

Charcot-Marie-Tooth Association

Financial Statements
Years Ended December 31, 2019 and 2018



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CHARCOT-MARIE-TOOTH ASSOCIATION

CONTENTS

INDEPENDENT AUDITOR'S REPORT	1
FINANCIAL STATEMENTS	
<i>Statements of Assets, Liabilities and Net Assets – Modified Cash Basis</i>	3
<i>Statements of Revenues, Support and Expenses – Modified Cash Basis</i>	4
<i>Statements of Functional Expenses – Modified Cash Basis</i>	5
<i>Notes to Financial Statements</i>	7



INDEPENDENT AUDITOR'S REPORT

Board of Directors Charcot-Marie-Tooth Association

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, 2019 and 2018, 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.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with the modified cash basis of accounting as described in Note 2; this includes 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 Responsibility

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with U.S. generally accepted auditing standards. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements 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 entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

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, 2019 and 2018, 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 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.

BBD, LLP.

**Philadelphia, Pennsylvania
May 20, 2020**

CHARCOT-MARIE-TOOTH ASSOCIATION

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

December 31, 2019 and 2018

	<u>2019</u>	<u>2018</u>
ASSETS		
Cash	\$ 2,264,899	\$ 1,603,177
Investments	<u>2,083,642</u>	<u>2,042,232</u>
Total assets	<u>\$ 4,348,541</u>	<u>\$ 3,645,409</u>
LIABILITIES	<u>\$ -</u>	<u>\$ -</u>
NET ASSETS		
Without donor restrictions	587,511	561,978
With donor restrictions	<u>3,761,030</u>	<u>3,083,431</u>
Total net assets	<u>4,348,541</u>	<u>3,645,409</u>
Total liabilities and net assets	<u>\$ 4,348,541</u>	<u>\$ 3,645,409</u>

See accompanying notes

CHARCOT-MARIE-TOOTH ASSOCIATION

STATEMENTS OF REVENUES, SUPPORT AND EXPENSES - MODIFIED CASH BASIS

Years ended December 31, 2019 and 2018

	2019			2018		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
REVENUE AND SUPPORT						
Contributions and grants	\$ 1,335,097	\$ 2,284,664	\$ 3,619,761	\$ 1,230,260	\$ 2,828,291	\$ 4,058,551
Special events income	726,341	-	726,341	531,203	-	531,203
Support group revenue	524,963	-	524,963	469,701	-	469,701
Investment income	2,237	58,761	60,998	1,808	24,937	26,745
Other revenue	13,357	-	13,357	8,704	-	8,704
Net assets released from restrictions	1,665,826	(1,665,826)	-	890,551	(890,551)	-
Total revenue and support	<u>4,267,821</u>	<u>677,599</u>	<u>4,945,420</u>	<u>3,132,227</u>	<u>1,962,677</u>	<u>5,094,904</u>
EXPENSES						
Program services						
Research, education and other	3,700,919	-	3,700,919	2,748,978	-	2,748,978
Supporting services						
Management and general	219,460	-	219,460	227,490	-	227,490
Fundraising	321,909	-	321,909	283,905	-	283,905
Total expenses	<u>4,242,288</u>	<u>-</u>	<u>4,242,288</u>	<u>3,260,373</u>	<u>-</u>	<u>3,260,373</u>
CHANGE IN NET ASSETS	25,533	677,599	703,132	(128,146)	1,962,677	1,834,531
NET ASSETS						
Beginning of year	<u>561,978</u>	<u>3,083,431</u>	<u>3,645,409</u>	<u>690,124</u>	<u>1,120,754</u>	<u>1,810,878</u>
End of year	<u>\$ 587,511</u>	<u>\$ 3,761,030</u>	<u>\$ 4,348,541</u>	<u>\$ 561,978</u>	<u>\$ 3,083,431</u>	<u>\$ 3,645,409</u>

See accompanying notes

CHARCOT-MARIE-TOOTH ASSOCIATION

STATEMENT OF FUNCTIONAL EXPENSES - MODIFIED CASH BASIS

Year ended December 31, 2019 with comparative totals for 2018

	Research, Education and Other	Management and General	Fundraising	Totals	
				2019	2018
Salaries and benefits	\$ 519,312	\$ 83,367	\$ 114,700	\$ 717,379	\$ 763,390
Advertising and promotion	73,029	4,736	18,849	96,614	63,470
Camp fees	154,823	-	-	154,823	120,750
Special event costs	262,105	-	104,966	367,071	231,236
Research grants	2,033,581	-	-	2,033,581	1,136,525
Information technology	113,564	6,639	13,355	133,558	222,905
Meetings and travel	163,884	25,676	548	190,108	224,107
Office expense	82,724	61,768	58,080	202,572	180,367
Professional fees	275,986	37,274	6,975	320,235	287,906
Miscellaneous	<u>21,911</u>	<u>-</u>	<u>4,436</u>	<u>26,347</u>	<u>29,717</u>
Total expenses	<u>\$ 3,700,919</u>	<u>\$ 219,460</u>	<u>\$ 321,909</u>	<u>\$ 4,242,288</u>	<u>\$ 3,260,373</u>

