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Form 990

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

2020

Open to Public Inspection

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

A For the 2020 calendar year, or tax year beginning 01-01-2020 , and ending 12-31-2020

B Check if applicable:  
☐ Address change  
☐ Name change  
☐ Initial return  
☐ Final return/terminated  
☐ Amended return  
☐ Application pending

C Name of organization  
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION  
  
Doing business as  
TSC ALLIANCE  
  
Number and street (or P.O. box if mail is not delivered to street address) Room/suite  
8737 COLESVILLE ROAD NO 400  
  
City or town, state or province, country, and ZIP or foreign postal code  
SILVER SPRING, MD 20910

D Employer identification number  
95-3018799  
  
E Telephone number  
(301) 562-9890  
  
G Gross receipts \$ 5,266,631

F Name and address of principal officer:  
KARI L ROSBECK  
8737 COLESVILLE ROAD NO 400  
SILVER SPRING, MD 20910

H(a) Is this a group return for subordinates?  
☐ Yes ☒ No  
H(b) Are all subordinates included?  
☐ Yes ☐ No  
If "No," attach a list. (see instructions)  
H(c) Group exemption number ▶

I Tax-exempt status: ☒ 501(c)(3) ☐ 501(c) ( ) ◀ (insert no.) ☐ 4947(a)(1) or ☐ 527

J Website: ▶ WWW.TSALLIANCE.ORG

K Form of organization: ☒ Corporation ☐ Trust ☐ Association ☐ Other ▶

L Year of formation: 1975

M State of legal domicile: CA

Part I Summary

Activities & Governance

1 Briefly describe the organization's mission or most significant activities:  
FINDING A CURE FOR TUBEROUS SCLEROSIS COMPLEX WHILE IMPROVING THE LIVES OF THOSE AFFECTED.

2 Check this box ☐ if the organization discontinued its operations or disposed of more than 25% of its net assets.

3 Number of voting members of the governing body (Part VI, line 1a) . . . . . 3 27

4 Number of independent voting members of the governing body (Part VI, line 1b) . . . . . 4 27

5 Total number of individuals employed in calendar year 2020 (Part V, line 2a) . . . . . 5 22

6 Total number of volunteers (estimate if necessary) . . . . . 6 2,284

7a Total unrelated business revenue from Part VIII, column (C), line 12 . . . . . 7a 0

7b Net unrelated business taxable income from Form 990-T, line 39 . . . . . 7b 0

Revenue

8 Contributions and grants (Part VIII, line 1h) . . . . . 5,527,543 4,345,011

9 Program service revenue (Part VIII, line 2g) . . . . . 461,658 792,685

10 Investment income (Part VIII, column (A), lines 3, 4, and 7d ) . . . . . 27,826 11,770

11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) . . . . . 699,207 -21,302

12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12) . . . . . 6,716,234 5,128,164

Expenses

13 Grants and similar amounts paid (Part IX, column (A), lines 1–3 ) . . . . . 617,106 685,788

14 Benefits paid to or for members (Part IX, column (A), line 4) . . . . . 0 0

15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10) . . . . . 2,223,956 2,382,792

16a Professional fundraising fees (Part IX, column (A), line 11e) . . . . . 0 0

16b Total fundraising expenses (Part IX, column (D), line 25) ▶941,587

17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e) . . . . . 2,798,273 2,353,610

18 Total expenses. Add lines 13–17 (must equal Part IX, column (A), line 25) . . . . . 5,639,335 5,422,190

19 Revenue less expenses. Subtract line 18 from line 12 . . . . . 1,076,899 -294,026

Net Assets or Fund Balances

20 Total assets (Part X, line 16) . . . . . 10,351,316 11,657,873

21 Total liabilities (Part X, line 26) . . . . . 594,729 2,195,312

22 Net assets or fund balances. Subtract line 21 from line 20 . . . . . 9,756,587 9,462,561

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.

Sign Here

\*\*\*\*\*  
Signature of officer  
KARI L ROSBECK, PRESIDENT & CEO  
Type or print name and title

2021-04-12  
Date

Paid Preparer Use Only

Print/Type preparer's name Preparer's signature Date 2021-04-12 Check ☐ if self-employed PTIN P00397829

Firm's name ▶ RSM US LLP Firm's EIN ▶ 42-0714325

Firm's address ▶ 2021 L STREET NW SUITE 400  
WASHINGTON, DC 20036 Phone no. (202) 293-2200

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

For Paperwork Reduction Act Notice, see the separate instructions. Cat. No. 11282Y Form 990 (2020)

**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:

THE NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, D/B/A TSC ALLIANCE, IS DEDICATED TO FINDING A CURE FOR TUBEROUS SCLEROSIS COMPLEX WHILE IMPROVING THE LIVES OF THOSE AFFECTED.

**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

If "Yes," describe these new services on Schedule O.

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

If "Yes," describe these changes on Schedule O.

**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.

<b>4a</b>	(Code: ) (Expenses \$ 2,543,079 including grants of \$ 680,788 ) (Revenue \$ 901,832 )
See Additional Data	

<b>4b</b>	(Code: ) (Expenses \$ 698,125 including grants of \$ 5,000 ) (Revenue \$ )
See Additional Data	

<b>4c</b>	(Code: ) (Expenses \$ 502,083 including grants of \$ ) (Revenue \$ )
See Additional Data	

See Additional Data Table

<b>4d</b>	Other program services (Describe in Schedule O.)
	(Expenses \$ 240,862 including grants of \$ ) (Revenue \$ )

<b>4e</b>	<b>Total program service expenses ▶</b>	3,984,149
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**Part IV Checklist of Required Schedules**

	Yes	No
<b>1</b> Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A	<b>1</b> Yes	
<b>2</b> Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	<b>2</b> Yes	
<b>3</b> Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	<b>3</b>	No
<b>4 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? If "Yes," complete Schedule C, Part II	<b>4</b> Yes	
<b>5</b> 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? If "Yes," complete Schedule C, Part III	<b>5</b>	No
<b>6</b> 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? If "Yes," complete Schedule D, Part I	<b>6</b>	No
<b>7</b> Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	<b>7</b>	No
<b>8</b> Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III	<b>8</b>	No
<b>9</b> 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? If "Yes," complete Schedule D, Part IV	<b>9</b>	No
<b>10</b> Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi endowments? If "Yes," complete Schedule D, Part V	<b>10</b> Yes	
<b>11</b> 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.		
<b>a</b> Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI	<b>11a</b> Yes	
<b>b</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? If "Yes," complete Schedule D, Part VII	<b>11b</b>	No
<b>c</b> 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? If "Yes," complete Schedule D, Part VIII	<b>11c</b>	No
<b>d</b> 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? If "Yes," complete Schedule D, Part IX	<b>11d</b> Yes	
<b>e</b> Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	<b>11e</b> Yes	
<b>f</b> 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)? If "Yes," complete Schedule D, Part X	<b>11f</b>	No
<b>12a</b> Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	<b>12a</b>	No
<b>b</b> Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	<b>12b</b> Yes	
<b>13</b> Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	<b>13</b>	No
<b>14a</b> Did the organization maintain an office, employees, or agents outside of the United States?	<b>14a</b>	No
<b>b</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? If "Yes," complete Schedule F, Parts I and IV	<b>14b</b> Yes	
<b>15</b> 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? If "Yes," complete Schedule F, Parts II and IV	<b>15</b> Yes	
<b>16</b> 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? If "Yes," complete Schedule F, Parts III and IV	<b>16</b>	No
<b>17</b> 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? If "Yes," complete Schedule G, Part I (see instructions)	<b>17</b>	No
<b>18</b> Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II	<b>18</b> Yes	
<b>19</b> Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III	<b>19</b>	No
<b>20a</b> Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	<b>20a</b>	No
<b>b</b> If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	<b>20b</b>	
<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? If "Yes," complete Schedule I, Parts I and II	<b>21</b> Yes	

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

		Yes	No
<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? If "Yes," complete Schedule I, Parts I and III . . . . .	<b>22</b>	No
<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? If "Yes," complete Schedule J . . . . .	<b>23</b>	Yes
<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? If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a . . . . .	<b>24a</b>	No
<b>b</b>	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? . . . . .	<b>24b</b>	
<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>24c</b>	
<b>d</b>	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? . . . . .	<b>24d</b>	
<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? If "Yes," complete Schedule L, Part I . . . . .	<b>25a</b>	No
<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? If "Yes," complete Schedule L, Part I . . . . .	<b>25b</b>	No
<b>26</b>	Did the organization report any amount on Part X, line 5 or 22 for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? If "Yes," complete Schedule L, Part II . . . . .	<b>26</b>	No
<b>27</b>	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III . . . . .	<b>27</b>	No
<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, key employee, creator or founder, or substantial contributor? If "Yes," complete Schedule L, Part IV . . . . .	<b>28a</b>	No
<b>b</b>	A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV . . . . .	<b>28b</b>	No
<b>c</b>	A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? If "Yes," complete Schedule L, Part IV . . . . .	<b>28c</b>	No
<b>29</b>	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M . . . . .	<b>29</b>	Yes
<b>30</b>	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M . . . . .	<b>30</b>	No
<b>31</b>	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I . . . . .	<b>31</b>	No
<b>32</b>	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II . . . . .	<b>32</b>	No
<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? If "Yes," complete Schedule R, Part I . . . . .	<b>33</b>	No
<b>34</b>	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1 . . . . .	<b>34</b>	Yes
<b>35a</b>	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	<b>35a</b>	No
<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)? If "Yes," complete Schedule R, Part V, line 2 . . . . .	<b>35b</b>	
<b>36</b>	<b>Section 501(c)(3) organizations.</b> Did the organization make any transfers to an exempt non-charitable related organization? If "Yes," complete Schedule R, Part V, line 2 . . . . .	<b>36</b>	No
<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? If "Yes," complete Schedule R, Part VI . . . . .	<b>37</b>	No
<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. . . . .	<b>38</b>	Yes

