

**FOR TAX YEAR 2017**

CHARCOT-MARIE-TOOTH ASSOCIATION

Peterson Fieo & Co LLP  
103 Chesley Drive Suite 102  
Media, PA 19063-1757  
(610) 457-1486

Return of Organization Exempt From Income Tax

2017

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

Do not enter social security numbers on this form as it may be made public.

Go to www.irs.gov/Form990 for instructions and the latest information.

Open to Public Inspection

Department of the Treasury Internal Revenue Service

A For the 2017 calendar year, or tax year beginning, 2017, and ending, 20

Form header section containing B (Check if applicable), C (Name of organization: Charcot-Marie-Tooth Association), D (Employer identification no. 22-2480896), E (Telephone number (610) 499-9264), G (Gross receipts \$ 3,300,962), H(a) (Is this a group return for subordinates? No), H(b) (Are all subordinates included? No), I (Tax-exempt status: 501(c)(3)), J (Website: www.cmtausa.org), K (Form of organization: Corporation), L (Year of formation: 1983), M (State of legal domicile: PA)

Part I Summary

Table with 3 columns: Description, Prior Year, Current Year. Rows include: 1. Mission statement; 2-7. Governance and membership; 8-12. Revenue (Total: 3,138,829); 13-19. Expenses (Total: 2,539,687); 20-22. Net Assets or Fund Balances (Total: 1,762,032).

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Signature block containing: Sign Here, Amy Gray (Signature of officer), Amy Gray, Chief Executive Officer (Type or print name and title), Date: 06/19/2018

Paid Preparer Use Only section containing: Print/Type preparer's name (George Fieo CPA), Preparer's signature, Date (06-19-2018), Check self-employed (checked), PTIN (P00231326), Firm's name (Peterson Fieo & Co LLP), Firm's address (103 Chesley Drive Suite 102 Media PA 19063-1757), Firm's EIN, Phone no. (610-457-1486)

May the IRS discuss this return with the preparer shown above? (see instructions) Yes No

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III

1 Briefly describe the organization's mission: To support the development of new drugs to treat Charcot-Marie-Tooth disease (CMT), to improve the quality of life for people with CMT and ultimately, to find a cure.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? Yes No

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? Yes No

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code: ) (Expenses \$ 1,858,108 including grants of \$ 884,528 ) (Revenue \$ 2,020,783 ) The organization awards research fellowships and grants for research on Charcot-Marie-Tooth Disease. It also hosts bi-annual meetings of all researchers receiving its funding to promote knowledge exchange and synergy. It uses the services of a medical research consultant to oversee the selection of the recipients of the research funding and to write the grants and contracts with these researchers (see Part VII, Section B)

4b (Code: ) (Expenses \$ 203,733 including grants of \$ ) (Revenue \$ 59,415 ) The organization organize and conducts support groups, conferences and educational webinars for patients, their families and medical practitioners to share knowledge and promote awareness of Charcot-Marie-Tooth Disease.

4c (Code: ) (Expenses \$ 177,950 including grants of \$ ) (Revenue \$ 502,770 ) The organization publishes a bi-monthly newsletter and other educational publications and maintains a website for patients, their families and medical practitioners to assist in understanding and treating Charcot-Marie-Tooth Disease.

4d Other program services (Describe in Schedule O.) (Expenses \$ including grants of \$ ) (Revenue \$ )

4e Total program service expenses 2,239,791

**Part IV Checklist of Required Schedules**

|     |  | Yes | No |
|-----|--|-----|----|
| 1   | Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A . . . . .</i>   | X   |    |
| 2   | Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> (see instructions)? . . . . .   | X   |    |
| 3   | Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I . . . . .</i>  |     | X  |
| 4   | <b>Section 501(c)(3) organizations.</b> Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II . . . . .</i>   | X   |    |
| 5   | Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III . . . . .</i>   |     | X  |
| 6   | Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I . . . . .</i>  |     | X  |
| 7   | Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II . . . . .</i>  |     | X  |
| 8   | Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III . . . . .</i>   |     | X  |
| 9   | Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV . . . . .</i>            |     | X  |
| 10  | Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V . . . . .</i>  |     | X  |
| 11  | If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.  |     |    |
| a   | Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI . . . . .</i>   | X   |    |
| b   | Did the organization report an amount for investments - other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII . . . . .</i>   |     | X  |
| c   | Did the organization report an amount for investments - program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII . . . . .</i>   |     | X  |
| d   | Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX . . . . .</i>  |     | X  |
| e   | Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X . . . . .</i>   |     | X  |
| f   | Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X . . . . .</i>  |     | X  |
| 12a | Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII . . . . .</i>  | X   |    |
| b   | Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional . . . . .</i>   |     | X  |
| 13  | Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E . . . . .</i>   |     | X  |
| 14a | Did the organization maintain an office, employees, or agents outside of the United States? . . . . .  |     | X  |
| b   | Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV . . . . .</i> | X   |    |
| 15  | Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV . . . . .</i>  | X   |    |
| 16  | Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV . . . . .</i>  |     | X  |
| 17  | Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I (see instructions) . . . . .</i>   |     | X  |
| 18  | Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II. . . . .</i>   | X   |    |
| 19  | Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III. . . . .</i>   |     | X  |

**Part IV Checklist of Required Schedules** (continued)

|            |  | Yes | No |
|------------|--|-----|----|
| <b>20a</b> | Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i> . . . . .   |     | X  |
| <b>b</b>   | If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? . . . . .   |     |    |
| <b>21</b>  | Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i> . . . . .   | X   |    |
| <b>22</b>  | Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i> . . . . .   | X   |    |
| <b>23</b>  | Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i> . . . . .  | X   |    |
| <b>24a</b> | Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i> . . . . .                            |     | X  |
| <b>b</b>   | Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? . . . . .  |     |    |
| <b>c</b>   | Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? . . . . .   |     |    |
| <b>d</b>   | Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? . . . . .  |     |    |
| <b>25a</b> | <b>Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations.</b> Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i> . . . . .   |     | X  |
| <b>b</b>   | Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i> . . . . .                                       |     | X  |
| <b>26</b>  | Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If "Yes," complete Schedule L, Part II</i> . . . . .                                 |     | X  |
| <b>27</b>  | Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i> . . . . . |     | X  |
| <b>28</b>  | Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):  |     |    |
| <b>a</b>   | A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i> . . . . .   |     | X  |
| <b>b</b>   | A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i> . . . . .  |     | X  |
| <b>c</b>   | An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i> . . . . .  |     | X  |
| <b>29</b>  | Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> . . . . .  |     | X  |
| <b>30</b>  | Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i> . . . . .  |     | X  |
| <b>31</b>  | Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> . . . . .  |     | X  |
| <b>32</b>  | Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i> . . . . .  |     | X  |
| <b>33</b>  | Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i> . . . . .  |     | X  |
| <b>34</b>  | Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i> . . . . .  |     | X  |
| <b>35a</b> | Did the organization have a controlled entity within the meaning of section 512(b)(13)? . . . . .  |     | X  |
| <b>b</b>   | If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i> . . . . .   |     |    |
| <b>36</b>  | <b>Section 501(c)(3) organizations.</b> Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i> . . . . .   |     | X  |
| <b>37</b>  | Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i> . . . . .   |     | X  |
| <b>38</b>  | Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? <b>Note.</b> All Form 990 filers are required to complete Schedule O.   | X   |    |

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response or note to any line in this Part V

Table with columns for question numbers (1a-14b), descriptions, and Yes/No checkboxes. Includes questions about Form 1096, Form W-2G, backup withholding, Form W-3, unrelated business gross income, foreign accounts, prohibited tax shelter transactions, deductible contributions, and 501(c)(7), (12), and (29) organizations.

Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions.

Check if Schedule O contains a response or note to any line in this Part VI [X]

Section A. Governing Body and Management

Table with 4 columns: Question, Line Number, Yes, No. Rows include questions about voting members, family relationships, management delegation, and meeting documentation.

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)

Table with 4 columns: Question, Line Number, Yes, No. Rows include questions about local chapters, conflict of interest policies, whistleblower policies, and compensation review processes.

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed - Pennsylvania
18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (Section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
20 State the name, address, and telephone number of the person who possesses the organization's books and records: Kimberly Magee (610) 499-9264, PO Box 105, Glenolden, PA 19036

**Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors**

Check if Schedule O contains a response or note to any line in this Part VII

**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees**

**1a** Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

| (A)<br>Name and Title                             | (B)<br>Average hours per week (list any hours for related organizations below dotted line) | (C)<br>Position (do not check more than one box, unless person is both an officer and a director/trustee) |                       |         |              |                              |        | (D)<br>Reportable compensation from the organization (W-2/1099-MISC) | (E)<br>Reportable compensation from related organizations (W-2/1099-MISC) | (F)<br>Estimated amount of other compensation from the organization and related organizations |
|---|--|---|-----------------------|---------|--------------|------------------------------|--------|--|---|---|
|   |  | Individual trustee or director  | Institutional trustee | Officer | Key employee | Highest compensated employee | Former |  |   |   |
| (1) <u>Herbert Beron</u><br>Secretary             |  | X   |                       | X       |              |                              |        | 0  | 0   | 0   |
| (2) <u>Giles Bouchard</u><br>Chairman             |  | X   |                       |         |              |                              |        | 0  | 0   | 0   |
| (3) <u>Thomas Dubensky</u><br>Director            |  | X   |                       |         |              |                              |        | 0  | 0   | 0   |
| (4) <u>Laura Fava</u><br>Director                 |  | X   |                       |         |              |                              |        | 0  | 0   | 0   |
| (5) <u>Gary Gasper</u><br>Treasurer               |  | X   |                       |         |              |                              |        | 0  | 0   | 0   |
| (6) <u>Alan Korowitz</u><br>Director              |  | X   |                       |         |              |                              |        | 0  | 0   | 0   |
| (7) <u>Steven O'Donnell</u><br>Director           |  | X   |                       |         |              |                              |        | 0  | 0   | 0   |
| (8) <u>Chris Ouellette</u><br>Director            |  | X   |                       |         |              |                              |        | 0  | 0   | 0   |
| (9) <u>Phyllis Sanders</u><br>Director            |  | X   |                       |         |              |                              |        | 0  | 0   | 0   |
| (10) <u>Kimberly Magee</u><br>Director of Finance | 40.00  |   |                       | X       |              |                              |        | 75,000   | 0   | 0   |
| (11) <u>Amy Gray</u><br>Chief Executive Officer   | 40.00  |   |                       | X       |              |                              |        | 152,692  | 0   | 0   |
| (12)  |  |   |                       |         |              |                              |        |  |   |   |
| (13)  |  |   |                       |         |              |                              |        |  |   |   |
| (14)  |  |   |                       |         |              |                              |        |  |   |   |



