILITIES AND NET ASSETS - MODIFIED CASH BASIS

December 31, 2021 and 2020

	<u>2021</u>	<u>2020</u>
ASSETS		
Cash	\$ 3,884,618	\$ 3,573,013
Investments	<u>2,144,083</u>	<u>2,113,643</u>
Total assets	<u>\$ 6,028,701</u>	<u>\$ 5,686,656</u>
LIABILITIES	<u>\$ -</u>	<u>\$ -</u>
NET ASSETS		
Without donor restrictions		
Operating	422,694	699,054
Board designated	<u>129,521</u>	<u>342,716</u>
	552,215	1,041,770
With donor restrictions	<u>5,476,486</u>	<u>4,644,886</u>
Total net assets	<u>6,028,701</u>	<u>5,686,656</u>
Total liabilities and net assets	<u>\$ 6,028,701</u>	<u>\$ 5,686,656</u>

See accompanying notes

CHARCOT-MARIE-TOOTH ASSOCIATION

STATEMENTS OF REVENUES, SUPPORT AND EXPENSES - MODIFIED CASH BASIS

Years ended December 31, 2021 and 2020

	2021			2020		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
REVENUE AND SUPPORT						
Contributions and grants	\$ 1,296,265	\$ 3,162,493	\$ 4,458,758	\$ 1,220,308	\$ 3,250,399	\$ 4,470,707
Special events income	523,431	-	523,431	487,254	-	487,254
Support group revenue	295,341	-	295,341	320,597	-	320,597
Investment income	-	19,834	19,834	494	32,747	33,241
Other revenue	-	-	-	6,691	-	6,691
Net assets released from restrictions	<u>2,350,727</u>	<u>(2,350,727)</u>	<u>-</u>	<u>2,399,290</u>	<u>(2,399,290)</u>	<u>-</u>
Total revenue and support	<u>4,465,764</u>	<u>831,600</u>	<u>5,297,364</u>	<u>4,434,634</u>	<u>883,856</u>	<u>5,318,490</u>
EXPENSES						
Program services						
Research, education and other	4,277,563	-	4,277,563	3,618,309	-	3,618,309
Supporting services						
Management and general	477,640	-	477,640	194,701	-	194,701
Fundraising	<u>200,116</u>	<u>-</u>	<u>200,116</u>	<u>167,365</u>	<u>-</u>	<u>167,365</u>
Total expenses	<u>4,955,319</u>	<u>-</u>	<u>4,955,319</u>	<u>3,980,375</u>	<u>-</u>	<u>3,980,375</u>
CHANGE IN NET ASSETS	(489,555)	831,600	342,045	454,259	883,856	1,338,115
NET ASSETS						
Beginning of year	<u>1,041,770</u>	<u>4,644,886</u>	<u>5,686,656</u>	<u>587,511</u>	<u>3,761,030</u>	<u>4,348,541</u>
End of year	<u>\$ 552,215</u>	<u>\$ 5,476,486</u>	<u>\$ 6,028,701</u>	<u>\$ 1,041,770</u>	<u>\$ 4,644,886</u>	<u>\$ 5,686,656</u>

See accompanying notes

CHARCOT-MARIE-TOOTH ASSOCIATION

STATEMENT OF FUNCTIONAL EXPENSES - MODIFIED CASH BASIS

Year ended December 31, 2021 with comparative totals for 2020

	Research, Education and Other	Management and General	Fundraising	Totals	
				2021	2020
Salaries and benefits	\$ 623,903	\$ 81,488	\$ 88,621	\$ 794,012	\$ 732,822
Advertising and promotion	81,642	7,510	9,433	98,585	62,655
Camp fees	96,583	-	-	96,583	47,358
Special event costs	157,804	-	20,886	178,690	119,987
Research grants	2,494,564	-	-	2,494,564	2,245,542
Information technology	144,488	16,999	8,499	169,986	108,175
Meetings and travel	1,728	961	-	2,689	29,588
Office expense	150,258	45,732	54,913	250,903	172,610
Professional fees	522,639	324,950	16,176	863,765	424,950
Miscellaneous	3,954	-	1,588	5,542	36,688
Total expenses	\$ 4,277,563	\$ 477,640	\$ 200,116	\$ 4,955,319	\$ 3,980,375

See accompanying notes

CHARCOT-MARIE-TOOTH ASSOCIATION

STATEMENT OF FUNCTIONAL EXPENSES - MODIFIED CASH BASIS

Year ended December 31, 2020

	Research, Education and Other	Management and General	Fundraising	Total
Salaries and benefits	\$ 575,057	\$ 91,447	\$ 66,318	\$ 732,822
Advertising and promotion	49,370	4,511	8,774	62,655
Camp fees	47,358	-	-	47,358
Special event costs	102,857	-	17,130	119,987
Research grants	2,245,542	-	-	2,245,542
Information technology	91,949	10,818	5,408	108,175
Meetings and travel	15,644	13,944	-	29,588
Office expense	96,837	22,395	53,378	172,610
Professional fees	385,415	25,770	13,765	424,950
Miscellaneous	<u>8,280</u>	<u>25,816</u>	<u>2,592</u>	<u>36,688</u>
Total expenses	<u>\$ 3,618,309</u>	<u>\$ 194,701</u>	<u>\$ 167,365</u>	<u>\$ 3,980,375</u>