**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 . . . . . ☐

	Yes	No
<b>1a</b> Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable . . . . .	<b>1a</b>	30
<b>b</b> Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable . . . . .	<b>1b</b>	0
<b>c</b> Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? . . . . .	<b>1c</b>	Yes

**Part V** **Statements Regarding Other IRS Filings and Tax Compliance** (continued)

<b>2a</b> Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return . . . . .	<div style="border: 1px solid black; width: 100px; height: 30px; margin: 0 auto; text-align: center;">2a</div> <div style="border: 1px solid black; width: 100px; height: 30px; margin: 0 auto; text-align: center;">22</div>			
<b>b</b> If at least one is reported on line 2a, did the organization file all required federal employment tax returns? <b>Note.</b> If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)			<b>2b</b> Yes	
<b>3a</b> Did the organization have unrelated business gross income of \$1,000 or more during the year? . . . . .			<b>3a</b>	No
<b>b</b> If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in Schedule O . . . . .			<b>3b</b>	
<b>4a</b> At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)? . . . . .			<b>4a</b>	No
<b>b</b> If "Yes," enter the name of the foreign country: <span style="border-bottom: 1px solid black; display: inline-block; width: 150px;"></span> See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).				
<b>5a</b> Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? . . . . .			<b>5a</b>	No
<b>b</b> Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?			<b>5b</b>	No
<b>c</b> If "Yes," to line 5a or 5b, did the organization file Form 8886-T? . . . . .			<b>5c</b>	
<b>6a</b> Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions? . . . . .			<b>6a</b>	No
<b>b</b> If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible? . . . . .			<b>6b</b>	
<b>7 Organizations that may receive deductible contributions under section 170(c).</b>				
<b>a</b> Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor? . . . . .			<b>7a</b> Yes	
<b>b</b> If "Yes," did the organization notify the donor of the value of the goods or services provided? . . . . .			<b>7b</b> Yes	
<b>c</b> Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282? . . . . .			<b>7c</b>	No
<b>d</b> If "Yes," indicate the number of Forms 8282 filed during the year . . . . .	<div style="border: 1px solid black; width: 40px; height: 20px; margin: 0 auto; text-align: center;">7d</div>			
<b>e</b> Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?			<b>7e</b>	No
<b>f</b> Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? . . . . .			<b>7f</b>	No
<b>g</b> If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required? . . . . .			<b>7g</b>	
<b>h</b> If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C? . . . . .			<b>7h</b>	
<b>8 Sponsoring organizations maintaining donor advised funds.</b> Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year? . . . . .				
<b>9 Sponsoring organizations maintaining donor advised funds.</b>				
<b>a</b> Did the sponsoring organization make any taxable distributions under section 4966? . . . . .			<b>9a</b>	
<b>b</b> Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? . . . . .			<b>9b</b>	
<b>10 Section 501(c)(7) organizations.</b> Enter:				
<b>a</b> Initiation fees and capital contributions included on Part VIII, line 12 . . . . .	<div style="border: 1px solid black; width: 40px; height: 20px; margin: 0 auto; text-align: center;">10a</div>			
<b>b</b> Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	<div style="border: 1px solid black; width: 40px; height: 20px; margin: 0 auto; text-align: center;">10b</div>			
<b>11 Section 501(c)(12) organizations.</b> Enter:				
<b>a</b> Gross income from members or shareholders . . . . .	<div style="border: 1px solid black; width: 40px; height: 20px; margin: 0 auto; text-align: center;">11a</div>			
<b>b</b> Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.) . . . . .	<div style="border: 1px solid black; width: 40px; height: 20px; margin: 0 auto; text-align: center;">11b</div>			
<b>12a Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?				
<b>b</b> If "Yes," enter the amount of tax-exempt interest received or accrued during the year.	<div style="border: 1px solid black; width: 40px; height: 20px; margin: 0 auto; text-align: center;">12b</div>			
<b>13 Section 501(c)(29) qualified nonprofit health insurance issuers.</b>				
<b>a</b> Is the organization licensed to issue qualified health plans in more than one state? . . . . . <b>Note.</b> See the instructions for additional information the organization must report on Schedule O.			<b>13a</b>	
<b>b</b> Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans . . . . .	<div style="border: 1px solid black; width: 40px; height: 20px; margin: 0 auto; text-align: center;">13b</div>			
<b>c</b> Enter the amount of reserves on hand . . . . .	<div style="border: 1px solid black; width: 40px; height: 20px; margin: 0 auto; text-align: center;">13c</div>			
<b>14a</b> Did the organization receive any payments for indoor tanning services during the tax year? . . . . .			<b>14a</b>	No
<b>b</b> If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O . . . . .			<b>14b</b>	
<b>15</b> Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? . . . . . If "Yes," see instructions and file Form 4720, Schedule N.			<b>15</b>	No
<b>16</b> Is the organization an educational institution subject to the section 4968 excise tax on net investment income? . . . . . If "Yes," complete Form 4720, Schedule O.			<b>16</b>	No

**Part VI**

**Governance, Management, and Disclosure** For each "Yes" response to lines 2 through 7b below, and for a "No" response to lines 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 ☒

**Section A. Governing Body and Management**

		Yes	No
<b>1a</b> Enter the number of voting members of the governing body at the end of the tax year	<b>1a</b> 27		
If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O.			
<b>b</b> Enter the number of voting members included in line 1a, above, who are independent	<b>1b</b> 27		
<b>2</b> Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?	<b>2</b>		No
<b>3</b> Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?	<b>3</b>		No
<b>4</b> Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	<b>4</b>		No
<b>5</b> Did the organization become aware during the year of a significant diversion of the organization's assets?	<b>5</b>		No
<b>6</b> Did the organization have members or stockholders?	<b>6</b>	Yes	
<b>7a</b> Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?	<b>7a</b>	Yes	
<b>b</b> Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	<b>7b</b>		No
<b>8</b> Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:			
<b>a</b> The governing body?	<b>8a</b>	Yes	
<b>b</b> Each committee with authority to act on behalf of the governing body?	<b>8b</b>	Yes	
<b>9</b> Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O	<b>9</b>		No

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

	Yes	No
<b>10a</b> Did the organization have local chapters, branches, or affiliates?	<b>10a</b>	Yes
<b>b</b> If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	<b>10b</b>	Yes
<b>11a</b> Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	<b>11a</b>	Yes
<b>b</b> Describe in Schedule O the process, if any, used by the organization to review this Form 990.		
<b>12a</b> Did the organization have a written conflict of interest policy? If "No," go to line 13	<b>12a</b>	Yes
<b>b</b> Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	<b>12b</b>	Yes
<b>c</b> Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	<b>12c</b>	Yes
<b>13</b> Did the organization have a written whistleblower policy?	<b>13</b>	Yes
<b>14</b> Did the organization have a written document retention and destruction policy?	<b>14</b>	Yes
<b>15</b> Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		
<b>a</b> The organization's CEO, Executive Director, or top management official	<b>15a</b>	Yes
<b>b</b> Other officers or key employees of the organization	<b>15b</b>	Yes
If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions).		
<b>16a</b> Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?	<b>16a</b>	No
<b>b</b> If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?	<b>16b</b>	

**Section C. Disclosure**

**17** List the states with which a copy of this Form 990 is required to be filed▶

AL, AR, CA, FL, GA, HI, IL, IN, KS, KY, MD, MA, MI, MN, MS, NH, NJ, NM, NY, NC, OR, PA, RI, SC, TN, UT, VA, WI, WV

**18** Section 6104 requires an organization to make its Form 1023 (or 1024-A if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.

☒ Own website ☒ Another's website ☒ Upon request ☐ Other (explain in Schedule O)

**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:  
▶THE ORGANIZATION 8737 COLESVILLE ROAD NO 400 SILVER SPRING, MD 20910 (301) 562-9890

## 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 ☐

**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, or 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.

See instructions for the order in which to list the persons above.