**Part VII Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees** (continued)

| (A)<br>Name and title  | (B)<br>Average hours per week (list any hours for related organizations below dotted line) | (C)<br>Position<br>(do not check more than one box, unless person is both an officer and a director/trustee) |                       |         |              |                              |                | (D)<br>Reportable compensation from the organization (W-2/1099-MISC) | (E)<br>Reportable compensation from related organizations (W-2/1099-MISC) | (F)<br>Estimated amount of other compensation from the organization and related organizations |
|--|--|--|-----------------------|---------|--------------|------------------------------|----------------|--|---|---|
|  |  | Individual trustee or director   | Institutional trustee | Officer | Key employee | Highest compensated employee | Former         |  |   |   |
| (15) -----   |  |  |                       |         |              |                              |                |  |   |   |
| (16) -----   |  |  |                       |         |              |                              |                |  |   |   |
| (17) -----   |  |  |                       |         |              |                              |                |  |   |   |
| (18) -----   |  |  |                       |         |              |                              |                |  |   |   |
| (19) -----   |  |  |                       |         |              |                              |                |  |   |   |
| (20) -----   |  |  |                       |         |              |                              |                |  |   |   |
| (21) -----   |  |  |                       |         |              |                              |                |  |   |   |
| (22) -----   |  |  |                       |         |              |                              |                |  |   |   |
| (23) -----   |  |  |                       |         |              |                              |                |  |   |   |
| (24) -----   |  |  |                       |         |              |                              |                |  |   |   |
| (25) -----   |  |  |                       |         |              |                              |                |  |   |   |
| <b>1b Sub-total</b> . . . . .  |  |  |                       |         |              |                              |                |  |   |   |
| <b>c Total from continuation sheets to Part VII, Section A</b> . . . . . |  |  |                       |         |              |                              |                |  |   |   |
| <b>d Total (add lines 1b and 1c)</b> . . . . .                           |  |  |                       |         |              |                              | <b>227,692</b> | <b>0</b>   | <b>0</b>  |   |

**2** Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization **1**

|  | Yes | No |
|--|-----|----|
| <b>3</b> Did the organization list any <b>former</b> officer, director, or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i> . . . . .                                       |     | X  |
| <b>4</b> For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i> . . . . . | X   |    |
| <b>5</b> Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i> . . . . .                       |     | X  |

**Section B. Independent Contractors**

**1** Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

| (A)<br>Name and business address                                 | (B)<br>Description of services | (C)<br>Compensation |
|--|--------------------------------|---------------------|
| HumanFirst Therapeutics LLC, 9600 Dewitt Drive Suite 1, MD 20910 | medical research               | 151,997             |
|  |                                |                     |
|  |                                |                     |
|  |                                |                     |
|  |                                |                     |

**2** Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization **1**

**Part VIII Statement of Revenue**

Check if Schedule O contains a response or note to any line in this Part VIII

|  |  |  | (A)<br>Total revenue | (B)<br>Related or<br>exempt<br>function<br>revenue | (C)<br>Unrelated<br>business<br>revenue | (D)<br>Revenue<br>excluded from tax<br>under sections<br>512-514 |         |
|--|--|--|----------------------|--|---|--|---------|
| <b>Contributions, Gifts, Grants<br/>and Other Similar<br/>Amounts</b>                  | <b>1a</b> Federated campaigns . . . . .  | <b>1a</b>  |                      |  |   |  |         |
|  | <b>b</b> Membership dues . . . . .   | <b>1b</b>  | 59,415               |  |   |  |         |
|  | <b>c</b> Fundraising events . . . . .  | <b>1c</b>  |                      |  |   |  |         |
|  | <b>d</b> Related organizations . . . . .   | <b>1d</b>  |                      |  |   |  |         |
|  | <b>e</b> Government grants (contributions) . .   | <b>1e</b>  |                      |  |   |  |         |
|  | <b>f</b> All other contributions, gifts, grants,<br>and similar amounts not included above   | <b>1f</b>  | 2,029,465            |  |   |  |         |
|  | <b>g</b> Noncash contributions included in lines 1a-1f: \$   |  |                      |  |   |  |         |
|  | <b>h Total.</b> Add lines 1a-1f . . . . . ▶  |  | 2,088,880            |  |   |  |         |
| <b>Program Service<br/>Revenue</b>   | <b>2a Support group revenue</b>  |  | <b>Business Code</b> |  |   |  |         |
|  |  |  | 624100               | 494,088  | 494,088                                 |  |         |
|  | <b>b</b>   |  |                      |  |   |  |         |
|  | <b>c</b>   |  |                      |  |   |  |         |
|  | <b>d</b>   |  |                      |  |   |  |         |
|  | <b>e</b>   |  |                      |  |   |  |         |
|  | <b>f</b> All other program service revenue . . . . .   |  |                      |  |   |  |         |
| <b>g Total.</b> Add lines 2a-2f . . . . . ▶  |  | 494,088  |                      |  |   |  |         |
| <b>Other Revenue</b>   | <b>3</b> Investment income (including dividends, interest,<br>and other similar amounts) . . . . . ▶   |  | 835                  | 835  |   |  |         |
|  | <b>4</b> Income from investment of tax-exempt bond proceeds . . . ▶  |  |                      |  |   |  |         |
|  | <b>5</b> Royalties . . . . . ▶   |  |                      |  |   |  |         |
|  | <b>6a</b> Gross rents . . . . .  | (i) Real   | (ii) Personal        |  |   |  |         |
|  |  | <b>b</b> Less: rental expenses . . . . .                           |                      |  |   |  |         |
|  |  | <b>c</b> Rental income or (loss) . . . . .                         |                      |  |   |  |         |
|  |  | <b>d</b> Net rental income or (loss) . . . . . ▶                   |                      |  |   |  |         |
|  | <b>7a</b> Gross amount from sales of<br>assets other than inventory  | (i) Securities   | (ii) Other           |  |   |  |         |
|  |  | <b>b</b> Less: cost or other basis<br>and sales expenses . . . . . |                      |  |   |  |         |
|  |  | <b>c</b> Gain or (loss) . . . . .                                  |                      |  |   |  |         |
|  |  | <b>d</b> Net gain or (loss) . . . . . ▶                            |                      |  |   |  |         |
|  | <b>8a</b> Gross income from fundraising<br>events (not including \$ _____<br>of contributions reported on line 1c).<br>See Part IV, line 18 . . . . . <b>a</b> |  |                      | 708,477  |   |  |         |
|  |  | <b>b</b> Less: direct expenses . . . . . <b>b</b>                  |                      | 153,017  |   |  |         |
|  |  | <b>c</b> Net income or (loss) from fundraising events . . . . . ▶  |                      | 555,460  |   |  | 555,460 |
|  | <b>9a</b> Gross income from gaming activities.<br>See Part IV, line 19 . . . . . <b>a</b>  |  |                      |  |   |  |         |
| <b>b</b> Less: direct expenses . . . . . <b>b</b>                                      |  |  |                      |  |   |  |         |
| <b>c</b> Net income or (loss) from gaming activities . . . . . ▶                       |  |  |                      |  |   |  |         |
| <b>10a</b> Gross sales of inventory, less<br>returns and allowances . . . . . <b>a</b> |  |  | 8,682                |  |   |  |         |
|  | <b>b</b> Less: cost of goods sold . . . . . <b>b</b>   |  | 9,116                |  |   |  |         |
|  | <b>c</b> Net income or (loss) from sales of inventory . . . . . ▶  |  | (434)                |  |   | (434)  |         |
| Miscellaneous Revenue  |  | <b>Business Code</b>   |                      |  |   |  |         |
| <b>11a</b>   |  |  |                      |  |   |  |         |
|  |  |  |                      |  |   |  |         |
|  |  |  |                      |  |   |  |         |
|  | <b>d</b> All other revenue . . . . .   |  |                      |  |   |  |         |
|  | <b>e Total.</b> Add lines 11a-11d . . . . . ▶  |  |                      |  |   |  |         |
| <b>12 Total revenue.</b> See instructions . . . . . ▶                                  |  |  | 3,138,829            | 494,923  | 0                                       | 555,026  |         |

