

# Charcot-Marie-Tooth Association

Financial Statements

Years Ended December 31, 2020 and 2019



1835 Market Street, 3rd Floor  
Philadelphia, PA 19103

215/567-7770 | [bbdcpa.com](http://bbdcpa.com)

# 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  
Glenolden, Pennsylvania**

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, 2020 and 2019, 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, 2020 and 2019, 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  
June 21, 2021**

# CHARCOT-MARIE-TOOTH ASSOCIATION

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

December 31, 2020 and 2019

	<u>2020</u>	<u>2019</u>
<b>ASSETS</b>		
Cash	\$ 3,573,013	\$ 2,264,899
Investments	<u>2,113,643</u>	<u>2,083,642</u>
<b>Total assets</b>	<u>\$ 5,686,656</u>	<u>\$ 4,348,541</u>
<b>LIABILITIES</b>	<u>\$ -</u>	<u>\$ -</u>
<b>NET ASSETS</b>		
Without donor restrictions		
Operating	699,054	441,431
Board designated	<u>342,716</u>	<u>146,080</u>
	1,041,770	587,511
With donor restrictions	<u>4,644,886</u>	<u>3,761,030</u>
<b>Total net assets</b>	<u>5,686,656</u>	<u>4,348,541</u>
<b>Total liabilities and net assets</b>	<u>\$ 5,686,656</u>	<u>\$ 4,348,541</u>

---

See accompanying notes

# CHARCOT-MARIE-TOOTH ASSOCIATION

## STATEMENTS OF REVENUES, SUPPORT AND EXPENSES - MODIFIED CASH BASIS

Years ended December 31, 2020 and 2019

	2020			2019		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
<b>REVENUE AND SUPPORT</b>						
Contributions and grants	\$ 1,220,308	\$ 3,250,399	\$ 4,470,707	\$ 1,335,097	\$ 2,284,664	\$ 3,619,761
Special events income	487,254	-	487,254	726,341	-	726,341
Support group revenue	320,597	-	320,597	524,963	-	524,963
Investment income	494	32,747	33,241	2,237	58,761	60,998
Other revenue	6,691	-	6,691	13,357	-	13,357
Net assets released from restrictions	2,399,290	(2,399,290)	-	1,665,826	(1,665,826)	-
<b>Total revenue and support</b>	<b>4,434,634</b>	<b>883,856</b>	<b>5,318,490</b>	<b>4,267,821</b>	<b>677,599</b>	<b>4,945,420</b>
<b>EXPENSES</b>						
Program services						
Research, education and other	3,618,309	-	3,618,309	3,700,919	-	3,700,919
Supporting services						
Management and general	194,701	-	194,701	219,460	-	219,460
Fundraising	167,365	-	167,365	321,909	-	321,909
<b>Total expenses</b>	<b>3,980,375</b>	<b>-</b>	<b>3,980,375</b>	<b>4,242,288</b>	<b>-</b>	<b>4,242,288</b>
<b>CHANGE IN NET ASSETS</b>	<b>454,259</b>	<b>883,856</b>	<b>1,338,115</b>	<b>25,533</b>	<b>677,599</b>	<b>703,132</b>
<b>NET ASSETS</b>						
Beginning of year	587,511	3,761,030	4,348,541	561,978	3,083,431	3,645,409
<b>End of year</b>	<b>\$ 1,041,770</b>	<b>\$ 4,644,886</b>	<b>\$ 5,686,656</b>	<b>\$ 587,511</b>	<b>\$ 3,761,030</b>	<b>\$ 4,348,541</b>

See accompanying notes

# CHARCOT-MARIE-TOOTH ASSOCIATION

## STATEMENT OF FUNCTIONAL EXPENSES - MODIFIED CASH BASIS

Year ended December 31, 2020 with comparative totals for 2019

---

	<b>Research, Education and Other</b>	<b>Management and General</b>	<b>Fundraising</b>	<b>Totals</b>	
				<b>2020</b>	<b>2019</b>
Salaries and benefits	\$ 575,057	\$ 91,447	\$ 66,318	\$ 732,822	\$ 717,379
Advertising and promotion	49,370	4,511	8,774	62,655	96,614
Camp fees	47,358	-	-	47,358	154,823
Special event costs	102,857	-	17,130	119,987	367,071
Research grants	2,245,542	-	-	2,245,542	2,033,581
Information technology	91,949	10,818	5,408	108,175	133,558
Meetings and travel	15,644	13,944	-	29,588	190,108
Office expense	96,837	22,395	53,378	172,610	202,572
Professional fees	385,415	25,770	13,765	424,950	320,235
Miscellaneous	<u>8,280</u>	<u>25,816</u>	<u>2,592</u>	<u>36,688</u>	<u>26,347</u>
<b>Total expenses</b>	<b><u>\$ 3,618,309</u></b>	<b><u>\$ 194,701</u></b>	<b><u>\$ 167,365</u></b>	<b><u>\$ 3,980,375</u></b>	<b><u>\$ 4,242,288</u></b>

---

See accompanying notes

# CHARCOT-MARIE-TOOTH ASSOCIATION

## STATEMENT OF FUNCTIONAL EXPENSES - MODIFIED CASH BASIS

Year ended December 31, 2019

---

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

---

See accompanying notes

# CHARCOT-MARIE-TOOTH ASSOCIATION

## NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

---

### (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, 2020 and 2019.

#### **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, 2020 and 2019

---

**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.

### **Reclassifications**

Certain items in the 2019 financial statements have been reclassified to conform to the 2020 presentation.