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

[illegible]

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

<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>	1,030,829	12,778	117,208

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 ▶ 7

		Yes	No
3	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>		No
4	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>	Yes	
5	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>		No

## 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) Name and business address	(B) Description of services	(C) Compensation
PSYCHOGENICS INC 20 GRAMERCY PARK SOUTH NEW YORK, NY 10003	RESEARCH LAB SERVICES	601,033
VAN ANDEL RESEARCH INSTITUTE 333 BOSTWICK AVE NE GRAND RAPIDS, MI 49503	LABORATORY SERVICES	144,738
CAVAROCCHI RUSCIO DENNIS AND ASSOCIATES 600 MARYLAND AVE SW WASHINGTON, DC 20024	GOVERNMENT RELATIONS	113,547
GRAHAM-PELTON CONSULTING 39 BEECHWOOD ROAD SUMMIT, NJ 07901	DEVELOPMENT STRATEGY	109,122

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 ▶ 4



Part VIII

Statement of Revenue

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

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514	
Contributions, Gifts, Grants and Other Similar Amounts	1a	Federated campaigns . . .	1a	28,836			
	b	Membership dues . . .	1b	4,208			
	c	Fundraising events . . .	1c	1,192,939			
	d	Related organizations	1d	330,875			
	e	Government grants (contributions)	1e	371,820			
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	2,416,333			
	g	Noncash contributions included in lines 1a - 1f:\$	1g	91,027			
	h	Total. Add lines 1a-1f . . . . . ▶	4,345,011				
Program Service Revenue			Business Code				
	2a	CONTRACT REVENUE	900099	791,210	791,210		
	b	CONFERENCE REVENUE	900099	1,475		1,475	
	c						
	d						
	e						
	f	All other program service revenue.					
g	Total. Add lines 2a-2f. . . . . ▶	792,685					
Other Revenue	3		Investment income (including dividends, interest, and other similar amounts) . . . . . ▶	11,188		11,188	
	4		Income from investment of tax-exempt bond proceeds ▶				
	5		Royalties . . . . . ▶				
	6a	Gross rents	(i) Real	(ii) Personal			
	b	Less: rental expenses					
	c	Rental income or (loss)					
	d	Net rental income or (loss) . . . . . ▶					
	7a	Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other			
			87,545				
	b	Less: cost or other basis and sales expenses	86,963				
	c	Gain or (loss)	582				
	d	Net gain or (loss) . . . . . ▶	582			582	
	8a	Gross income from fundraising events (not including \$ 1,192,939 of contributions reported on line 1c). See Part IV, line 18 . . . . .					
			8a	52,486			
	b	Less: direct expenses . . . . .	8b	51,504			
c	Net income or (loss) from fundraising events . . . ▶	982			982		
9a	Gross income from gaming activities. See Part IV, line 19 . . . . .						
		9a					
b	Less: direct expenses . . . . .	9b					
c	Net income or (loss) from gaming activities . . . ▶						
10a	Gross sales of inventory, less returns and allowances . . .						
		10a					
b	Less: cost of goods sold . . .	10b					
c	Net income or (loss) from sales of inventory . . . ▶						
Miscellaneous Revenue		Business Code					
11a	CHANGE INT-ENDOWMENT	900099	-22,284			-22,284	
b							
c							
d	All other revenue . . . . .						
e	Total. Add lines 11a-11d . . . . . ▶		-22,284				
12	Total revenue. See instructions . . . . . ▶		5,128,164	791,210	0	-8,057	

**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>	<b>(A)</b> Total expenses	<b>(B)</b> Program service expenses	<b>(C)</b> Management and general expenses	<b>(D)</b> Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 . . . . .	633,006	633,006		
<b>2</b> Grants and other assistance to domestic individuals. See Part IV, line 22 . . . . .				
<b>3</b> Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16. . . . .	52,782	52,782		
<b>4</b> Benefits paid to or for members . . . . .				
<b>5</b> Compensation of current officers, directors, trustees, and key employees . . . . .	667,009	335,572	232,186	99,251
<b>6</b> Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) . . . . .				
<b>7</b> Other salaries and wages . . . . .	1,374,953	906,889	115,728	352,336
<b>8</b> Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions) . . . . .	39,528	25,520	2,182	11,826
<b>9</b> Other employee benefits . . . . .	162,832	103,675	11,963	47,194
<b>10</b> Payroll taxes . . . . .	138,470	83,373	20,023	35,074
<b>11</b> Fees for services (non-employees):				
<b>a</b> Management . . . . .				
<b>b</b> Legal . . . . .	19,257	6,482	11,733	1,042
<b>c</b> Accounting . . . . .	27,285		27,285	
<b>d</b> Lobbying . . . . .	112,980	112,980		
<b>e</b> Professional fundraising services. See Part IV, line 17				
<b>f</b> Investment management fees . . . . .				
<b>g</b> Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	376,676	192,073	6,480	178,123
<b>12</b> Advertising and promotion . . . . .				
<b>13</b> Office expenses . . . . .	207,621	97,144	5,374	105,103
<b>14</b> Information technology . . . . .	169,610	110,221	26,682	32,707
<b>15</b> Royalties . . . . .				
<b>16</b> Occupancy . . . . .	119,343	71,577	17,454	30,312
<b>17</b> Travel . . . . .	109,888	100,966	664	8,258
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials . . . . .				
<b>19</b> Conferences, conventions, and meetings . . . . .	63,378	53,553	9,749	76
<b>20</b> Interest . . . . .				
<b>21</b> Payments to affiliates . . . . .				
<b>22</b> Depreciation, depletion, and amortization . . . . .	70,346	47,126	6,541	16,679
<b>23</b> Insurance . . . . .	8,049	4,833	1,184	2,032
<b>24</b> 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.)				
<b>a</b> PRECLINICAL CONSORTIUM	815,227	815,227		
<b>b</b> NHD BIOSAMPLE REPOSIT	208,188	208,188		
<b>c</b> DUES AND SUBSCRIPTIONS	40,684	20,749		19,935
<b>d</b> MISCELLANEOUS EXPENSES	5,078	2,213	1,226	1,639
<b>e</b> All other expenses				
<b>25 Total functional expenses.</b> Add lines 1 through 24e	5,422,190	3,984,149	496,454	941,587
<b>26 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 checked="" type="checkbox"/> if following SOP 98-2 (ASC 958-720).	66,240	33,120	0	33,120

**Part X Balance Sheet**Check if Schedule O contains a response or note to any line in this Part IX ☐

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash—non-interest-bearing . . . . .	809,370	<b>1</b>	1,097,500
	<b>2</b> Savings and temporary cash investments . . . . .	1,227,121	<b>2</b>	1,238,876
	<b>3</b> Pledges and grants receivable, net . . . . .	2,033,626	<b>3</b>	1,578,285
	<b>4</b> Accounts receivable, net . . . . .	10,243	<b>4</b>	113,491
	<b>5</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons . . . . .		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B) . . . . .		<b>6</b>	
	<b>7</b> Notes and loans receivable, net . . . . .		<b>7</b>	
	<b>8</b> Inventories for sale or use . . . . .		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges . . . . .	251,370	<b>9</b>	392,003
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	<b>10a</b> 735,604		
	<b>b</b> Less: accumulated depreciation	<b>10b</b> 225,237	80,221	<b>10c</b> 510,367
	<b>11</b> Investments—publicly traded securities . . . . .	27,556	<b>11</b>	
	<b>12</b> Investments—other securities. See Part IV, line 11 . . . . .		<b>12</b>	
	<b>13</b> Investments—program-related. See Part IV, line 11 . . . . .		<b>13</b>	
	<b>14</b> Intangible assets . . . . .		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11 . . . . .	5,911,809	<b>15</b>	6,727,351
<b>16</b> <b>Total assets.</b> Add lines 1 through 15 (must equal line 33) . . . . .	10,351,316	<b>16</b>	11,657,873	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses . . . . .	532,853	<b>17</b>	435,478
	<b>18</b> Grants payable . . . . .		<b>18</b>	
	<b>19</b> Deferred revenue . . . . .	54,700	<b>19</b>	422,226
	<b>20</b> Tax-exempt bond liabilities . . . . .		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D		<b>21</b>	
	<b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons . . . . .		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties . . . . .		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties . . . . .		<b>24</b>	
	<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	7,176	<b>25</b>	1,337,608
	<b>26</b> <b>Total liabilities.</b> Add lines 17 through 25 . . . . .	594,729	<b>26</b>	2,195,312
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions . . . . .	5,661,364	<b>27</b>	5,954,477
	<b>28</b> Net assets with donor restrictions . . . . .	4,095,223	<b>28</b>	3,508,084
	<b>Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds . . . . .		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building or equipment fund . . . . .		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds		<b>31</b>	
<b>32</b> <b>Total net assets or fund balances</b> . . . . .	9,756,587	<b>32</b>	9,462,561	
<b>33</b> <b>Total liabilities and net assets/fund balances</b> . . . . .	10,351,316	<b>33</b>	11,657,873	

**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>	5,128,164
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	5,422,190
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	-294,026
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	9,756,587
<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>9</b>	Other changes in net assets or fund balances (explain in Schedule O)	<b>9</b>	0
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	<b>10</b>	9,462,561

**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 _____ 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? 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: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		No
<b>b</b> Were the organization's financial statements audited by an independent accountant? 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: <input type="checkbox"/> Separate basis <input checked="" type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	Yes	
<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? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.	Yes	
<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?		No
<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.		