**Part IX Statement of Functional Expenses**

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

Check if Schedule O contains a response or note to any line in this Part IX

| <b>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</b> |   | (A)<br>Total expenses | (B)<br>Program service expenses | (C)<br>Management and general expenses | (D)<br>Fundraising expenses |
|---|---|-----------------------|---------------------------------|--|-----------------------------|
| 1   | Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 . . .  | 874,028               | 874,028                         |  |                             |
| 2   | Grants and other assistance to domestic individuals. See Part IV, line 22 . . . . .   | 10,500                | 10,500                          |  |                             |
| 3   | Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16 . . . . .  |                       |                                 |  |                             |
| 4   | Benefits paid to or for members . . . . .   |                       |                                 |  |                             |
| 5   | Compensation of current officers, directors, trustees, and key employees . . . . .  |                       |                                 |  |                             |
| 6   | Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) . . . . .   |                       |                                 |  |                             |
| 7   | Other salaries and wages . . . . .  | 546,775               | 434,342                         | 22,500                                 | 89,933                      |
| 8   | Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions) . .  | 12,727                | 10,072                          | 531                                    | 2,124                       |
| 9   | Other employee benefits . . . . .   | 3,993                 | 3,224                           | 154                                    | 615                         |
| 10  | Payroll taxes . . . . .   | 36,987                | 29,362                          | 1,524                                  | 6,101                       |
| 11  | Fees for services (non-employees):  |                       |                                 |  |                             |
| a   | Management . . . . .  |                       |                                 |  |                             |
| b   | Legal . . . . .   | 21,326                | 21,085                          | 241                                    |                             |
| c   | Accounting . . . . .  | 17,290                |                                 | 17,290                                 |                             |
| d   | Lobbying . . . . .  | 30,520                | 30,520                          |  |                             |
| e   | Professional fundraising services. See Part IV, line 17 .   | 6,921                 |                                 |  | 6,921                       |
| f   | Investment management fees . . . . .  |                       |                                 |  |                             |
| g   | Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O.) . .  | 194,247               | 181,778                         |  | 12,469                      |
| 12  | Advertising and promotion . . . . .   | 22,487                | 22,487                          |  |                             |
| 13  | Office expenses . . . . .   | 33,185                | 22,723                          | 7,460                                  | 3,002                       |
| 14  | Information technology . . . . .  | 79,560                | 67,626                          |  | 11,934                      |
| 15  | Royalties . . . . .   |                       |                                 |  |                             |
| 16  | Occupancy . . . . .   | 14,695                | 12,241                          | 1,602                                  | 852                         |
| 17  | Travel . . . . .  | 77,721                | 72,734                          | 3,969                                  | 1,018                       |
| 18  | Payments of travel or entertainment expenses for any federal, state, or local public officials . . . . .  |                       |                                 |  |                             |
| 19  | Conferences, conventions, and meetings . . . . .  | 63,870                | 63,870                          |  |                             |
| 20  | Interest . . . . .  |                       |                                 |  |                             |
| 21  | Payments to affiliates . . . . .  |                       |                                 |  |                             |
| 22  | Depreciation, depletion, and amortization . . . . .   | 12,239                |                                 | 12,239                                 |                             |
| 23  | Insurance . . . . .   | 9,764                 |                                 | 9,764                                  |                             |
| 24  | Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)   |                       |                                 |  |                             |
| a   | <b>bank charges &amp; collection fe</b>   | 34,977                |                                 |  | 34,977                      |
| b   | <b>direct expenses</b>  | 259,053               | 234,223                         |  | 24,830                      |
| c   | <b>publications &amp; supplies</b>  | 62,472                | 61,580                          |  | 892                         |
| d   | <b>recruiting expense</b>   | 99,150                | 79,320                          |  | 19,830                      |
| e   | All other expenses _____  | 15,200                | 8,076                           | 6,174                                  | 950                         |
| 25  | <b>Total functional expenses.</b> Add lines 1 through 24e .   | 2,539,687             | 2,239,791                       | 83,448                                 | 216,448                     |
| 26  | <b>Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720) . . . . . |                       |                                 |  |                             |

**Part X Balance Sheet**

Check if Schedule O contains a response or note to any line in this Part X

|   |  | (A)<br>Beginning of year |           | (B)<br>End of year |        |
|---|--|--------------------------|-----------|--------------------|--------|
| <b>Assets</b>   | <b>1</b> Cash - non-interest-bearing   | 1,002,637                | 1         | 1,685,878          |        |
|   | <b>2</b> Savings and temporary cash investments  |                          | 2         |                    |        |
|   | <b>3</b> Pledges and grants receivable, net  | 160,544                  | 3         | 125,000            |        |
|   | <b>4</b> Accounts receivable, net  |                          | 4         |                    |        |
|   | <b>5</b> Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L   |                          | 5         |                    |        |
|   | <b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions). Complete Part II of Schedule L |                          | 6         |                    |        |
|   | <b>7</b> Notes and loans receivable, net   |                          | 7         |                    |        |
|   | <b>8</b> Inventories for sale or use   |                          | 8         |                    |        |
|   | <b>9</b> Prepaid expenses and deferred charges   | 8,789                    | 9         | 7,650              |        |
|   | <b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D   | 10a 55,718               |           |                    |        |
|   | <b>b</b> Less: accumulated depreciation  | 10b 38,483               | 19,474    | 10c                | 17,235 |
|   | <b>11</b> Investments - publicly traded securities   |                          | 11        |                    |        |
|   | <b>12</b> Investments - other securities. See Part IV, line 11   |                          | 12        |                    |        |
|   | <b>13</b> Investments - program-related. See Part IV, line 11  |                          | 13        |                    |        |
|   | <b>14</b> Intangible assets  |                          | 14        |                    |        |
|   | <b>15</b> Other assets. See Part IV, line 11   |                          | 15        |                    |        |
| <b>16 Total assets.</b> Add lines 1 through 15 (must equal line 34)   |  | 1,191,444                | 16        | 1,835,763          |        |
| <b>Liabilities</b>  | <b>17</b> Accounts payable and accrued expenses  | 28,554                   | 17        | 73,731             |        |
|   | <b>18</b> Grants payable   | 363,888                  | 18        |                    |        |
|   | <b>19</b> Deferred revenue   |                          | 19        |                    |        |
|   | <b>20</b> Tax-exempt bond liabilities  |                          | 20        |                    |        |
|   | <b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D  |                          | 21        |                    |        |
|   | <b>22</b> Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L   |                          | 22        |                    |        |
|   | <b>23</b> Secured mortgages and notes payable to unrelated third parties   |                          | 23        |                    |        |
|   | <b>24</b> Unsecured notes and loans payable to unrelated third parties   |                          | 24        |                    |        |
| <b>25</b> Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D |  | 25                       |           |                    |        |
| <b>26 Total liabilities.</b> Add lines 17 through 25  |  | 392,442                  | 26        | 73,731             |        |
| <b>Net Assets or Fund Balances</b>  | <b>Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.</b>   |                          |           |                    |        |
|   | <b>27</b> Unrestricted net assets  | (47,139)                 | 27        | 641,278            |        |
|   | <b>28</b> Temporarily restricted net assets  | 846,141                  | 28        | 1,120,754          |        |
|   | <b>29</b> Permanently restricted net assets  |                          | 29        |                    |        |
|   | <b>Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34.</b>  |                          |           |                    |        |
|   | <b>30</b> Capital stock or trust principal, or current funds   |                          | 30        |                    |        |
|   | <b>31</b> Paid-in or capital surplus, or land, building, or equipment fund   |                          | 31        |                    |        |
|   | <b>32</b> Retained earnings, endowment, accumulated income, or other funds   |                          | 32        |                    |        |
| <b>33</b> Total net assets or fund balances   | 799,002  | 33                       | 1,762,032 |                    |        |
| <b>34</b> Total liabilities and net assets/fund balances  | 1,191,444  | 34                       | 1,835,763 |                    |        |

**Part XI Reconciliation of Net Assets**

Check if Schedule O contains a response or note to any line in this Part XI

|           |  |           |                  |
|-----------|--|-----------|------------------|
| <b>1</b>  | Total revenue (must equal Part VIII, column (A), line 12)  | <b>1</b>  | <b>3,138,829</b> |
| <b>2</b>  | Total expenses (must equal Part IX, column (A), line 25)   | <b>2</b>  | <b>2,539,687</b> |
| <b>3</b>  | Revenue less expenses. Subtract line 2 from line 1   | <b>3</b>  | <b>599,142</b>   |
| <b>4</b>  | Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))                      | <b>4</b>  | <b>799,002</b>   |
| <b>5</b>  | Net unrealized gains (losses) on investments   | <b>5</b>  |                  |
| <b>6</b>  | Donated services and use of facilities   | <b>6</b>  |                  |
| <b>7</b>  | Investment expenses  | <b>7</b>  |                  |
| <b>8</b>  | Prior period adjustments   | <b>8</b>  | <b>363,888</b>   |
| <b>9</b>  | Other changes in net assets or fund balances (explain in Schedule O)   | <b>9</b>  | <b>0</b>         |
| <b>10</b> | Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B)) | <b>10</b> | <b>1,762,032</b> |

**Part XII Financial Statements and Reporting**

Check if Schedule O contains a response or note to any line in this Part XII

|           |   | Yes | No |
|-----------|---|-----|----|
| <b>1</b>  | Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____<br>If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.   |     |    |
| <b>2a</b> | Were the organization's financial statements compiled or reviewed by an independent accountant? . . . . .<br>If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both:<br><input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis |     | X  |
| <b>b</b>  | Were the organization's financial statements audited by an independent accountant? . . . . .<br>If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both:<br><input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis                | X   |    |
| <b>c</b>  | If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? . . . . .<br>If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.   | X   |    |
| <b>3a</b> | As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? . . . . .  |     | X  |
| <b>b</b>  | If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits . . . . .  |     |    |

**SCHEDULE A**  
**(Form 990 or 990-EZ)**

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

▶ Attach to Form 990 or Form 990-EZ.

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2017**

**Open to Public Inspection**

Name of the organization

Employer identification number

**Charcot-Marie-Tooth Association**

**22-2480896**

**Part I Reason for Public Charity Status** (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1  A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i)**.
- 2  A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E (Form 990 or 990-EZ).)
- 3  A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.
- 4  A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state: \_\_\_\_\_
- 5  An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6  A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7  An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8  A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 9  An agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: \_\_\_\_\_
- 10  An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions - subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 11  An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12  An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2)**. See **section 509(a)(3)**. Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
  - a  **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
  - b  **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
  - c  **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
  - d  **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
  - e  Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
  - f Enter the number of supported organizations . . . . .
  - g Provide the following information about the supported organization(s).

| (i) Name of supported organization | (ii) EIN | (iii) Type of organization (described on lines 1-10 above (see instructions)) | (iv) Is the organization listed in your governing document? |    | (v) Amount of monetary support (see instructions) | (vi) Amount of other support (see instructions) |
|------------------------------------|----------|---|---|----|---|---|
|                                    |          |   | Yes   | No |   |   |
| (A)                                |          |   |   |    |   |   |
| (B)                                |          |   |   |    |   |   |
| (C)                                |          |   |   |    |   |   |
| (D)                                |          |   |   |    |   |   |
| (E)                                |          |   |   |    |   |   |
| <b>Total</b>                       |          |   |   |    |   |   |

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Table with 7 columns: (a) 2013, (b) 2014, (c) 2015, (d) 2016, (e) 2017, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Tax revenues levied for the organization's benefit; 3 The value of services or facilities furnished by a governmental unit; 4 Total. Add lines 1 through 3; 5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f); 6 Public support. Subtract line 5 from line 4.

Section B. Total Support

Table with 7 columns: (a) 2013, (b) 2014, (c) 2015, (d) 2016, (e) 2017, (f) Total. Rows include: 7 Amounts from line 4; 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources; 9 Net income from unrelated business activities, whether or not the business is regularly carried on; 10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.); 11 Total support. Add lines 7 through 10; 12 Gross receipts from related activities, etc. (see instructions); 13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here.