# CHARCOT-MARIE-TOOTH ASSOCIATION

## NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

### (3) INVESTMENTS

Investments at December 31, 2020 and 2019 consisted of the following:

	<u>2020</u>	<u>2019</u>
Money market funds	\$1,431,516	\$ 411,846
Certificates of deposit	606,946	1,608,226
Equity exchange traded fund	<u>75,181</u>	<u>63,570</u>
	<u>\$2,113,643</u>	<u>\$2,083,642</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>2020</u>	<u>2019</u>
Interest and dividends	\$24,592	\$42,833
Net realized and unrealized gain on investments	<u>8,649</u>	<u>18,165</u>
	<u>\$33,241</u>	<u>\$60,998</u>

### (4) NET ASSETS WITHOUT DONOR RESTRICTIONS – BOARD DESIGNATED

At December 31, 2020 and 2019, the Board has designated \$342,716 and \$146,080, 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, 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>
	<u>Balance</u> <u>December 31, 2018</u>	<u>Additions</u>	<u>Releases</u>	<u>Balance</u> <u>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>

# CHARCOT-MARIE-TOOTH ASSOCIATION

## NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

---

### (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 \$13,626 and \$12,915 for the years ended December 31, 2020 and 2019, respectively.

### (7) PAYCHECK PROTECTION PROGRAM

On April 7, 2020, the Association received loan proceeds in the amount of \$127,675 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.

On December 4, 2020, the Small Business Administration forgave 100% of the PPP loan payable and has included the proceeds of \$127,675 as contributions and grants in the 2020 statement of activities.

On February 22, 2021, the Association received a second loan under the PPP in the amount of \$139,445.

### (8) DATA BREACH

This past year, the CMTA notified donors of a data breach to the donor database.

In December of 2017, Susan Ruediger resigned from the CMTA. During her last month of employment at CMTA, Susan Ruediger downloaded the CMTA donor database (which consisted of more than 43,000 donors at the time) from the CMTA's web-based storage space to a spreadsheet on her laptop. Even though the CMTA requested she return all CMTA property prior to her departure, unbeknownst to the CMTA until just recently, the CMTA's donor list remained in Ruediger's possession since her departure from the CMTA.

In April of 2018, Susan Ruediger and Pat Livney formed the CMT Research Foundation. And, Susan Ruediger acknowledges utilization of some portion of the CMTA donor list to assist in soliciting donations for her new organization, the CMT Research Foundation.

As soon as the CMTA became aware of the potential issue, the CMTA engaged a forensic accounting firm and sought legal counsel to determine the validity and specifics of the suspected breach. The forensics report confirmed that **no credit card, Social Security numbers or bank account information were compromised**.

As a matter of practice, the CMTA did not store this type of information in the donor system at the time of the incident.

The CMTA attempted to address this matter through demand letters, but unfortunately Susan Ruediger and the CMT Research Foundation were not willing to resolve the matter in a way that satisfied CMTA's donor privacy concerns and the CMTA has proceeded with legal action.

A judge recently ruled in the CMTA's favor and ordered Susan Ruediger and CMT Research Foundation to return the donor list and all derivatives of it as well as cease contact with any donors that derived from the list. The CMTA is still working through the process of getting this done.

Susan Ruediger has admitted to taking other CMTA materials and documents, however, at this stage the CMTA is unsure of the extent of the taking or use.

# CHARCOT-MARIE-TOOTH ASSOCIATION

## NOTES TO FINANCIAL STATEMENTS

December 31, 2020 and 2019

---

The CMTA remain steadfastly committed to the financial obligations to the CMT community and its mission cause—more than 90 cents of every dollar spent will continue to go toward improving the quality of life, helping develop treatments and searching for a cure for those impacted by CMT. The CMTA is also assuring donors that donations will not be used to fund the litigation and donor dollars will be used to continue to accelerate research and support our community.

### (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>2020</u>	<u>2019</u>
Cash	\$ 3,573,013	\$ 2,264,899
Investments	<u>2,113,643</u>	<u>2,083,642</u>
Total financial assets	5,686,656	4,348,541
Less: financial assets not available for general operations within one year		
Restricted by donors for specific purposes	(4,644,886)	(3,761,030)
Designated by the Board of Directors	<u>(342,716)</u>	<u>(146,080)</u>
Total financial assets available within one year	<u>\$ 699,054</u>	<u>\$ 441,431</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 June 21, 2021, 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, 2020 that require recognition or disclosure in the financial statements.