Software ID:	
Software Version:	
EIN:	95-3018799
Name:	NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Form 990 (2020)

Form 990, Part III, Line 4a:

RESEARCH PROGRAM STIMULATES AND SUPPORTS BASIC, TRANSLATIONAL, AND CLINICAL RESEARCH ON THE VARIOUS MANIFESTATIONS OF TUBEROUS SCLEROSIS COMPLEX (TSC) TO FURTHER THE DEVELOPMENT OF CLINICAL THERAPIES AND, ULTIMATELY, A CURE FOR TSC. DIRECTED BY STEVEN L. ROBERDS, PHD, CHIEF SCIENTIFIC OFFICER, THE TSC ALLIANCE RESEARCH PROGRAM BUILDS AND FOSTERS COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS BY COLLECTING AND DISTRIBUTING TSC NATURAL HISTORY DATA AND BIOSAMPLES, THROUGH COLLABORATIVE PRECLINICAL AND CLINICAL RESEARCH PROGRAMS, AND BY HOSTING BIENNIAL INTERNATIONAL TSC RESEARCH CONFERENCES.SINCE 1984, THE TSC ALLIANCE HAS INVESTED \$27.7 MILLION INTO TSC RESEARCH PROJECTS THROUGH GRANTS AND CONTRACTS: \$18.5 MILLION IN RESEARCH GRANTS AND POSTDOCTORAL FELLOWSHIPS, \$4.4 MILLION INTO THE NATURAL HISTORY DATABASE AND BIOSAMPLE REPOSITORY, \$4.1 MILLION INTO THE PRECLINICAL CONSORTIUM AND \$0.7 MILLION INTO THE CLINICAL RESEARCH CONSORTIUM. GRANT AND FELLOWSHIP APPLICATIONS ARE REVIEWED IN A THREE-STEP PROCESS: (1) ALL APPLICATIONS ARE REVIEWED BY A COMMITTEE COMPRISED OF SCIENTISTS KNOWLEDGEABLE ABOUT THE TOPIC AREA FOR SCIENTIFIC MERIT AND OF CAREGIVERS OR ADULTS AFFECTED BY TSC FOR POTENTIAL IMPACT ON THE LIVES OF THOSE AFFECTED BY TSC; (2) THE SCIENCE AND MEDICAL COMMITTEE OF THE BOARD OF DIRECTORS EVALUATES THE GRANT REVIEW COMMITTEE'S RECOMMENDATIONS AND THE RELEVANCE OF THE APPLICATIONS TO THE TSC ALLIANCE'S FUNDING PRIORITIES; AND (3) THE BOARD OF DIRECTORS THEN REVIEWS THE RECOMMENDATIONS OF THE SCIENCE AND MEDICAL COMMITTEE AND MAKES FINAL APPROVAL FOR FUNDING. FOR A COMPLETE LIST OF CURRENTLY FUNDED PROJECTS AND AN ARCHIVE OF PAST AWARDEES, PLEASE VISIT [TSALLIANCE.ORG/GRANTS](https://tscalliance.org/grants).IMPLEMENTED IN 2006, THE TSC NATURAL HISTORY DATABASE CAPTURES CLINICAL DATA TO DOCUMENT THE IMPACT OF THE DISEASE ON A PERSON'S HEALTH OVER THEIR LIFETIME. THE DATABASE SERVES AS A RESOURCE OF INFORMATION THAT HELPS TSC RESEARCHERS BETTER UNDERSTAND THE PROGRESSION OF THE DISEASE, DESIGN HYPOTHESIS-DRIVEN QUESTIONS TO HASTEN THE DISCOVERY OF NEW TREATMENTS AND IDENTIFY PERSONS WITH TSC WHO ARE ELIGIBLE TO PARTICIPATE IN RESEARCH STUDIES. AS OF DECEMBER 2020, 2,268 PEOPLE WITH TSC WERE ENROLLED IN THE PROJECT FROM AMONG 18 U.S.-BASED SITES AND THROUGH THE TSC ALLIANCE. THE TSC ALLIANCE PROVIDES FUNDING TO PARTICIPATING CLINICS TO PERFORM DATA ENTRY, MONITORS THE INTEGRITY OF THE DATABASE, AND MAKES DATA AVAILABLE TO INVESTIGATORS TO ANSWER SPECIFIC RESEARCH QUESTIONS AND IDENTIFY POTENTIAL PARTICIPANTS FOR CLINICAL TRIALS AND STUDIES. IN 2020, THE TSC ALLIANCE ADDED A COVID-19 SUB-PROJECT TO ADDRESS DETAILED QUESTIONS ABOUT COVID-19 INFECTION IN INDIVIDUALS WITH TSC.BUILDING UPON THE NATURAL HISTORY DATABASE, THE TSC BIOSAMPLE REPOSITORY IS A TSC ALLIANCE-DIRECTED PROJECT INITIATED IN 2014 THAT WILL IMPACT RESEARCH OVER THE NEXT TEN YEARS OR MORE. THE TSC ALLIANCE'S SCIENCE AND MEDICAL COMMITTEE IDENTIFIED THIS AS A GAP THAT CAN ONLY BE FILLED EFFECTIVELY WITH LEADERSHIP OF THE TSC ALLIANCE, GUIDED BY A STEERING COMMITTEE OF CLINICIANS AND RESEARCHERS. HIGH-QUALITY BIOSAMPLES SUCH AS BLOOD, DNA, AND TISSUES LINKED TO DETAILED CLINICAL DATA ARE CRITICAL FOR RESEARCHERS TO UNDERSTAND WHY TSC IS SO DIFFERENT FROM PERSON TO PERSON. SAMPLES IN THE REPOSITORY ARE LINKED TO DETAILED CLINICAL DATA IN OUR EXISTING TSC NATURAL HISTORY DATABASE (NHD) AND ARE AVAILABLE TO QUALIFIED RESEARCHERS WORLDWIDE. SAMPLES ARE HOUSED AT AND DISTRIBUTED FROM THE VAN ANDEL INSTITUTE IN GRAND RAPIDS, MI, UNDER CONTROL OF THE TSC ALLIANCE. THE TSC BIOSAMPLE REPOSITORY ENDED 2020 WITH 1,571 BIOSAMPLES: 421 BLOOD SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 358 BUCCAL SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 29 TISSUE SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 374 BLOOD SAMPLES FROM THE TSC CLINICAL RESEARCH CONSORTIUM COLLABORATIVE PROJECTS, AND 389 DNA SAMPLES FROM THE TSC AUTISM CENTER OF EXCELLENCE NETWORK AUTISM BIOMARKER STUDY. WE CONTINUE TO GROW THE BIOSAMPLE REPOSITORY BY COLLECTING BLOOD SAMPLES ANNUALLY FROM PARTICIPANTS WHO VOLUNTEER TO DO SO, ENABLING RESEARCHERS TO STUDY CHANGES IN PROTEINS AND OTHER MOLECULES IN THE BLOOD OVER TIME; ADDING ADDITIONAL TSC CLINICS AS PARTICIPATING BIOSAMPLE REPOSITORY COLLECTION SITES; AND COLLECTING BLOOD USING MOBILE PHLEBOTOMY, ENABLING PEOPLE TO DONATE SAMPLES REGARDLESS OF WHERE THEY LIVE IN THE US AND WHETHER THEY ARE SEEN AT A TSC CLINIC. IN 2020, WE ACQUIRED 65 BLOOD SAMPLES VIA MOBILE PHLEBOTOMY, INCLUDING 4 FROM PARTICIPANTS WHO WERE DIAGNOSED WITH COVID-19. TO ENCOURAGE AND ENABLE MORE RESEARCHERS TO UTILIZE BIOSAMPLES, THE TSC ALLIANCE FUNDED THREE SEED GRANTS IN 2020, TOTALING \$60,000, TO LABS WHO SUBMITTED MERITORIOUS AND INNOVATIVE IDEAS FOR RESEARCH ON TSC BIOSAMPLES.THE TSC ALLIANCE LAUNCHED THE TSC PRECLINICAL CONSORTIUM IN 2015 TO HELP ADVANCE MORE DRUG CANDIDATES INTO CLINICAL TESTING. TO ACHIEVE THIS END, THE PRECLINICAL CONSORTIUM PROVIDES THE INFRASTRUCTURE TO FOSTER COLLABORATION BETWEEN ACADEMIA AND PHARMACEUTICAL INDUSTRY RESEARCHERS AND FOR ACCESS TO RESOURCES DESIGNED TO HELP FACILITATE DRUG DEVELOPMENT IN TSC. COLLABORATING WITH THE TSC COMMUNITY, THE CONSORTIUM HAS IDENTIFIED AND IMPLEMENTED ROBUST AND REPRODUCIBLE CELL AND ANIMAL MODELS FOR TSC MANIFESTATIONS INCLUDING TUMORS, EPILEPSY, AND TSC-ASSOCIATED NEUROPSYCHIATRIC DISORDERS (TAND). THE TSC ALLIANCE HAS LICENSES TO USE SPECIFIC TSC MOUSE MODELS FOR EXPERIMENTS CARRIED OUT BY THE PRECLINICAL CONSORTIUM, AND ALL MOUSE LICENSE AGREEMENTS INCLUDE THE RIGHTS FOR THE TSC ALLIANCE TO PERFORM EXPERIMENTS UNDER CONTRACT FOR COMMERCIAL ENTITIES. THIS ENSURES DATA GENERATED BY THE PRECLINICAL CONSORTIUM CAN BE USED TO ACCELERATE THE DEVELOPMENT OF NEW TREATMENTS BY COMMERCIAL ENTITIES AS WELL AS ACADEMIC INVESTIGATORS. EXPERIMENTS ARE EXECUTED AT PARTNERING RESEARCH INSTITUTIONS TO ENSURE CONSISTENCY IN TESTING, DATA ACQUISITION AND INTERPRETATION. EPILEPSY STUDIES ARE CONDUCTED AT PSYCHOGENICS (US), AND THE TUMOR GRAFT MODEL AND CELL-BASED ASSAYS ARE CONDUCTED AT PORSOLT (FRANCE). THE VAN ANDEL RESEARCH INSTITUTE, A NON-PROFIT RESEARCH ORGANIZATION, MAINTAINS A COLONY OF TSC2+/- AJ MICE AND L7-CRE-TSC2 MICE ON BEHALF OF THE PRECLINICAL CONSORTIUM. TWICE A YEAR, THE PRECLINICAL CONSORTIUM HAS A CALL FOR COMPOUND NOMINATIONS TO CONTINUE TO REFRESH OUR PIPELINE BASED ON THE LATEST DATA AND NOVEL IDEAS. THE NOMINATIONS ARE PEER-REVIEWED BY CONSORTIUM MEMBERS AND PRIORITIZED BY THE PRECLINICAL CONSORTIUM STEERING COMMITTEE FOR FUNDING BY THE TSC ALLIANCE. IF THE TSC ALLIANCE FUNDS THE STUDY, THE DATA ARE SHARED WITH THE CONSORTIUM FOR TRANSPARENCY AND STIMULATION OF ADDITIONAL HYPOTHESES. AN ANNUAL FACE-TO-FACE MEMBERS MEETING IS TYPICALLY HELD EACH YEAR IN APRIL TO KEEP MEMBERS ENGAGED AND ALIGNED ON THE CONSORTIUM'S STRATEGY AND PRIORITIES. PARTNERSHIP WITH PHARMACEUTICAL COMPANIES IS AN IMPORTANT ASPECT OF THE CONSORTIUM, AS THESE ORGANIZATIONS HAVE THE INFRASTRUCTURE TO EFFICIENTLY MOVE PRECLINICAL RESEARCH FINDINGS TO CLINICAL TESTING AND EVENTUALLY COMMERCIAL DISTRIBUTION. AS OF DECEMBER 2020, 7 COMPANIES WERE ACTIVE MEMBERS OF THE CONSORTIUM. THE CONSORTIUM HAS HAD 14 COMPANY MEMBERS SINCE 2016. THERE IS NATURAL TURNOVER OF INDUSTRY MEMBERSHIP, PRINCIPALLY DRIVEN BY RESEARCH DATA GENERATED BY TESTING THEIR DRUGS. DUE TO INTELLECTUAL PROPERTY CONSIDERATIONS, MOST COMPANIES FULLY FUND THEIR STUDIES THROUGH THE TSC ALLIANCE, WHICH ALLOWS THE COMPANY TO KEEP ITS DATA CONFIDENTIAL. THESE CONFIDENTIAL STUDIES ALSO INCUR A 10% OVERHEAD PAID BY THE COMPANY, WHICH IS A SOURCE OF REVENUE FOR THE TSC ALLIANCE. SINCE INCEPTION, THE CONSORTIUM HAS HELPED ADVANCE THE EVALUATION OF DRUGS FOR TSC BY CONDUCTING 54 STUDIES, EVALUATING 44 CANDIDATE DRUGS. IN 2020, THE TSC PRECLINICAL CONSORTIUM EVALUATED 13 CANDIDATE DRUGS IN MOUSE MODELS AND SCREENED AN ADDITIONAL 10 COMPOUNDS IN CELL-BASED MODELS OF TSC.