Section C. Computation of Public Support Percentage

Table with 3 columns: Line number, Description, and Percentage. Rows include: 14 Public support percentage for 2017 (line 6, column (f) divided by line 11, column (f)); 15 Public support percentage from 2016 Schedule A, Part II, line 14; 16a 33 1/3% support test - 2017. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization; b 33 1/3% support test - 2016. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization; 17a 10%-facts-and-circumstances test - 2017. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization; b 10%-facts-and-circumstances test - 2016. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization; 18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions.

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Table with 7 columns: (a) 2013, (b) 2014, (c) 2015, (d) 2016, (e) 2017, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions, merchandise sold or services performed; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total. Add lines 1 through 5; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 7c Add lines 7a and 7b; 8 Public support. (Subtract line 7c from line 6.)

Section B. Total Support

Table with 7 columns: (a) 2013, (b) 2014, (c) 2015, (d) 2016, (e) 2017, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 10c Add lines 10a and 10b; 11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on; 12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.); 13 Total support. (Add lines 9, 10c, 11, and 12.)

14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here

Section C. Computation of Public Support Percentage

Table with 3 columns: Line number, Percentage, and Total percentage. Rows include: 15 Public support percentage for 2017 (line 8, column (f) divided by line 13, column (f)); 16 Public support percentage from 2016 Schedule A, Part III, line 15

Section D. Computation of Investment Income Percentage

Table with 3 columns: Line number, Percentage, and Total percentage. Rows include: 17 Investment income percentage for 2017 (line 10c, column (f) divided by line 13, column (f)); 18 Investment income percentage from 2016 Schedule A, Part III, line 17

19a 33 1/3% support tests - 2017. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization

b 33 1/3% support tests - 2016. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions



**Schedule B**  
(Form 990, 990-EZ,  
or 990-PF)

Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

OMB No. 1545-0047

**2017**

- ▶ Attach to Form 990, Form 990-EZ, or Form 990-PF.
- ▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

|   |  |
|---|--|
| <b>Name of the organization</b><br><b>Charcot-Marie-Tooth Association</b> | <b>Employer identification number</b><br><b>22-2480896</b> |
|---|--|

**Organization type** (check one):

**Filers of:**

**Section:**

- |                    |   |
|--------------------|---|
| Form 990 or 990-EZ | <input checked="" type="checkbox"/> 501(c)( <b>3</b> ) (enter number) organization                        |
|                    | <input type="checkbox"/> 4947(a)(1) nonexempt charitable trust <b>not</b> treated as a private foundation |
|                    | <input type="checkbox"/> 527 political organization   |
| Form 990-PF        | <input type="checkbox"/> 501(c)(3) exempt private foundation  |
|                    | <input type="checkbox"/> 4947(a)(1) nonexempt charitable trust treated as a private foundation            |
|                    | <input type="checkbox"/> 501(c)(3) taxable private foundation   |

Check if your organization is covered by the **General Rule** or a **Special Rule**.

**Note:** Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

**General Rule**

- For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

**Special Rules**

- For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of **(1)** \$5,000 or **(2)** 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.
- For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I, II, and III.
- For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year . . . . . ▶ \$ \_\_\_\_\_

**Caution:** An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990, 990-EZ, or 990-PF), but it **must** answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).





**SCHEDULE C**  
**(Form 990 or 990-EZ)**

**Political Campaign and Lobbying Activities**

OMB No. 1545-0047

**2017**

For Organizations Exempt From Income Tax Under section 501(c) and section 527

- ▶ **Complete if the organization is described below.**
- ▶ **Attach to Form 990 or Form 990-EZ.**
- ▶ **Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

**If the organization answered "Yes," on Form 990, Part IV, line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then**

- Section 501(c)(3) organizations: Complete Parts I-A and B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and C below. Do not complete Part I-B.
- Section 527 organizations: Complete Part I-A only.

**If the organization answered "Yes," on Form 990, Part IV, line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then**

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B.
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B. Do not complete Part II-A.

**If the organization answered "Yes," on Form 990, Part IV, line 5 (Proxy Tax) (see separate instructions) or Form 990-EZ, Part V, line 35c (Proxy Tax) (see separate instructions), then**

- Section 501(c)(4), (5), or (6) organizations: Complete Part III.

|  |   |
|--|---|
| Name of organization<br><b>Charcot-Marie-Tooth Association</b> | Employer identification number<br><b>22-2480896</b> |
|--|---|

**Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.**

- 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV. (see instructions for definition of "political campaign activities")
- 2 Political campaign activity expenditures (see instructions) . . . . . ▶ \$ \_\_\_\_\_
- 3 Volunteer hours for political campaign activities (see instructions) . . . . .

**Part I-B Complete if the organization is exempt under section 501(c)(3).**

- 1 Enter the amount of any excise tax incurred by the organization under section 4955 . . . . . ▶ \$ \_\_\_\_\_
- 2 Enter the amount of any excise tax incurred by organization managers under section 4955 . . . . . ▶ \$ \_\_\_\_\_
- 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? . . . . .  **Yes**  **No**
- 4a Was a correction made? . . . . .  **Yes**  **No**
- b If "Yes," describe in Part IV.

**Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).**

- 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities . . . . . ▶ \$ \_\_\_\_\_
- 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities . . . . . ▶ \$ \_\_\_\_\_
- 3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL, line 17b . . . . . ▶ \$ \_\_\_\_\_
- 4 Did the filing organization file **Form 1120-POL** for this year? . . . . .  **Yes**  **No**
- 5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC). If additional space is needed, provide information in Part IV.

| (a) Name | (b) Address | (c) EIN | (d) Amount paid from filing organization's funds. If none, enter -0-. | (e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-. |
|----------|-------------|---------|---|--|
| (1)      | -----       |         |   |  |
| (2)      | -----       |         |   |  |
| (3)      | -----       |         |   |  |
| (4)      | -----       |         |   |  |
| (5)      | -----       |         |   |  |
| (6)      | -----       |         |   |  |

**Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).**

**A** Check  if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).

**B** Check  if the filing organization checked box A and "limited control" provisions apply.

| <b>Limits on Lobbying Expenditures</b><br><b>(The term "expenditures" means amounts paid or incurred.)</b>  |   | <b>(a) Filing organization's totals</b>                | <b>(b) Affiliated group totals</b>  |                    |                               |   |  |   |  |  |   |                   |              |  |  |
|---|---|--|---|--------------------|-------------------------------|---|--|---|--|--|---|-------------------|--------------|--|--|
| <b>1a</b>   | Total lobbying expenditures to influence public opinion (grass roots lobbying) . . . . .  |  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| <b>b</b>  | Total lobbying expenditures to influence a legislative body (direct lobbying) . . . . .   | <b>30,520</b>  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| <b>c</b>  | Total lobbying expenditures (add lines 1a and 1b) . . . . .   | <b>30,520</b>  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| <b>d</b>  | Other exempt purpose expenditures . . . . .   | <b>2,332,560</b>                                       |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| <b>e</b>  | Total exempt purpose expenditures (add lines 1c and 1d) . . . . .   | <b>2,363,080</b>                                       |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| <b>f</b>  | Lobbying nontaxable amount. Enter the amount from the following table in both columns.  | <b>268,154</b>   |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| <table border="1"> <thead> <tr> <th><b>If the amount on line 1e, column (a) or (b) is:</b></th> <th><b>The lobbying nontaxable amount is:</b></th> </tr> </thead> <tbody> <tr> <td>Not over \$500,000</td> <td>20% of the amount on line 1e.</td> </tr> <tr> <td>Over \$500,000 but not over \$1,000,000</td> <td>\$100,000 plus 15% of the excess over \$500,000.</td> </tr> <tr> <td>Over \$1,000,000 but not over \$1,500,000</td> <td>\$175,000 plus 10% of the excess over \$1,000,000.</td> </tr> <tr> <td>Over \$1,500,000 but not over \$17,000,000</td> <td>\$225,000 plus 5% of the excess over \$1,500,000.</td> </tr> <tr> <td>Over \$17,000,000</td> <td>\$1,000,000.</td> </tr> </tbody> </table> |   | <b>If the amount on line 1e, column (a) or (b) is:</b> | <b>The lobbying nontaxable amount is:</b>   | Not over \$500,000 | 20% of the amount on line 1e. | Over \$500,000 but not over \$1,000,000 | \$100,000 plus 15% of the excess over \$500,000. | Over \$1,000,000 but not over \$1,500,000 | \$175,000 plus 10% of the excess over \$1,000,000. | Over \$1,500,000 but not over \$17,000,000 | \$225,000 plus 5% of the excess over \$1,500,000. | Over \$17,000,000 | \$1,000,000. |  |  |
| <b>If the amount on line 1e, column (a) or (b) is:</b>  | <b>The lobbying nontaxable amount is:</b>   |  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| Not over \$500,000  | 20% of the amount on line 1e.   |  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| Over \$500,000 but not over \$1,000,000   | \$100,000 plus 15% of the excess over \$500,000.  |  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| Over \$1,000,000 but not over \$1,500,000   | \$175,000 plus 10% of the excess over \$1,000,000.  |  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| Over \$1,500,000 but not over \$17,000,000  | \$225,000 plus 5% of the excess over \$1,500,000.   |  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| Over \$17,000,000   | \$1,000,000.  |  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| <b>g</b>  | Grassroots nontaxable amount (enter 25% of line 1f) . . . . .   | <b>67,039</b>  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| <b>h</b>  | Subtract line 1g from line 1a. If zero or less, enter -0- . . . . .   |  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| <b>i</b>  | Subtract line 1f from line 1c. If zero or less, enter -0- . . . . .   |  |   |                    |                               |   |  |   |  |  |   |                   |              |  |  |
| <b>j</b>  | If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year? . . . . . |  | <input checked="" type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>No</b> |                    |                               |   |  |   |  |  |   |                   |              |  |  |

**4-Year Averaging Period Under section 501(h)**  
**(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the separate instructions for lines 2a through 2f.)**

| <b>Lobbying Expenditures During 4-Year Averaging Period</b>      |                 |                 |                 |                 |                  |
|--|-----------------|-----------------|-----------------|-----------------|------------------|
| Calendar year (or fiscal year beginning in)                      | <b>(a) 2014</b> | <b>(b) 2015</b> | <b>(c) 2016</b> | <b>(d) 2017</b> | <b>(e) Total</b> |
| <b>2a</b> Lobbying nontaxable amount                             | <b>269,312</b>  | <b>314,955</b>  | <b>293,971</b>  | <b>268,154</b>  | <b>1,146,392</b> |
| <b>b</b> Lobbying ceiling amount (150% of line 2a, column (e))   |                 |                 |                 |                 | <b>1,719,588</b> |
| <b>c</b> Total lobbying expenditures                             | <b>26,250</b>   | <b>30,300</b>   | <b>31,725</b>   | <b>30,520</b>   | <b>118,795</b>   |
| <b>d</b> Grassroots nontaxable amount                            | <b>67,328</b>   | <b>78,739</b>   | <b>73,493</b>   | <b>67,039</b>   | <b>286,599</b>   |
| <b>e</b> Grassroots ceiling amount (150% of line 2d, column (e)) |                 |                 |                 |                 | <b>429,899</b>   |
| <b>f</b> Grassroots lobbying expenditures                        |                 |                 |                 |                 |                  |

Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes," response on lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.