See accompanying notes

CHARCOT-MARIE-TOOTH ASSOCIATION

STATEMENT OF FUNCTIONAL EXPENSES - MODIFIED CASH BASIS

Year ended December 31, 2018

	<u>Research, Education and Other</u>	<u>Management and General</u>	<u>Fundraising</u>	<u>2018</u>
Salaries and benefits	\$ 567,790	\$ 83,159	\$ 112,441	\$ 763,390
Advertising and promotion	46,286	3,637	13,547	63,470
Camp fees	120,750	-	-	120,750
Special event costs	162,766	-	68,470	231,236
Research grants	1,136,525	-	-	1,136,525
Information technology	195,509	5,105	22,291	222,905
Meetings and travel	193,107	28,397	2,603	224,107
Office expense	74,355	55,680	50,332	180,367
Professional fees	229,419	51,512	6,975	287,906
Miscellaneous	<u>22,471</u>	<u>-</u>	<u>7,246</u>	<u>29,717</u>
Total expenses	<u>\$ 2,748,978</u>	<u>\$ 227,490</u>	<u>\$ 283,905</u>	<u>\$ 3,260,373</u>

See accompanying notes

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

December 31, 2019 and 2018

(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, 2019 and 2018.

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

December 31, 2019 and 2018

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.

The Association invests in a professionally-managed portfolio that contains various types of investments (**See Note 3**). Such investments are exposed to market and credit risk. Due to the level of risk associated with such investments, and the level of uncertainty related to changes in the value of such investments, it is at least reasonably possible that the amounts reported in the financial statements could change materially in the near term.

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, 2019 and 2018

Accounting Pronouncements Adopted

In June 2018, the FASB issued ASU 2018-08, Not-for-Profit Entities (Topic 958); Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made. This ASU clarifies and improves the scope and accounting guidance for contributions received and made and assists entities in evaluating whether transactions should be accounted for as contributions with the scope of Topic 958, Not-for-Profit Entities, or as exchange transactions subject to other guidance, and in determining whether a contribution is conditional. The Association adopted ASU 2018-08 on January 1, 2019.

Reclassifications

Certain items in the 2018 financial statements have been reclassified to conform to the 2019 presentation.

(3) INVESTMENTS

Investments at December 31, 2019 and 2018 consisted of the following:

	<u>2019</u>	<u>2018</u>
Money market funds	\$ 411,846	\$ 291,909
Certificates of deposit	1,608,226	1,701,886
Equity exchange traded fund	<u>63,570</u>	<u>48,437</u>
	<u>\$2,083,642</u>	<u>\$2,042,232</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>2019</u>	<u>2018</u>
Interest and dividends	\$42,833	\$26,540
Net realized and unrealized gain on investments	<u>18,165</u>	<u>205</u>
	<u>\$60,998</u>	<u>\$26,745</u>

(4) NET ASSETS WITH DONOR RESTRICTIONS

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

	<u>Balance December 31, 2018</u>	<u>Additions</u>	<u>Releases</u>	<u>Balance December 31, 2019</u>
Subject to expenditure for specified purposes				
Strategy to Accelerate Research (STAR) initiative	\$ 990,332	\$2,225,235	\$(1,665,826)	\$1,549,741
Research and diagnostic improvement	<u>2,093,099</u>	<u>118,190</u>	<u>-</u>	<u>2,211,289</u>
	<u>\$3,083,431</u>	<u>\$2,343,425</u>	<u>\$(1,665,826)</u>	<u>\$3,761,030</u>
	<u>Balance December 31, 2017</u>	<u>Additions</u>	<u>Releases</u>	<u>Balance December 31, 2018</u>
Subject to expenditure for specified purposes				
Strategy to Accelerate Research (STAR) initiative	\$1,120,754	\$ 760,129	\$(890,551)	\$ 990,332
Research and diagnostic improvement	<u>-</u>	<u>2,093,099</u>	<u>-</u>	<u>2,093,099</u>
	<u>\$1,120,754</u>	<u>\$2,853,228</u>	<u>\$(890,551)</u>	<u>\$3,083,431</u>

CHARCOT-MARIE-TOOTH ASSOCIATION

NOTES TO FINANCIAL STATEMENTS

December 31, 2019 and 2018

(5) 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 \$12,915 and \$12,779 for the years ended December 31, 2019 and 2018, respectively.

(6) LIQUIDITY AND AVAILABILITY OF RESOURCES

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

Cash	\$ 2,264,899
Investments	<u>2,083,642</u>
Total financial assets	4,348,541
Less: financial assets not available for general operations within one year	
Restricted by donor for specific purposes	<u>(3,761,030)</u>
Total financial assets available within one year	<u>\$ 587,511</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.

(7) SUBSEQUENT EVENTS

Management has evaluated subsequent events through May 20, 2020, 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 certain developments, including the duration and spread of the outbreak, all of which are uncertain and cannot be predicted. At this point, the extent to which COVID-19 may impact the Association's financial condition or results of operations is uncertain.

No other material subsequent events have occurred since December 31, 2019 that require recognition or disclosure in the financial statements.