### **Form 990, Part III, Line 4b:**

SUPPORT SERVICES DEVELOPS PROGRAMS AND SERVICES THAT PROVIDE INDIVIDUALS WITH TSC DIRECT ACCESS TO INFORMATION, RESOURCES, AND SPECIALISTS EXPERIENCED IN THE DIAGNOSIS, TREATMENT AND MANAGEMENT OF TSC. IN 2020 THE TSC ALLIANCE FACILITATED 28,447 PEER-TO-PEER SUPPORTS FROM ADULT REGIONAL COORDINATORS (12 VOLUNTEERS IN 8 REGIONS NATIONWIDE), CLINIC AMBASSADORS (22 VOLUNTEERS IN 26 TSC CLINICS AND TSC CENTERS OF EXCELLENCE NATIONWIDE), DEPENDENT ADULT TRANSITION RESOURCE COORDINATORS (32 VOLUNTEERS IN 26 STATES AND PUERTO RICO), EDUCATION PARENT MENTORS (31 VOLUNTEERS IN 22 STATES), AND COMMUNITY ALLIANCE LEADERS (93 VOLUNTEERS IN 33 REGIONS ACROSS THE UNITED STATES) WITH ACTIVE FUTURE LEADERS (6 VOLUNTEERS) AND PAST FUTURE LEADERS (8 VOLUNTEERS) WHO HAVE AGREED TO REMAIN AS LEADERS FOR OTHER YOUNG ADULTS WITH TSC. EDUCATION PARENT MENTORS ATTENDED 115 SCHOOL MEETINGS (IEPS, EVALUATION TEAM MEETINGS, 504 PLAN MEETINGS, RESOLUTION MEETINGS, AND MEDIATIONS) IN PERSON, THROUGH SKYPE/ FACETIME, AND VIA CONFERENCE CALLS TO SUPPORT FAMILIES IN ATTAINING EDUCATIONAL SERVICES FOR THEIR CHILDREN THROUGHOUT THE COUNTRY. SEVERAL SCHOOL SYSTEMS ALSO REQUESTED "TSC 101" IN AN EFFORT TO HELP THEM UNDERSTAND THE COMPLEXITIES OF TSC AND LEARNING ISSUES FOR CHILDREN WITH TSC. THE COMMUNITY PROGRAMS TEAM SUPPORTS A NETWORK OF 33 VOLUNTEER BRANCHES OF THE ORGANIZATION, CALLED COMMUNITY ALLIANCES, DIVIDED INTO 2 REGIONS, WITH A COMMUNITY PROGRAM MANAGER ASSIGNED TO EACH REGION TO MANAGE THE DAY-TO-DAY ACTIVITIES WITHIN THEIR REGIONS. AS OF DECEMBER 31, 2020, THERE WERE 98 LEADERSHIP POSITIONS (50 COMMUNITY ALLIANCE CHAIRS, CO-CHAIRS, VICE CHAIRS AND 48 WALK/FUNDRAISING CHAIRS AND CO-CHAIRS) WITH 3 OPEN POSITIONS. IN 2020, THESE COMMUNITY ALLIANCES PROVIDED LOCAL TSC EDUCATION AND PERSONAL SUPPORT THROUGHOUT THE COUNTRY TO 4,988 FAMILIES/INDIVIDUALS LIVING WITH TSC. TO HELP THE TSC COMMUNITY NAVIGATE THE CHALLENGES OF COVID-19, THE TSC ALLIANCE CREATED A SECTION OF OUR WEBSITE DEDICATED TO SHARING IMPORTANT INFORMATION ABOUT THE PANDEMIC SPECIFICALLY CURATED TO MEET THE NEEDS OF THOSE IMPACTED BY TSC. THE TSC ALLIANCE COVID-19 LANDING PAGE, [WWW.TSALLIANCE.ORG/COVID-19](http://WWW.TSALLIANCE.ORG/COVID-19), INCLUDES RESOURCES FOR TSC MEDICAL PROFESSIONALS (WITH THE HELP OF OUR PROFESSIONAL ADVISORY BOARD); VACCINE POSITION STATEMENT; LISTING OF TSC CLINICS OFFERING TELEHEALTH; FDA DRUG SHORTAGES; SUPPLY CHAIN UPDATES; CO-PAY SAVINGS PROGRAMS DURING COVID-19; COVID-19 FAQS; COMMUNITY EDUCATIONAL RESOURCES; AND WEBINAR SERIES. THERE WERE 23,447 VIEWS ON THE COVID-19 LANDING PAGE IN 2020. THE TSC ALLIANCE ALSO LAUNCHED A WEEKLY EDUCATIONAL SERIES ON MARCH 23 WITH PROGRAMMING LASTING 11 WEEKS. THIS EFFORT INCLUDED FIVE VIRTUAL TOWN HALLS IN PARTNERSHIP WITH OTHER NONPROFIT ORGANIZATIONS AS WELL AS HOSTING TWO WORLD FORUM WEBINARS FOR TSCI ON MAY 12 AND 26. - MARCH 20: TSC/LAM VIRTUAL TOWN HALL: COVID-19 UPDATE, CO-HOSTED WITH THE LAM FOUNDATION- APRIL 10: VIRTUAL TOWN HALL: ACCESSIBILITY TO CARE, CO-HOSTED WITH THE CHILD NEUROLOGY FOUNDATION AND DUP15Q ALLIANCE- MAY 1: VIRTUAL TOWN HALL: ACCESSIBILITY TO TREATMENTS (INCLUDING DRUG SUPPLY), CO-HOSTED WITH THE DRAVET SYNDROME FOUNDATION AND LGS FOUNDATION- MAY 15: VIRTUAL TOWN HALL: RESCUE MEDS, SEIZURE TRACKER AND A FUTURE GLIMPSE AT FORECASTING SEIZURE RISK, CO-HOSTED WITH SEIZURE TRACKER- MAY 22: TSC/LAM VIRTUAL TOWN HALL: MOVING ON FROM SHELTER IN PLACE, CO-HOSTED WITH THE LAM FOUNDATION THE TSC ALLIANCE ALSO PRESENTED 15 WEBINARS ON TOPICS OF RELEVANCE TO TSC INDIVIDUALS AND FAMILIES, INCLUDING SCHOOLING AT HOME, ANXIETY, SELF-CARE, FILING FOR UNEMPLOYMENT, RESEARCH UPDATES, COMMUNITY PROGRAMS UPDATE, REMOTE BEHAVIORAL INTERVENTIONS AND OTHERS. NINE OPEN FORUMS WERE HELD, PROVIDING A PLATFORM FOR CAREGIVERS, TEENS, SIBLINGS AND ADULTS WITH TSC TO OPENLY DISCUSS ISSUES RELATED TO COVID-19 AND TSC. IN TOTAL, THERE WERE 9,151 VIEWS OF THE WEBINAR AND TOWN HALL SERIES. THE TSC ALLIANCE CO-HOSTED 3 VIRTUAL REGIONAL CONFERENCES WITH THE LAM FOUNDATION FEATURING REGIONAL PROFESSIONALS IN MEMPHIS, GAINSVILLE AND DENVER. THESE EVENTS ATTRACTED A TOTAL OF 818 REGISTERED ATTENDEES, INCLUDING 636 ATTENDEES ON THE DAY OF THE CONFERENCE, 1,106 SUBSEQUENT VIDEO VIEWS, AND 424 VISITS TO THE VIRTUAL EXHIBIT HALLS. THERE WERE 21 SPEAKERS FROM 12 DIFFERENT INSTITUTES, REPRESENTING TSC CLINICS, TSC CENTERS OF EXCELLENCE OR LAM CLINICS.