See accompanying notes

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

December 31, 2021 and 2020

(1) NATURE OF OPERATIONS

The Charcot-Marie-Tooth Association (the "**Association**") was established to create awareness of Charcot-Marie-Tooth ("**CMT**") disorders within the healthcare community and the general public, and to be a leading source of information regarding CMT disorders. The Association encourages, promotes and supports research into the cause, treatment and cure of CMT disorders. The Association also facilitates education and support for persons affected by CMT disorders.

(2) SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Basis of Accounting

The financial statements have been prepared on the modified cash basis of accounting, a comprehensive basis of accounting other than generally accepted accounting principles. Under the cash basis, revenue is recognized when received rather than when earned and expenses are recognized when paid rather than when the obligation is incurred. The cash basis has been modified by the recording of investments.

Basis of Presentation

The Association reports information regarding its financial position and activities according to the following 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 without donor restrictions and reported in the statements of revenues, support and expenses – modified cash basis 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, 2021 and 2020.

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 an orderly transaction between market participants at the measurement date. Accounting standards establish a fair value hierarchy for inputs used in measuring fair value that maximizes the use of observable inputs and minimizes 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 asset 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 prices that are readily and regularly available in an active market, valuation of these assets and liabilities does not require a significant degree of judgment.

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

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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.

Accounting Estimates

Management makes estimates and assumptions that affect the reported amounts of assets and liabilities at the date of the financial statements, as well as the reported amounts of revenues and expenses during the reported period. Actual results could differ from those estimates.

Investments

Investments in equity securities with readily determinable fair values and all investments in debt securities are reported at fair value, as determined by quoted market prices, with gains and losses included in the statements of revenues, support and expenses – modified cash basis. Interest income is recorded as received.

Revenue and Support

Contributions and grants, special events income and support group revenue received are recorded as net assets without donor restrictions or with donor restrictions depending on the absence or existence and nature of any donor restrictions. Donor-restricted contributions and grants, special events income and support group revenue whose restrictions are satisfied in the same period are reported as net assets without donor restrictions.

Income Taxes

The Association is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code. The Association qualifies for the charitable contribution deduction under Section 170(b)(1)(A) and has been classified as an organization other than a private foundation under Section 509(a)(2). However, income from certain activities not directly related to the Association's tax-exempt purpose may be subject to taxation as unrelated business income.

Accounting standards require entities to evaluate, measure, recognize and disclose any uncertain income tax positions taken on their tax returns. Accounting standards prescribe a minimum threshold that a tax position is required to meet in order to be recognized in the financial statements. The Association believes that it had no uncertain tax positions.

Functional Allocation of Expenses

The costs of providing various programs and other activities have been presented on a functional basis in the statements of revenue, support and expenses – modified cash basis and functional expenses – modified cash basis. Expenses directly attributable to a specific functional area are reported as expenses of that functional area. Expenses not directly attributable to a specific functional area are allocated. Significant expenses that are allocated include salaries and benefits, information technology and professional fees, which are allocated based on estimates of time and effort.

Concentrations of Credit Risk

Cash is a financial instrument which potentially subjects the Association to concentrations of credit risk. The Association maintains cash deposits at high-quality financial institutions. At times, such deposits may exceed federally-insured limits.

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

December 31, 2021 and 2020

(3) INVESTMENTS

Investments at December 31, 2021 and 2020 consisted of the following:

	<u>2021</u>	<u>2020</u>
Money market funds	\$ 448,388	\$1,431,516
Certificates of deposit	1,598,897	606,946
Equity exchange traded fund	<u>96,798</u>	<u>75,181</u>
	<u>\$2,144,083</u>	<u>\$2,113,643</u>

Investments are measured at fair value using Level 1 (quoted prices in active markets) valuation inputs, except for certificates of deposit which are measured using Level 2 valuation inputs.

Investment income consisted of the following:

	<u>2021</u>	<u>2020</u>
Interest and dividends	\$ 9,495	\$24,592
Net realized and unrealized gain on investments	<u>10,339</u>	<u>8,649</u>
	<u>\$19,834</u>	<u>\$33,241</u>

(4) NET ASSETS WITHOUT DONOR RESTRICTIONS – BOARD DESIGNATED

At December 31, 2021 and 2020, the Board has designated \$129,521 and \$342,716, respectively, of its net assets without donor restrictions to support the Associations Strategy to Accelerate Research (STAR) initiative.