Table with 3 main columns: (a) Yes/No, (b) Amount. Rows include: 1 During the year, did the filing organization attempt to influence foreign, national, state or local legislation...; 2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?; 2b If "Yes," enter the amount of any tax incurred under section 4912; 2c If "Yes," enter the amount of any tax incurred by organization managers under section 4912; 2d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

Table with 3 columns: Question, Yes, No. Rows include: 1 Were substantially all (90% or more) dues received nondeductible by members?; 2 Did the organization make only in-house lobbying expenditures of \$2,000 or less?; 3 Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year?

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No," OR (b) Part III-A, line 3, is answered "Yes."

Table with 2 main columns: Question, Amount. Rows include: 1 Dues, assessments and similar amounts from members; 2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid); 3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues; 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditure next year?; 5 Taxable amount of lobbying and political expenditures (see instructions)

Part IV Supplemental Information

Provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, lines 1 and 2 (see instructions); and Part II-B, line 1. Also, complete this part for any additional information.

Blank lines for providing supplemental information as required by the instructions.

SCHEDULE D (Form 990)

Supplemental Financial Statements

OMB No. 1545-0047

Complete if the organization answered "Yes" on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.

2017

Attach to Form 990.

Open to Public Inspection

Go to www.irs.gov/Form990 for instructions and the latest information.

Department of the Treasury Internal Revenue Service

Name of the organization Charcot-Marie-Tooth Association Employer identification number 22-2480896

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.

Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

Table with 2 columns: (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate value of contributions, grants, and end of year, and two questions about donor advisement.

Part II Conservation Easements.

Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

Table with 2 columns: Description, Held at the End of the Tax Year. Rows include purpose(s) of conservation easements, total number, acreage, and other details.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.

Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

Table with 2 columns: Description, Amount. Rows include questions about reporting works of art and historical treasures.

**Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets** (continued)

- 3** Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):
- a**  Public exhibition
  - b**  Scholarly research
  - c**  Preservation for future generations
  - d**  Loan or exchange programs
  - e**  Other \_\_\_\_\_
- 4** Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5** During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?  Yes  No

**Part IV Escrow and Custodial Arrangements.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a** Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?  Yes  No
- b** If "Yes," explain the arrangement in Part XIII and complete the following table:
- |  | Amount    |
|--|-----------|
| <b>c</b> Beginning balance             | <b>1c</b> |
| <b>d</b> Additions during the year     | <b>1d</b> |
| <b>e</b> Distributions during the year | <b>1e</b> |
| <b>f</b> Ending balance                | <b>1f</b> |
- 2a** Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?  Yes  No
- b** If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided on Part XIII

**Part V Endowment Funds.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

|   | (a) Current year | (b) Prior year | (c) Two years back | (d) Three years back | (e) Four years back |
|---|------------------|----------------|--------------------|----------------------|---------------------|
| <b>1a</b> Beginning of year balance                     |                  |                |                    |                      |                     |
| <b>b</b> Contributions                                  |                  |                |                    |                      |                     |
| <b>c</b> Net investment earnings, gains, and losses     |                  |                |                    |                      |                     |
| <b>d</b> Grants or scholarships                         |                  |                |                    |                      |                     |
| <b>e</b> Other expenditures for facilities and programs |                  |                |                    |                      |                     |
| <b>f</b> Administrative expenses                        |                  |                |                    |                      |                     |
| <b>g</b> End of year balance                            |                  |                |                    |                      |                     |

- 2** Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a** Board designated or quasi-endowment  \_\_\_\_\_ %
  - b** Permanent endowment  \_\_\_\_\_ %
  - c** Temporarily restricted endowment  \_\_\_\_\_ %
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a** Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- |  | Yes           | No |
|--|---------------|----|
| <b>(i)</b> unrelated organizations   | <b>3a(i)</b>  |    |
| <b>(ii)</b> related organizations  | <b>3a(ii)</b> |    |
| <b>b</b> If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R? | <b>3b</b>     |    |
- 4** Describe in Part XIII the intended uses of the organization's endowment funds.

**Part VI Land, Buildings, and Equipment.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

| Description of property  | (a) Cost or other basis (investment) | (b) Cost or other basis (other) | (c) Accumulated depreciation | (d) Book value |
|--|--------------------------------------|---------------------------------|------------------------------|----------------|
| <b>1a</b> Land   |                                      |                                 |                              |                |
| <b>b</b> Buildings   |                                      |                                 |                              |                |
| <b>c</b> Leasehold improvements  |                                      |                                 |                              |                |
| <b>d</b> Equipment   |                                      | 55,718                          | 38,483                       | 17,235         |
| <b>e</b> Other   |                                      |                                 |                              |                |
| <b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.) |                                      |                                 |                              | 17,235         |



**Part VII Investments - Other Securities.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

| (a) Description of security or category<br>(including name of security)     | (b) Book value | (c) Method of valuation:<br>Cost or end-of-year market value |
|---|----------------|--|
| (1) Financial derivatives . . . . .   |                |  |
| (2) Closely-held equity interests . . . . .                                 |                |  |
| (3) Other _____   |                |  |
| (A) _____   |                |  |
| (B) _____   |                |  |
| (C) _____   |                |  |
| (D) _____   |                |  |
| (E) _____   |                |  |
| (F) _____   |                |  |
| (G) _____   |                |  |
| (H) _____   |                |  |
| <b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 12.) ▶ |                |  |

**Part VIII Investments - Program Related.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

| (a) Description of investment   | (b) Book value | (c) Method of valuation:<br>Cost or end-of-year market value |
|---|----------------|--|
| (1) _____   |                |  |
| (2) _____   |                |  |
| (3) _____   |                |  |
| (4) _____   |                |  |
| (5) _____   |                |  |
| (6) _____   |                |  |
| (7) _____   |                |  |
| (8) _____   |                |  |
| (9) _____   |                |  |
| <b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 13.) ▶ |                |  |

**Part IX Other Assets.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

| (a) Description   | (b) Book value |
|---|----------------|
| (1) _____   |                |
| (2) _____   |                |
| (3) _____   |                |
| (4) _____   |                |
| (5) _____   |                |
| (6) _____   |                |
| (7) _____   |                |
| (8) _____   |                |
| (9) _____   |                |
| <b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 15.) . . . . . ▶ |                |

**Part X Other Liabilities.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

| 1. (a) Description of liability   | (b) Book value |  |
|---|----------------|--|
| (1) Federal income taxes  |                |  |
| (2) _____   |                |  |
| (3) _____   |                |  |
| (4) _____   |                |  |
| (5) _____   |                |  |
| (6) _____   |                |  |
| (7) _____   |                |  |
| (8) _____   |                |  |
| (9) _____   |                |  |
| <b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶ |                |  |

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII . . . . .

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

Table with 5 main rows and sub-rows (a-e) for adjustments. Total revenue reported as 3,138,829.

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

Table with 5 main rows and sub-rows (a-e) for adjustments. Total expenses reported as 2,539,687.

Part XIII Supplemental Information.

Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

Series of horizontal lines for providing supplemental information.

**SCHEDULE F  
(Form 990)**

**Statement of Activities Outside the United States**

OMB No. 1545-0047

**2017**

▶ **Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.**

▶ **Attach to Form 990.**

▶ **Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

Name of the organization

Employer identification number

**Charcot-Marie-Tooth Association**

**22-2480896**

**Part I General Information on Activities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

**1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? . . . . .  **Yes**  **No**

**2 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

**3 Activities per Region.** (The following Part I, line 3 table can be duplicated if additional space is needed.)

| (a) Region  | (b) Number of offices in the region | (c) Number of employees, agents, and independent contractors in the region | (d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region) | (e) If activity listed in (d) is a program service, describe specific type of service(s) in the region | (f) Total expenditures for and investments in the region |
|---|-------------------------------------|--|--|--|--|
| <b>Europe (including (1)Iceland and Greenland)</b>          |                                     | <b>1</b>   | <b>Grant making</b>  | <b>grant making</b>  | <b>75,145</b>  |
| (2)   |                                     |  |  |  |  |
| (3)   |                                     |  |  |  |  |
| (4)   |                                     |  |  |  |  |
| (5)   |                                     |  |  |  |  |
| (6)   |                                     |  |  |  |  |
| (7)   |                                     |  |  |  |  |
| (8)   |                                     |  |  |  |  |
| (9)   |                                     |  |  |  |  |
| (10)  |                                     |  |  |  |  |
| (11)  |                                     |  |  |  |  |
| (12)  |                                     |  |  |  |  |
| (13)  |                                     |  |  |  |  |
| (14)  |                                     |  |  |  |  |
| (15)  |                                     |  |  |  |  |
| (16)  |                                     |  |  |  |  |
| (17)  |                                     |  |  |  |  |
| <b>3a Sub-total . . . . .</b>                               |                                     | <b>1</b>   |  |  | <b>75,145</b>  |
| <b>b Total from continuation sheets to Part I . . . . .</b> |                                     |  |  |  |  |
| <b>c Totals (add lines 3a and 3b)</b>                       |                                     | <b>1</b>   |  |  | <b>75,145</b>  |