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**Form 990, Part III, Line 4c:**

PUBLIC HEALTH EDUCATION HEIGHTENS AWARENESS OF TSC THROUGHOUT THE GENERAL PUBLIC TO BROADEN THE SCOPE OF SUPPORT AND UNDERSTANDING BEYOND TSC INDIVIDUALS AND THEIR FAMILIES. DURING 2020, THE TSC ALLIANCE PRODUCED TWO ISSUES OF ITS NATIONAL MAGAZINE, PERSPECTIVE, WHICH IS MAILED TO APPROXIMATELY 14,500 CONSTITUENTS AS WELL AS POSTED ON THE WEBSITE. THE TSC ALLIANCE'S WEBSITE INCREASES AWARENESS AND PROVIDES EXTENSIVE EDUCATION THROUGH AN AVERAGE OF MORE THAN 22,300 UNIQUE VISITORS EACH MONTH. THE TSC ALLIANCE ALSO RELIES HEAVILY ON SOCIAL MEDIA TO EDUCATE CONSTITUENTS AND PROMOTE NEW RESOURCES AND EVENTS. ITS FACEBOOK GROUP BOASTS MORE THAN 10,000 MEMBERS, WHILE ITS TWITTER AND INSTAGRAM ACCOUNTS BOTH HAVE 2,400-PLUS FOLLOWERS. THE TSC ALLIANCE'S PODCAST SERIES, CALLED TSC NOW, PRODUCED 11 EPISODES WITH 1,906 DOWNLOADS. SIX ISSUES OF THE ELECTRONIC, TSC MATTERS, WERE DISTRIBUTED TO 1,006 SUBSCRIBERS. THE TSC ALLIANCE'S ONLINE EDUCATIONAL PLATFORM, TSC ACADEMY, INTRODUCED 3 NEW COURSES COVERING THE TOPICS OF CBD, FDA REVIEW PROCESS AND STATE AND LOCAL ADVOCACY. TO INCREASE PUBLIC AWARENESS, THE TSC ALLIANCE PARTICIPATED IN THE SIXTH ANNUAL TSC GLOBAL AWARENESS DAY ON MAY 15 AS WELL AS TSC AWARENESS MONTH THROUGHOUT MAY. THE TSC ALLIANCE AGAIN HEAVILY PROMOTED INFANTILE SPASMS AWARENESS WEEK, DECEMBER 1 TO 7. THIS AWARENESS CAMPAIGN INCLUDED A SOCIAL MEDIA CAMPAIGN AND TARGETED NATIONAL PRINT PUBLICATIONS, MEDICAL TRADE MAGAZINES AND PODCASTS, RESULTING IN 10 MEDIA PLACEMENTS, 31.7 MILLION-PLUS IMPRESSIONS AND 550-PLUS SOCIAL ENGAGEMENTS. IN 2020, THE TSC ALLIANCE'S VARIOUS NEWS RELEASES CULMINATED IN 694 MILLION IMPRESSIONS.

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**Describe the exempt purpose achievements for each of the organization's three largest program services by expenses. Section 501(c)(3) and (4) organizations and 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.**

(Code: )	(Expenses \$ 149,611	including grants of \$	(Revenue \$ )
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GOVERNMENT RELATIONS EFFORTS FOCUS ON INCREASING FEDERAL AND STATE APPROPRIATIONS FOR TSC RESEARCH, RAISING AWARENESS, AND COLLABORATING WITH GOVERNMENT PARTNERS TO DRIVE TSC RESEARCH FORWARD AND IMPROVE CLINICAL CARE AND TREATMENT OPTIONS FOR INDIVIDUALS WITH TSC. ON THE STATE LEVEL, THE TSC ALLIANCE ADVOCATED FOR STATE FUNDING FOR TSC CENTERS IN MISSOURI AND MARYLAND, RESULTING IN AT LEAST \$500,000 IN STATE APPROPRIATIONS. THE ANNUAL TSC ALLIANCE MARCH ON CAPITOL HILL TO ADVOCATE FOR FEDERAL FUNDING FOR THE TUBEROUS SCLEROSIS COMPLEX RESEARCH PROGRAM (TSCRP) AT THE DEPARTMENT OF DEFENSE'S (DOD) CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP) TOOK PLACE IN EARLY MARCH 2020. MORE THAN 120 MEMBERS OF THE TSC COMMUNITY PARTICIPATED AND ASKED THEIR SENATORS AND REPRESENTATIVES TO SIGN ONTO DEAR COLLEAGUE LETTERS IN SUPPORT OF THE TSCRP. MANY OTHER ADVOCATES WHO WERE NOT ABLE TO TRAVEL TO WASHINGTON, DC MET WITH THEIR SENATORS AND REPRESENTATIVES IN THEIR HOME STATES TO MAKE THE CASE FOR CONTINUED FUNDING. THE FY21 HOUSE DEAR COLLEAGUE LETTER WAS CO-SPONSORED BY REPRESENTATIVES MARKWAYNE MULLIN (R-OK) AND DAVE LOEBSACK (D-IA) AND CLOSED WITH 216 SIGNERS. THE FY21 SENATE DEAR COLLEAGUE LETTER, SPONSORED BY SENATORS KEVIN CRAMER (R-ND) AND JON TESTER (D-MT), CLOSED WITH 35 SIGNATURES. SENATORS CRAMER AND TESTER WERE BOTH NEW SPONSORS FOR FY21. IN FY2021, THE TSC RESEARCH PROGRAM AT THE CDMRP RECEIVED AN \$8 MILLION APPROPRIATION, BRINGING THE CUMULATIVE FUNDING TO \$97 MILLION SINCE 2002 AS A RESULT OF OUR SUCCESSFUL GRASSROOTS EFFORTS. RESEARCH PERFORMED THROUGH THIS PROGRAM HAS RECENTLY LED TO ADDITIONAL CLINICAL TRIALS INCLUDING DETERMINING IF IMATINIB, A DRUG FDA-APPROVED FOR CANCER, CAN SAFELY IMPROVE LEVELS OF VEGF-D, A BIOMARKER OF LYMPHANGIOLEIOMYOMATOSIS (LAM), A LIFE-THREATENING LUNG MANIFESTATION OF TSC, FUNDED IN FY2013; TESTING A COMBINATION OF TWO DRUGS TO TREAT LAM FUNDED IN FY2012; A MULTI-SITE CLINICAL TRIAL TESTING THE EFFICACY OF AN EXPERIMENTAL TOPICAL RAPAMYCIN CREAM TO TREAT THE DISFIGURING FACIAL TUMORS, CALLED FACIAL ANGIOFIBROMAS, CAUSED BY TSC FUNDED IN FY2010; A CLINICAL RESEARCH NETWORK WAS CREATED TO TEST POTENTIAL NEW THERAPIES, TO VALIDATE BIOMARKERS, AND TO LEARN THE NATURAL HISTORY OF LEADING TO A CLINICAL TRIAL FUNDED IN FY2012. DATA OBTAINED FROM AN FY2010 TSCRP CLINICAL RESEARCH AWARD TO DEFINE EARLY AUTISM PREDICTORS IN TSC AND AN FY2014 TSCRP AWARD FOR A PILOT CLINICAL TRIAL IS BEING TESTED IN A LARGE, NIH-FUNDED CLINICAL TRIAL LOOKING AT THE EFFECTIVENESS OF A BEHAVIORAL INTERVENTION STRATEGY, JASPER, TO IMPROVE OUTCOMES IN CHILDREN WITH AUTISM. THE TSCRP HAS ALSO FUNDED RESEARCH TO DEVELOP ANIMAL MODELS OF TSC THAT HAVE SEIZURES, ENABLING A BETTER UNDERSTANDING OF THE ETIOLOGY OF TSC. BASED ON DATA FROM TSCRP-FUNDED ANIMAL MODELS OF TSC THAT HAVE SEIZURES AND SHARE PATHOLOGY RELATED TO THAT OF TRAUMATIC BRAIN INJURY, AN INDUSTRY-SPONSORED CLINICAL TRIAL DEMONSTRATED THE EFFECTIVENESS THE MTOR INHIBITOR, EVEROLIMUS, AT TREATING EPILEPSY IN MANY INDIVIDUALS WITH TSC. NONE OF THIS PROGRESS WOULD HAVE BEEN POSSIBLE WITHOUT THE CRITICAL SUPPORT PROVIDED THROUGH THE TSCRP.