(5) NET ASSETS WITH DONOR RESTRICTIONS

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

	<u>Balance</u> <u>December 31, 2020</u>	<u>Additions</u>	<u>Releases</u>	<u>Balance</u> <u>December 31, 2021</u>
Subject to expenditure for specified purposes				
Strategy to Accelerate Research (STAR) initiative	\$2,531,243	\$3,151,887	\$(2,350,727)	\$3,332,403
Research and diagnostic improvement	<u>2,113,643</u>	<u>30,440</u>	<u>-</u>	<u>2,144,083</u>
	<u>\$4,644,886</u>	<u>\$3,182,327</u>	<u>\$(2,350,727)</u>	<u>\$5,476,486</u>
	<u>Balance</u> <u>December 31, 2019</u>	<u>Additions</u>	<u>Releases</u>	<u>Balance</u> <u>December 31, 2020</u>
Subject to expenditure for specified purposes				
Strategy to Accelerate Research (STAR) initiative	\$1,549,741	\$3,251,334	\$(2,269,832)	\$2,531,243
Research and diagnostic improvement	<u>2,211,289</u>	<u>31,812</u>	<u>(129,458)</u>	<u>2,113,643</u>
	<u>\$3,761,030</u>	<u>\$3,283,146</u>	<u>\$(2,399,290)</u>	<u>\$4,644,886</u>

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

December 31, 2021 and 2020

(6) RETIREMENT PLAN

The Association participates in a 403(b) plan that covers substantially all of its employees. Employees can contribute any percentage of their income up 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 \$13,364 and \$13,626 for the years ended December 31, 2021 and 2020, respectively.

(7) PAYCHECK PROTECTION PROGRAM

On February 22, 2021, the Association received a second loan in the amount of \$139,445 under the Paycheck Protection Program ("**PPP**"). Established as part of the Coronavirus Aid, Relief and Economic Security Act (Cares Act), the PPP provides for loans to qualifying businesses in amounts up to 2.5 times the business' average monthly payroll expenses. PPP loans and accrued interest are forgivable after a "covered period" (eight or 24 weeks) as long as the borrower maintains its payroll levels and uses the loan proceeds for eligible purposes, including payroll, benefits, rent and utilities.

The loan was fully forgiven by the Small Business Administration in October 2021 and the gain is included in contributions and grants in the 2021 statement of activities.

(8) DATA BREACH

In September of 2021, the CMTA was able to resolve the donor data breach that was first communicated to donors in the spring of 2021. Transparency is a core value of the CMTA, and the organization is communicated the following details to the donor community about this resolved issue.

In December 2017, a former employee of our organization, Susan Ruediger, downloaded the CMTA's entire donor database following her notice of resignation from the CMTA and before her last day of employment in January 2018. In April 2018, Ms. Ruediger and Pat Livney, former CEO of the CMTA, formed the CMT Research Foundation ("**CMTRF**"). Sometime thereafter, CMTRF began using portions of the database to solicit donations for CMTRF.

The CMTA first became aware of this data breach in early 2021. Shortly after, the CMTA attempted to resolve the matter directly with Ms. Ruediger and CMTRF but were unable to do so. Unfortunately, the CMTA was forced to take legal action, which was underwritten by the CMTA board of directors.

During the course of the investigation, Ms. Ruediger and CMTRF acknowledged possession of the CMTA's donor database information and that they used it to solicit donations for their organization. Ms. Ruediger also acknowledged possession of other CMTA materials.

On March 29, 2021, a judge ruled in favor of the CMTA and ordered Ms. Ruediger and CMTRF to return the donor database information. Following the court order, a forensics firm was hired to scrub CMTRF devices and platforms of the CMTA donor information and derivatives. The forensics firm also confirmed the return or deletion of all information that was given to third party vendors.

As of September 2021, the CMTA confirmed through communication from the forensics firm and law firms that all donor information from the CMTA has been permanently removed from CMTRF computers and devices; and the CMTA notified the Court that the matter is resolved.

The CMTA remains focused on its mission to develop treatments and a cure for CMT, and to help improve the quality of life of everyone living with this disease.

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

December 31, 2021 and 2020

(9) LIQUIDITY AND AVAILABILITY OF RESOURCES

The following table reflects the Association's financial assets as of the statements of assets, liabilities and net assets – modified cash basis date, which has been reduced by financial assets not available within one year.

	<u>2021</u>	<u>2020</u>
Cash	\$ 3,884,618	\$ 3,573,013
Investments	<u>2,144,083</u>	<u>2,113,643</u>
Total financial assets	6,028,701	5,686,656
Less: financial assets not available for general operations within one year		
Restricted by donors for specific purposes	(5,476,486)	(4,644,886)
Designated by the Board of Directors	<u>(129,521)</u>	<u>(342,716)</u>
Total financial assets available within one year	<u>\$ 422,694</u>	<u>\$ 699,054</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 certificates of deposit.

(10) SUBSEQUENT EVENTS

Management has evaluated subsequent events through July 12, 2022, the date on which the financial statements were available to be issued. The extent of the impact of COVID-19 on the Association's operational and financial performance will depend on further developments, including the duration and spread of the outbreak, all of which cannot be predicted at this time. No other material subsequent events have occurred since December 31, 2021 that require recognition or disclosure in the financial statements.