**For Paperwork Reduction Act Notice, see the Instructions for Form 990.**

Schedule F (Form 990) 2017

**Part II** **Grants and Other Assistance to Organizations or Entities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

| 1    | (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region                               | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of noncash assistance | (h) Description of noncash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
|------|--------------------------|--|--|----------------------|--------------------------|---------------------------------|----------------------------------|---------------------------------------|---|
| (1)  |                          |  | Europe (including Iceland and Greenland) | High Dosag           | 14,949                   | wire trans                      |                                  | n/a                                   | Fair marke  |
| (2)  |                          |  | Europe (including Iceland and Greenland) | Genetherap           | 43,449                   | wire trans                      |                                  | n/a                                   | Fair marke  |
| (3)  |                          |  | Europe (including Iceland and Greenland) | Genetherap           | 16,747                   | wire trans                      |                                  | n/a                                   | Fair marke  |
| (4)  |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (5)  |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (6)  |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (7)  |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (8)  |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (9)  |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (10) |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (11) |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (12) |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (13) |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (14) |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (15) |                          |  |  |                      |                          |                                 |                                  |                                       |   |
| (16) |                          |  |  |                      |                          |                                 |                                  |                                       |   |

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter . . . . . ▶ 3

3 Enter total number of other organizations or entities . . . . . ▶ \_\_\_\_\_

**Part III** **Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 16.  
 Part III can be duplicated if additional space is needed.

| (a) Type of grant or assistance | (b) Region | (c) Number of recipients | (d) Amount of cash grant | (e) Manner of cash disbursement | (f) Amount of noncash assistance | (g) Description of noncash assistance | (h) Method of valuation (book, FMV, appraisal, other) |
|---------------------------------|------------|--------------------------|--------------------------|---------------------------------|----------------------------------|---------------------------------------|---|
| (1)                             |            |                          |                          |                                 |                                  |                                       |   |
| (2)                             |            |                          |                          |                                 |                                  |                                       |   |
| (3)                             |            |                          |                          |                                 |                                  |                                       |   |
| (4)                             |            |                          |                          |                                 |                                  |                                       |   |
| (5)                             |            |                          |                          |                                 |                                  |                                       |   |
| (6)                             |            |                          |                          |                                 |                                  |                                       |   |
| (7)                             |            |                          |                          |                                 |                                  |                                       |   |
| (8)                             |            |                          |                          |                                 |                                  |                                       |   |
| (9)                             |            |                          |                          |                                 |                                  |                                       |   |
| (10)                            |            |                          |                          |                                 |                                  |                                       |   |
| (11)                            |            |                          |                          |                                 |                                  |                                       |   |
| (12)                            |            |                          |                          |                                 |                                  |                                       |   |
| (13)                            |            |                          |                          |                                 |                                  |                                       |   |
| (14)                            |            |                          |                          |                                 |                                  |                                       |   |
| (15)                            |            |                          |                          |                                 |                                  |                                       |   |
| (16)                            |            |                          |                          |                                 |                                  |                                       |   |
| (17)                            |            |                          |                          |                                 |                                  |                                       |   |
| (18)                            |            |                          |                          |                                 |                                  |                                       |   |

**Part IV Foreign Forms**

- 1** Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)* . . . . .  Yes  No
- 2** Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990)* . . . . .  Yes  No
- 3** Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain Foreign Corporations (see Instructions for Form 5471)* . . . . .  Yes  No
- 4** Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)* . . . . .  Yes  No
- 5** Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865)* . . . . .  Yes  No
- 6** Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990)* . . . . .  Yes  No

**Part V Supplemental Information**

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

**01. Use of grant monitoring procedures (Part I, line 2)**

CMTA requires by contract period progress reports on the funded research. Its contracts

also include a full research plan with budgets & deliverables.

Multiple horizontal lines for supplemental information.

**SCHEDULE G  
(Form 990 or 990-EZ)**

Department of the Treasury  
Internal Revenue Service

**Supplemental Information Regarding Fundraising or Gaming Activities**

Complete if the organization answered "Yes" on Form 990, Part IV, line 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.

▶ Attach to Form 990 or Form 990-EZ.  
▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest instructions.

OMB No. 1545-0047

**2017**

**Open to Public  
Inspection**

Name of the organization

**Charcot-Marie-Tooth Association**

Employer identification number

**22-2480896**

**Part I Fundraising Activities.** Complete if the organization answered "Yes" on Form 990, Part IV, line 17.  
Form 990-EZ filers are not required to complete this part.

**1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.

- a  Mail solicitations
- b  Internet and email solicitations
- c  Phone solicitations
- d  In-person solicitations
- e  Solicitation of non-government grants
- f  Solicitation of government grants
- g  Special fundraising events

**2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees, or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?  **Yes**  **No**

**b** If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

| (i) Name and address of individual or entity (fundraiser) | (ii) Activity | (iii) Did fundraiser have custody or control of contributions? |    | (iv) Gross receipts from activity | (v) Amount paid to (or retained by) fundraiser listed in col. (i) | (vi) Amount paid to (or retained by) organization |
|---|---------------|--|----|-----------------------------------|---|---|
|   |               | Yes  | No |                                   |   |   |
| <b>1</b>  |               |  |    |                                   |   |   |
| <b>2</b>  |               |  |    |                                   |   |   |
| <b>3</b>  |               |  |    |                                   |   |   |
| <b>4</b>  |               |  |    |                                   |   |   |
| <b>5</b>  |               |  |    |                                   |   |   |
| <b>6</b>  |               |  |    |                                   |   |   |
| <b>7</b>  |               |  |    |                                   |   |   |
| <b>8</b>  |               |  |    |                                   |   |   |
| <b>9</b>  |               |  |    |                                   |   |   |
| <b>10</b>   |               |  |    |                                   |   |   |
| <b>Total</b> .....  |               |  |    |                                   |   |   |

**3** List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

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**Part II Fundraising Events.** Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

|  |   | (a) Event #1                    | (b) Event #2                    | (c) Other events           | (d) Total events                |
|--|---|---------------------------------|---------------------------------|----------------------------|---------------------------------|
|  |   | <b>All Star</b><br>(event type) | <b>NY Event</b><br>(event type) | <b>2</b><br>(total number) | (add col. (a) through col. (c)) |
| Revenue  | <b>1</b> Gross receipts . . . . .   | 222,376                         | 232,509                         | 253,592                    | 708,477                         |
|  | <b>2</b> Less: Contributions . . . . .  |                                 |                                 |                            |                                 |
|  | <b>3</b> Gross income (line 1 minus line 2) . . . . .                             | 222,376                         | 232,509                         | 253,592                    | 708,477                         |
| Direct Expenses  | <b>4</b> Cash prizes . . . . .  |                                 |                                 |                            |                                 |
|  | <b>5</b> Noncash prizes . . . . .   |                                 |                                 |                            |                                 |
|  | <b>6</b> Rent/facility costs . . . . .  |                                 |                                 |                            |                                 |
|  | <b>7</b> Food and beverages . . . . .   |                                 |                                 |                            |                                 |
|  | <b>8</b> Entertainment . . . . .  |                                 |                                 |                            |                                 |
|  | <b>9</b> Other direct expenses . . . . .  | 74,108                          | 54,522                          | 24,387                     | 153,017                         |
|  | <b>10</b> Direct expense summary. Add lines 4 through 9 in column (d) . . . . . ▶ |                                 |                                 |                            | 153,017                         |
| <b>11</b> Net income summary. Subtract line 10 from line 3, column (d) . . . . . ▶ |   |                                 |                                 | 555,460                    |                                 |

**Part III Gaming.** Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

|   |  | (a) Bingo   | (b) Pull tabs/instant bingo/progressive bingo                       | (c) Other gaming  | (d) Total gaming (add col. (a) through col. (c)) |
|---|--|---|---|---|--|
|   |  | <b>1</b> Gross revenue . . . . .                                    |   |   |  |
| Direct Expenses   | <b>2</b> Cash prizes . . . . .           |   |   |   |  |
|   | <b>3</b> Noncash prizes . . . . .        |   |   |   |  |
|   | <b>4</b> Rent/facility costs . . . . .   |   |   |   |  |
|   | <b>5</b> Other direct expenses . . . . . |   |   |   |  |
|   | <b>6</b> Volunteer labor . . . . .       | <input type="checkbox"/> Yes _____ %<br><input type="checkbox"/> No | <input type="checkbox"/> Yes _____ %<br><input type="checkbox"/> No | <input type="checkbox"/> Yes _____ %<br><input type="checkbox"/> No |  |
| <b>7</b> Direct expense summary. Add lines 2 through 5 in column (d) . . . . . ▶        |  |   |   |   |  |
| <b>8</b> Net gaming income summary. Subtract line 7 from line 1, column (d) . . . . . ▶ |  |   |   |   |  |

**9** Enter the state(s) in which the organization conducts gaming activities: \_\_\_\_\_  
**a** Is the organization licensed to conduct gaming activities in each of these states? . . . . .  Yes  No  
**b** If "No," explain: \_\_\_\_\_

**10a** Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? . . . . .  Yes  No  
**b** If "Yes," explain: \_\_\_\_\_

**SCHEDULE I  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Grants and Other Assistance to Organizations,  
Governments, and Individuals in the United States**  
Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.  
▶ Attach to Form 990.  
▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2017**

**Open to Public  
Inspection**

Name of the organization

**Charcot-Marie-Tooth Association**

Employer identification number

**22-2480896**

**Part I General Information on Grants and Assistance**

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? . . . . .  **Yes**  **No**
- 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

**Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments.** Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

| 1    | (a) Name and address of organization or government  | (b) EIN           | (c) IRC section (if applicable) | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of noncash assistance | (h) Purpose of grant or assistance |
|------|---|-------------------|---------------------------------|--------------------------|-----------------------------------|---|---------------------------------------|------------------------------------|
| (1)  | <b>UB Foundation Services, Inc<br/>PO Box 900<br/>Buffalo, NY 14226</b>                     | <b>16-0865182</b> |                                 | <b>91,104</b>            |                                   | <b>cash</b>   |                                       | <b>CMT Research</b>                |
| (2)  | <b>University of Iowa-Carver C<br/>200 Hawkins Drive 2007 RCP<br/>Iowa City, IA 52242</b>   | <b>42-6004813</b> |                                 | <b>56,484</b>            |                                   | <b>cash</b>   |                                       | <b>CMT Research</b>                |
| (3)  | <b>University of Miami<br/>PO Box 405803<br/>Atlanta, GA 30384</b>                          | <b>59-0624458</b> |                                 | <b>56,484</b>            |                                   | <b>cash</b>   |                                       | <b>CMT Research</b>                |
| (4)  | <b>University of Missouri Colu<br/>115 Business Loop 70W, Mizzou<br/>Columbia, MO 65211</b> | <b>43-6003859</b> |                                 | <b>44,620</b>            |                                   | <b>cash</b>   |                                       | <b>CMT Research</b>                |
| (5)  | <b>University of Pennsylvania<br/>PO Box 785541<br/>Philadelphia, PA 19178</b>              | <b>23-1352685</b> |                                 | <b>93,706</b>            |                                   | <b>cash</b>   |                                       | <b>CMT Research</b>                |
| (6)  | <b>University of Wisconsin Mad<br/>21 N. Park Street, Suite 6401<br/>Madison, WI 53715</b>  | <b>39-6006492</b> |                                 | <b>12,500</b>            |                                   | <b>cash</b>   |                                       | <b>CMT Research</b>                |
| (7)  | <b>Cedars-Sinai Medical Center<br/>8700 Beverly Blvd.<br/>Los Angeles, CA 90048</b>         | <b>95-1644600</b> |                                 | <b>72,021</b>            |                                   | <b>cash</b>   |                                       | <b>CMT Research</b>                |
| (8)  | <b>Columbia University<br/>622 W 113th Street<br/>New York, NY 10025</b>                    | <b>13-5598093</b> |                                 | <b>60,964</b>            |                                   | <b>cash</b>   |                                       | <b>CMT Research</b>                |
| (9)  | <b>MDA<br/>8400 E. Grant Road 170<br/>Tucson, AZ 85715</b>                                  | <b>13-1665552</b> |                                 | <b>28,897</b>            |                                   | <b>cash</b>   |                                       | <b>CMT Research</b>                |
| (10) | <b>not itemized</b>   |                   |                                 | <b>2,355</b>             |                                   | <b>cash</b>   | <b>n/a</b>                            | <b>CMT Research</b>                |

- 2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table . . . . . ▶
- 3 Enter total number of other organizations listed in the line 1 table . . . . . ▶

**Part III Grants and Other Assistance to Domestic Individuals.** Complete if the organization answered "Yes" on Form 990, Part IV, line 22.  
 Part III can be duplicated if additional space is needed.

| (a) Type of grant or assistance | (b) Number of recipients | (c) Amount of cash grant | (d) Amount of noncash assistance | (e) Method of valuation (book, FMV, appraisal, other) | (f) Description of noncash assistance |
|---------------------------------|--------------------------|--------------------------|----------------------------------|---|---------------------------------------|
| 1 fellowships                   | 3                        | 10,500                   |                                  | cash value  |                                       |
| 2                               |                          |                          |                                  |   |                                       |
| 3                               |                          |                          |                                  |   |                                       |
| 4                               |                          |                          |                                  |   |                                       |
| 5                               |                          |                          |                                  |   |                                       |
| 6                               |                          |                          |                                  |   |                                       |
| 7                               |                          |                          |                                  |   |                                       |

**Part IV Supplemental Information.** Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

**01. Monitoring procedures (Part I, line 2)**

CMTA requires by contract period progress reports on the funded research. Its contracts also include a full research plan with budgets & deliverables.

**SCHEDULE J  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

Name of the organization

**Compensation Information**

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 23.  
▶ Attach to Form 990.

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2017**

**Open to Public  
Inspection**

**Charcot-Marie-Tooth Association**

Employer identification number

**22-2480896**

**Part I Questions Regarding Compensation**

|  | Yes | No |
|--|-----|----|
| <b>1a</b> Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.  |     |    |
| <input checked="" type="checkbox"/> First-class or charter travel  |     |    |
| <input type="checkbox"/> Travel for companions   |     |    |
| <input type="checkbox"/> Tax indemnification and gross-up payments   |     |    |
| <input type="checkbox"/> Discretionary spending account  |     |    |
| <input type="checkbox"/> Housing allowance or residence for personal use   |     |    |
| <input type="checkbox"/> Payments for business use of personal residence   |     |    |
| <input type="checkbox"/> Health or social club dues or initiation fees   |     |    |
| <input type="checkbox"/> Personal services (such as maid, chauffeur, chef)   |     |    |
| <b>b</b> If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain . . . . .  | X   |    |
| <b>2</b> Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a? . . . . .  | X   |    |
| <b>3</b> Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III. |     |    |
| <input type="checkbox"/> Compensation committee  |     |    |
| <input type="checkbox"/> Independent compensation consultant   |     |    |
| <input type="checkbox"/> Form 990 of other organizations   |     |    |
| <input type="checkbox"/> Written employment contract   |     |    |
| <input type="checkbox"/> Compensation survey or study  |     |    |
| <input checked="" type="checkbox"/> Approval by the board or compensation committee  |     |    |
| <b>4</b> During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:  |     |    |
| <b>a</b> Receive a severance payment or change-of-control payment? . . . . .   |     | X  |
| <b>b</b> Participate in, or receive payment from, a supplemental nonqualified retirement plan? . . . . .   |     | X  |
| <b>c</b> Participate in, or receive payment from, an equity-based compensation arrangement? . . . . .  |     | X  |
| If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.  |     |    |
| <b>Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.</b>  |     |    |
| <b>5</b> For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:  |     |    |
| <b>a</b> The organization? . . . . .   |     | X  |
| <b>b</b> Any related organization? . . . . .   |     | X  |
| If "Yes" on line 5a or 5b, describe in Part III.   |     |    |
| <b>6</b> For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:  |     |    |
| <b>a</b> The organization? . . . . .   |     | X  |
| <b>b</b> Any related organization? . . . . .   |     | X  |
| If "Yes" on line 6a or 6b, describe in Part III.   |     |    |
| <b>7</b> For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III . . . . .   |     | X  |
| <b>8</b> Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III . . . . .   |     | X  |
| <b>9</b> If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)? . . . . .  |     |    |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule J (Form 990) 2017

**Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees.** Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that aren't listed on Form 990, Part VII.

**Note:** The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

| (A) Name and Title                                  |      | (B) Breakdown of W-2 and/or 1099-MISC compensation |                                     |                                     | (C) Retirement and other deferred compensation | (D) Nontaxable benefits | (E) Total of columns (B)(i)-(D) | (F) Compensation in column (B) reported as deferred on prior Form 990 |
|---|------|--|-------------------------------------|-------------------------------------|--|-------------------------|---------------------------------|---|
|   |      | (i) Base compensation                              | (ii) Bonus & incentive compensation | (iii) Other reportable compensation |  |                         |                                 |   |
| <b>Amy Gray</b><br><b>1 Chief Executive Officer</b> | (i)  | <b>152,692</b>                                     | <b>0</b>                            | <b>0</b>                            | <b>0</b>                                       | <b>0</b>                | <b>152,692</b>                  | <b>0</b>  |
|   | (ii) | <b>0</b>   | <b>0</b>                            | <b>0</b>                            | <b>0</b>                                       | <b>0</b>                | <b>0</b>                        | <b>0</b>  |
| <b>2</b>  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>3</b>  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>4</b>  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>5</b>  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>6</b>  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>7</b>  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>8</b>  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>9</b>  | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>10</b>   | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>11</b>   | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>12</b>   | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>13</b>   | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>14</b>   | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>15</b>   | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |
| <b>16</b>   | (i)  |  |                                     |                                     |  |                         |                                 |   |
|   | (ii) |  |                                     |                                     |  |                         |                                 |   |

**SCHEDULE O**  
**(Form 990 or 990-EZ)**

Department of the Treasury  
Internal Revenue Service

Name of the organization

**Supplemental Information to Form 990 or 990-EZ**

Complete to provide information for responses to specific questions on  
Form 990 or 990-EZ or to provide any additional information.

▶ Attach to Form 990 or 990-EZ.  
▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2017**

**Open to Public  
Inspection**

Employer identification number

**Charcot-Marie-Tooth Association**

**22-2480896**

**01. Officer, directors, etc. family relationship (Part VI, line 2)**

Gilles Bouchard (board chairman) and Chris Ouellette (board member) are brothers-in-law.

**02. Organizational document changes (Part VI, line 4)**

The By-Laws were changed to officially incorporate the Conflict of Interest Policy. In addition, four physicians were added to the Board as voting members. However, they do not vote on research spending.

**03. Form 990 governing body review (Part VI, line 11)**

Form 990 will be reviewed by the Board of Directors.

**04. Conflict of interest policy compliance (Part VI, line 12c)**

The organization had a workshop for all Board members on the Conflict of Interest Policy. The physicians on the Board disclose all pertinent research work, and do not vote on research spending.

**05. CEO, executive director, top management comp (Part VI, line 15a)**

The organization's Board of Directors determines the CEO's compensation annually, considering whatever factors and information it deems appropriate.

**06. Governing documents, etc, available to public (Part VI, line 19)**

Upon request by mail, telephone, and/or email audited financial statements are available on the CMTA's website.

**07. Not undergone required audits or steps for audit (part XII, line 3b)**

The CMTA has not changed its selection and oversight process during the tax year. The

**For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.**

Schedule O (Form 990 or 990-EZ) (2017)

Name of the organization

Employer identification number

**Charcot-Marie-Tooth Association**

**22-2480896**

Board of Directors assumes oversight of the independent auditor and the annual audit.

Multiple horizontal lines for text entry, mostly empty.

990

Overflow Statement

2017  
Page 1

Name(s) as shown on return

FEIN

Charcot-Marie-Tooth Association

22-2480896

| <u>Description</u> | <u>Amount</u>   |
|--------------------|-----------------|
| Telephone          | \$ 8,076        |
| <b>Total:</b>      | <b>\$ 8,076</b> |

| <u>Description</u> | <u>Amount</u>   |
|--------------------|-----------------|
| Taxes & fees       | \$ 5,699        |
| Telephone          | 475             |
| <b>Total:</b>      | <b>\$ 6,174</b> |

| <u>Description</u> | <u>Amount</u> |
|--------------------|---------------|
| Telephone          | \$ 950        |
| <b>Total:</b>      | <b>\$ 950</b> |



## Application for Automatic Extension of Time To File an Exempt Organization Return

Department of the Treasury  
Internal Revenue Service

▶ **File a separate application for each return.**  
▶ **Information about Form 8868 and its instructions is at [www.irs.gov/form8868](http://www.irs.gov/form8868).**

OMB No. 1545-1709

**Electronic filing (e-file).** You can electronically file Form 8868 to request a 6-month automatic extension of time to file any of the forms listed below with the exception of Form 8870, Information Return for Transfers Associated With Certain Personal Benefit Contracts, for which an extension request must be sent to the IRS in paper format (see Instructions). For more details on the electronic filing of this form, visit [www.irs.gov/efile](http://www.irs.gov/efile), click on Charities & Non-Profits, and click on e-file for *Charities and Non-Profits*.