(Code: )	(Expenses \$ 66,927	including grants of \$	(Revenue \$ )
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GLOBAL OUTREACH WORKS TO ADDRESS UNMET NEEDS WITHIN THE GLOBAL TSC COMMUNITY. THE PROGRAM PROVIDES THE OPPORTUNITY FOR THE TSC ALLIANCE TO SHARE EXPERIENCES AND ASSIST IN THE START-UP OF SUPPORT OF TSC-RELATED ORGANIZATIONS IN OTHER COUNTRIES. A GLOBAL ALLIANCE IS A STRUCTURED GROUP OF EMPOWERED AND CARING VOLUNTEERS WHO WORK CLOSELY WITH THE TSC ALLIANCE TO FACILITATE LOCAL CONNECTIONS FOR INDIVIDUALS AND FAMILIES AFFECTED BY TSC AND RAISE REVENUE AND AWARENESS WHILE SUPPORTING THE MISSION OF THE ORGANIZATION. THE TSC ALLIANCE HAS SIX GLOBAL PARTNERSHIPS, INCLUDING: TS ALLIANCE OF ISRAEL, TS CANADA ST, TS ALLIANCE OF MEXICO, TS ALLIANCE FOUNDATION (IN THAILAND), HUNGARIAN FOUNDATION FOR TUBEROUS SCLEROSIS, AND TS ALLIANCE OF INDIA. THIS TS ALLIANCE RECOGNIZES 10 TSC CLINICS IN GLOBAL ALLIANCE COUNTRIES.



**Form 990, Part III - 4 Program Service Accomplishments (See the Instructions)**

**Describe the exempt purpose achievements for each of the organization's three largest program services by expenses. Section 501(c)(3) and (4) organizations and 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.**

(Code: ) (Expenses \$ 24,324 including grants of \$ ) (Revenue \$ )

PROFESSIONAL EDUCATION EXPANDS PROGRAMS TO TARGET RESEARCHERS AND HEALTHCARE PROVIDERS CARING FOR INDIVIDUALS WITH TSC, MEDICAL STUDENTS, GENETIC COUNSELORS AND EDUCATORS TO MINIMIZE THE CONSEQUENCES OF IGNORANCE AND MISINFORMATION. THE TSC ALLIANCE PARTICIPATED IN AND PRESENTED AT 22 PROFESSIONAL MEETINGS IN 2020 INCLUDING: AMERICAN THORACIC SOCIETY (ATS) BOARD MEETING; NATIONAL INSTITUTE FOR NEUROLOGICAL DISORDERS AND STROKE (NINDS) COUNCIL MEETING; EPILEPSY LEARNING HEALTHCARE SYSTEM (ELHS) HIGH-LEVEL VIRTUAL LEARNING SESSION; DRUG INFORMATION ASSOCIATION (DIA) CONFERENCE ON PATIENT ENGAGEMENT; NINDS NONPROFIT FORUM; ATS PUBLIC ADVISORY ROUNDTABLE (ATS PAR) MEET THE EXPERTS, PATIENT/FAMILY EDUCATION FORUM; EPILEPSY LEADERSHIP COUNCIL (ELC) STEERING COMMITTEE MEETING; VIRTUAL WORLD ORPHAN DRUG CONGRESS; VIRTUAL EPILEPSY PIPELINE CONFERENCE; EVERYLIFE FOUNDATION FOR RARE DISEASES NEWBORN SCREENING BOOTCAMP; HEALTH RESEARCH ALLIANCE (HRA) MEMBERS MEETING; ATS LEADERSHIP SUMMIT; GLOBAL GENES RARE PATIENT ADVOCACY UN-SUMMIT; FASTERCURES PARTNERSHIP MATURITY MODEL WORKSHOP; ELHS FALL LEARNING SESSION; GLOBAL GENES: HOW PATIENTS IMPACT THE 505(B)(2) REGULATORY PROCESS; NATIONAL ASSOCIATION OF MANAGED CARE PHYSICIANS; INTERNATIONAL TSC RESEARCH CONFERENCE; EPILEPSY DAY AT DISNEYLAND; GLOBAL GENES RARE ENTREPRENEUR'S BOOTCAMP; AMERICAN EPILEPSY SOCIETY; AND MILKEN INSTITUTE FUTURE OF HEALTH SUMMIT.

Form 990, Part VII - Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors										
(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
CHRIS RUSSELL CHAIR	5.00 ..... 0.00	X		X				0	0	0
PETER CRINO MD PHD VICE CHAIR	5.00 ..... 0.00	X		X				0	0	0
TIM DILLS IMMEDIATE PAST CHAIR	5.00 ..... 0.00	X		X				0	0	0
LAURA MARKS SECRETARY	5.00 ..... 0.00	X		X				0	0	0
WILLIAM JOSEPH TREASURER	5.00 ..... 1.00	X		X				0	0	0
JULIE BLUM BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
MATT BOLGER BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
CASSANDRA CARROLL BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
MARK CARROLL BOARD MEMBER	2.00 ..... 1.00	X						0	0	0
SARA CHIEFFO BOARD MEMBER	2.00 ..... 0.00	X						0	0	0

Form 990, Part VII - Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors										
(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
DAVID COIT ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
MARGARET COX ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
BONNIE HOGUE DUFFY ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
STEVEN GOLDSTEIN ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
ROB GRANDIA ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
DANA HOLINKA ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
DARCY A KRUEGER ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
HEATHER LENS ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
JIM MAGINN ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
DIANE MCSWAIN ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0

Form 990, Part VII - Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors										
(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
MUSTAFA SAHIN ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
SEAN SHILLINGER ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
JUDY SHOULAK ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
MATTHEW SIMONIAN ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
VANESSA VAZQUEZ ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
PAUL WAXLAX ..... BOARD MEMBER	2.00 ..... 1.00	X						0	0	0
TARA ZIMMERMAN ..... BOARD MEMBER	2.00 ..... 0.00	X						0	0	0
KARI L ROSBECK ..... PRESIDENT & CEO	54.00 ..... 1.00			X				194,307	3,598	22,457
RICHARD GOLLUB ..... CFO	47.00 ..... 3.00			X				143,807	9,180	24,213
STEVEN L ROBERDS ..... CHIEF SCIENTIFIC OFFICER	45.00 ..... 0.00				X			208,882	0	21,307

Form 990, Part VII - Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors										
(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
JAYE D ISHAM ..... VP, COMMUNICATIONS STRATEGY	45.00 ..... 0.00					X		119,879	0	4,398
LISA M MOSS ..... SR. DIR. DONOR RELATIONS	45.00 ..... 0.00					X		109,573	0	18,518
APRIL COOPER ..... DIR. COMMUNITY PROGRAMS	45.00 ..... 0.00					X		107,298	0	4,722
DEAN RAGER-AGUIAR ..... DIR. PRECLINICAL RESEARCH	45.00 ..... 0.00					X		147,083	0	21,593

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

2020

Open to Public Inspection

Name of the organization  
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number  
95-3018799

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 **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		
Total						

**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 failed to qualify under the tests listed below, please complete Part III.)