**Automatic 6-Month Extension of Time.** Only submit original (no copies needed).

All corporations required to file an income tax return other than Form 990-T (including 1120-C filers), partnerships, REMICs, and trusts must use Form 7004 to request an extension of time to file income tax returns.

|   |  |  |
|---|--|--|
| <b>Type or print</b><br><br><small>File by the due date for filing your return. See instructions.</small> | Name of exempt organization or other filer, see instructions.<br><b>Charcot-Marie-Tooth Association</b>                | Employer identification number (EIN) or<br><b>22-2480896</b> |
|   | Number, street, and room or suite no. If a P.O. box, see instructions.<br><b>PO Box 105</b>                            | Social security number (SSN)                                 |
|   | City, town or post office, state, and ZIP code. For a foreign address, see instructions.<br><b>Glenolden, PA 19036</b> |  |

Enter the Return Code for the return that this application is for (file a separate application for each return) . . . . . 09

| Application Is For                       | Return Code | Application Is For                | Return Code |
|--|-------------|-----------------------------------|-------------|
| Form 990 or Form 990-EZ                  | 01          | Form 990-T (corporation)          | 07          |
| Form 990-BL                              | 02          | Form 1041-A                       | 08          |
| Form 4720 (individual)                   | 03          | Form 4720 (other than individual) | 09          |
| Form 990-PF                              | 04          | Form 5227                         | 10          |
| Form 990-T (sec. 401(a) or 408(a) trust) | 05          | Form 6069                         | 11          |
| Form 990-T (trust other than above)      | 06          | Form 8870                         | 12          |

• The books are in the care of ▶ **Kimberly Magee, PO Box 105, Glenolden, PA 19036**

Telephone No. ▶ **610-499-9264** FAX No. ▶ \_\_\_\_\_

- If the organization does not have an office or place of business in the United States, check this box . . . . . ▶
- If this is for a Group Return, enter the organization's four digit Group Exemption Number (GEN) \_\_\_\_\_ . If this is for the whole group, check this box . . . . . ▶  . If it is for part of the group, check this box . . . . ▶  and attach a list with the names and EINs of all members the extension is for.

1 I request an automatic 6-month extension of time until **11-15**, 20**18**, to file the exempt organization return for the organization named above. The extension is for the organization's return for:

- ▶  calendar year 20**17** or
- ▶  tax year beginning \_\_\_\_\_, 20\_\_\_\_, and ending \_\_\_\_\_, 20\_\_\_\_.

2 If the tax year entered in line 1 is for less than 12 months, check reason:  Initial return  Final return  Change in accounting period

|  |           |    |          |
|--|-----------|----|----------|
| 3a If this application is for Forms 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions.                                   | <b>3a</b> | \$ | <b>0</b> |
| b If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit. | <b>3b</b> | \$ | <b>0</b> |
| c <b>Balance due.</b> Subtract line 3b from line 3a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions.       | <b>3c</b> | \$ | <b>0</b> |

**Caution:** If you are going to make an electronic funds withdrawal (direct debit) with this Form 8868, see Form 8453-EO and Form 8879-EO for payment instructions.

**IRS e-file Signature Authorization  
for an Exempt Organization**

Department of the Treasury  
Internal Revenue Service

For calendar year 2017, or fiscal year beginning \_\_\_\_\_, and ending \_\_\_\_\_

▶ **Do not send to the IRS. Keep for your records.**

▶ **Go to [www.irs.gov/Form8879EO](http://www.irs.gov/Form8879EO) for the latest information.**

**2017**

Name of exempt organization

**Charcot-Marie-Tooth Association**

Employer identification number

**22-2480896**

Name and title of officer

**Amy Gray, Chief Executive Officer**

**Part I Type of Return and Return Information (Whole Dollars Only)**

Check the box for the return for which you are using this Form 8879-EO and enter the applicable amount, if any, from the return. If you check the box on line **1a, 2a, 3a, 4a, or 5a**, below, and the amount on that line for the return being filed with this form was blank, then leave line **1b, 2b, 3b, 4b, or 5b**, whichever is applicable, blank (do not enter -0-). But, if you entered -0- on the return, then enter -0- on the applicable line below. **Do not** complete more than one line in Part I.

|   |  |                            |
|---|--|----------------------------|
| <b>1a</b> Form 990 check here ▶ <input checked="" type="checkbox"/> | <b>b Total revenue</b> , if any (Form 990, Part VIII, column (A), line 12) . . . . . | <b>1b</b> <u>3,138,829</u> |
| <b>2a</b> Form 990-EZ check here ▶ <input type="checkbox"/>         | <b>b Total revenue</b> , if any (Form 990-EZ, line 9) . . . . .                      | <b>2b</b> _____            |
| <b>3a</b> Form 1120-POL check here ▶ <input type="checkbox"/>       | <b>b Total tax</b> (Form 1120-POL, line 22) . . . . .                                | <b>3b</b> _____            |
| <b>4a</b> Form 990-PF check here ▶ <input type="checkbox"/>         | <b>b Tax based on investment income</b> (Form 990-PF, Part VI, line 5) . . . . .     | <b>4b</b> _____            |
| <b>5a</b> Form 8868 check here ▶ <input type="checkbox"/>           | <b>b Balance Due</b> (Form 8868, line 3c) . . . . .                                  | <b>5b</b> _____            |

**Part II Declaration and Signature Authorization of Officer**

Under penalties of perjury, I declare that I am an officer of the above organization and that I have examined a copy of the organization's 2017 electronic return and accompanying schedules and statements and to the best of my knowledge and belief, they are true, correct, and complete. I further declare that the amount in Part I above is the amount shown on the copy of the organization's electronic return. I consent to allow my intermediate service provider, transmitter, or electronic return originator (ERO) to send the organization's return to the IRS and to receive from the IRS (a) an acknowledgement of receipt or reason for rejection of the transmission, (b) the reason for any delay in processing the return or refund, and (c) the date of any refund. If applicable, I authorize the U.S. Treasury and its designated Financial Agent to initiate an electronic funds withdrawal (direct debit) entry to the financial institution account indicated in the tax preparation software for payment of the organization's federal taxes owed on this return, and the financial institution to debit the entry to this account. To revoke a payment, I must contact the U.S. Treasury Financial Agent at 1-888-353-4537 no later than 2 business days prior to the payment (settlement) date. I also authorize the financial institutions involved in the processing of the electronic payment of taxes to receive confidential information necessary to answer inquiries and resolve issues related to the payment. I have selected a personal identification number (PIN) as my signature for the organization's electronic return and, if applicable, the organization's consent to electronic funds withdrawal.

**Officer's PIN: check one box only**

I authorize **Peterson Fieo & Co LLP** to enter my PIN **55455** as my signature  
ERO firm name Enter five numbers, but do not enter all zeros

on the organization's tax year 2017 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I also authorize the aforementioned ERO to enter my PIN on the return's disclosure consent screen.

As an officer of the organization, I will enter my PIN as my signature on the organization's tax year 2017 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I will enter my PIN on the return's disclosure consent screen.

Officer's signature ▶ \_\_\_\_\_

Date ▶ **06-01-2018**

**Part III Certification and Authentication**

**ERO's EFIN/PIN.** Enter your six-digit electronic filing identification number (EFIN) followed by your five-digit self-selected PIN.

**243869 55455**  
Do not enter all zeros

I certify that the above numeric entry is my PIN, which is my signature on the 2017 electronically filed return for the organization indicated above. I confirm that I am submitting this return in accordance with the requirements of **Pub. 4163**, Modernized e-File (MeF) Information for Authorized IRS e-file Providers for Business Returns.

ERO's signature ▶ \_\_\_\_\_

Date ▶ **06-19-2018**

**ERO Must Retain This Form - See Instructions  
Do Not Submit This Form to the IRS Unless Requested To Do So**

**For Paperwork Reduction Act Notice, see instructions.**

# Peterson Fieo & Co LLP

103 Chesley Drive Suite 102  
Media, PA 19063-1757  
gfieo@petersonfieo.com  
Phone: (610)457-1486 | Fax: (610)340-2370

June 19, 2018

Charcot-Marie-Tooth Association  
PO Box 105  
Glenolden, PA 19036

Your privacy is important to us. Read the following privacy policy.

We collect nonpublic personal information about you from various sources, including:

- \* Interviews regarding your tax situation
- \* Applications, organizers, or other documents that supply such information as your name, address, telephone number, Social Security Number, number of dependents, income, and other tax-related data
- \* Tax-related documents you provide that are required for processing tax returns, such as Forms W-2, 1099R, 1099-INT and 1099-DIV, and stock transactions

We do not disclose any nonpublic personal information about our clients or former clients to anyone, except as requested by our clients or as required by law.

We restrict access to personal information concerning you, except to our employees who need such information in order to provide products or services to you. We maintain physical, electronic, and procedural safeguards that comply with federal regulations to guard your personal information.

If you have any questions about our privacy policy, contact our office at (610)457-1486.

Sincerely,

George Fieo CPA  
Peterson Fieo & Co LLP

**Acknowledgement and General Information for  
Entities That File Returns Electronically**

**2017**

Name(s) as shown on return

Charcot-Marie-Tooth Association

Employer Identification Number

\*\*-\*\*\*0896

Entity address

PO Box 105

Glenolden, PA 19036

**Thank you for participating in IRS e-file.**

1.  2017 990 income tax return for Federal was filed electronically.  
The electronic filing services were provided by Peterson Fieo & Co LLP.
2.  990 income tax return was accepted on 06-19-2018 using a Personal Identification Number (PIN) as an electronic signature. The entity entered a PIN or authorized the Electronic Return Originator (ERO) to enter or generate a PIN signature.  
The submission ID assigned to this return is 2438692018170ic112y0.

**PLEASE DO NOT SEND A PAPER COPY OF ENTITY'S RETURN TO THE  
IRS. IF YOU DO, IT WILL DELAY THE PROCESSING OF THE RETURN.**