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ►		(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>1</b>	Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grant.") . . .	4,517,826	3,949,953	4,105,376	5,527,543	4,345,011	22,445,709
<b>2</b>	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf. . . .						
<b>3</b>	The value of services or facilities furnished by a governmental unit to the organization without charge..						
<b>4</b>	<b>Total.</b> Add lines 1 through 3	4,517,826	3,949,953	4,105,376	5,527,543	4,345,011	22,445,709
<b>5</b>	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) . . .						3,416,325
<b>6</b>	<b>Public support.</b> Subtract line 5 from line 4.						19,029,384

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ►		(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>7</b>	Amounts from line 4. . .	4,517,826	3,949,953	4,105,376	5,527,543	4,345,011	22,445,709
<b>8</b>	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources. . . .	15,431	10,393	13,784	27,444	11,188	78,240
<b>9</b>	Net income from unrelated business activities, whether or not the business is regularly carried on. . .	44,490					44,490
<b>10</b>	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.). . .	1,683	642	1,243	714		4,282
<b>11</b>	<b>Total support.</b> Add lines 7 through 10						22,572,721
<b>12</b>	Gross receipts from related activities, etc. (see instructions) . . . . .					<b>12</b>	7,774,339

**13** **First 5 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**

<b>14</b>	Public support percentage for 2020 (line 6, column (f) divided by line 11, column (f)) . . . . .	<b>14</b>	84.300 %
<b>15</b>	Public support percentage for 2019 Schedule A, Part II, line 14 . . . . .	<b>15</b>	82.340 %

**16a** **33 1/3% support test—2020.** 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—2019.** 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—2020.** 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—2019.** 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**

Calendar year (or fiscal year beginning in) ►	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .						
<b>2</b> Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 . . . . .						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf. . .						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge						
<b>6 Total.</b> Add lines 1 through 5						
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons						
<b>b</b> Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year.						
<b>c</b> Add lines 7a and 7b. .						
<b>8 Public support.</b> (Subtract line 7c from line 6.)						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ►	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
<b>9</b> Amounts from line 6. . .						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources. .						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						
<b>c</b> Add lines 10a and 10b.						
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on.						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . .						
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.) . .						
<b>14 First 5 years.</b> 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 <b>stop here.</b> . . . . . ► <input type="checkbox"/>						

**Section C. Computation of Public Support Percentage**

<b>15</b> Public support percentage for 2020 (line 8, column (f) divided by line 13, column (f)) . . . . .	<b>15</b>	
<b>16</b> Public support percentage from 2019 Schedule A, Part III, line 15 . . . . .	<b>16</b>	

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for <b>2020</b> (line 10c, column (f) divided by line 13, column (f)) . . . . .	<b>17</b>	
<b>18</b> Investment income percentage from <b>2019</b> Schedule A, Part III, line 17 . . . . .	<b>18</b>	

**19a 33 1/3% support tests—2020.** 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—2019.** 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 . . . . . ► ☐



**Part IV Supporting Organizations**

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, of Part I, complete Sections A and B. If you checked box 12b, of Part I, complete Sections A and C. If you checked box 12c, of Part I, complete Sections A, D, and E. If you checked box 12d, of Part I, complete Sections A and D, and complete Part V.)

**Section A. All Supporting Organizations**

	Yes	No
<b>1</b> Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>If "No," describe in <b>Part VI</b> how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i>		
<b>1</b>		
<b>2</b> Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in <b>Part VI</b> how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
<b>2</b>		
<b>3a</b> Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer lines 3b and 3c below.</i>		
<b>3a</b>		
<b>b</b> Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? <i>If "Yes," describe in <b>Part VI</b> when and how the organization made the determination.</i>		
<b>3b</b>		
<b>c</b> Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in <b>Part VI</b> what controls the organization put in place to ensure such use.</i>		
<b>3c</b>		
<b>4a</b> Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes" and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.</i>		
<b>4a</b>		
<b>b</b> Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>If "Yes," describe in <b>Part VI</b> how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i>		
<b>4b</b>		
<b>c</b> Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <i>If "Yes," explain in <b>Part VI</b> what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i>		
<b>4c</b>		
<b>5a</b> Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in <b>Part VI</b>, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>		
<b>5a</b>		
<b>b</b> <b>Type I or Type II only.</b> Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
<b>5b</b>		
<b>c</b> <b>Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
<b>5c</b>		
<b>6</b> Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If "Yes," provide detail in <b>Part VI</b>.</i>		
<b>6</b>		
<b>7</b> Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ) .</i>		
<b>7</b>		
<b>8</b> Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
<b>8</b>		
<b>9a</b> Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If "Yes," provide detail in <b>Part VI</b>.</i>		
<b>9a</b>		
<b>b</b> Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in <b>Part VI</b>.</i>		
<b>9b</b>		
<b>c</b> Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in <b>Part VI</b>.</i>		
<b>9c</b>		
<b>10a</b> Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If "Yes," answer line 10b below.</i>		
<b>10a</b>		
<b>b</b> Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings).</i>		
<b>10b</b>		

Part IV

Supporting Organizations (continued)

	Yes	No
<b>11</b> Has the organization accepted a gift or contribution from any of the following persons?		
<b>a</b> A person who directly or indirectly controls, either alone or together with persons described in lines 11b and 11c below, the governing body of a supported organization?		
<b>b</b> A family member of a person described in 11a above?		
<b>c</b> A 35% controlled entity of a person described in line 11a or 11b above? <i>If "Yes" to 11a, 11b, or 11c, provide detail in Part VI.</i>		

Section B. Type I Supporting Organizations

	Yes	No
<b>1</b> Did the officers, directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
<b>2</b> Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization.</i>		

Section C. Type II Supporting Organizations

	Yes	No
<b>1</b> Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

Section D. All Type III Supporting Organizations

	Yes	No
<b>1</b> Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
<b>2</b> Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization (s) or (ii) serving on the governing body of a supported organization? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
<b>3</b> By reason of the relationship described in line 2 above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally-Integrated Supporting Organizations

<b>1</b> Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions):		
<b>a</b> <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
<b>b</b> <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
<b>c</b> <input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions)		
<b>2</b> Activities Test. Answer lines 2a and 2b below.		
<b>a</b> Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
<b>b</b> Did the activities described in line 2a constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
<b>3</b> Parent of Supported Organizations. Answer lines 3a and 3b below.		
<b>a</b> Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>If "Yes" or "No" provide details in Part VI.</i>		
<b>b</b> Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? <i>If "Yes," describe in Part VI. the role played by the organization in this regard.</i>		

<b>Part V</b> <b>Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations</b>			
<b>1</b> <input type="checkbox"/> Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 ( <i>explain in Part VI</i> ). <b>See instructions.</b> All other Type III non-functionally integrated supporting organizations must complete Sections A through E.			
<b>Section A - Adjusted Net Income</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b>	Net short-term capital gain	<b>1</b>	
<b>2</b>	Recoveries of prior-year distributions	<b>2</b>	
<b>3</b>	Other gross income (see instructions)	<b>3</b>	
<b>4</b>	Add lines 1 through 3	<b>4</b>	
<b>5</b>	Depreciation and depletion	<b>5</b>	
<b>6</b>	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	<b>6</b>	
<b>7</b>	Other expenses (see instructions)	<b>7</b>	
<b>8</b>	<b>Adjusted Net Income</b> (subtract lines 5, 6 and 7 from line 4)	<b>8</b>	
<b>Section B - Minimum Asset Amount</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b>	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):	<b>1</b>	
<b>a</b>	Average monthly value of securities	<b>1a</b>	
<b>b</b>	Average monthly cash balances	<b>1b</b>	
<b>c</b>	Fair market value of other non-exempt-use assets	<b>1c</b>	
<b>d</b>	<b>Total</b> (add lines 1a, 1b, and 1c)	<b>1d</b>	
<b>e</b>	<b>Discount</b> claimed for blockage or other factors ( <i>explain in detail in Part VI</i> ):		
<b>2</b>	Acquisition indebtedness applicable to non-exempt use assets	<b>2</b>	
<b>3</b>	Subtract line 2 from line 1d	<b>3</b>	
<b>4</b>	Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).	<b>4</b>	
<b>5</b>	Net value of non-exempt-use assets (subtract line 4 from line 3)	<b>5</b>	
<b>6</b>	Multiply line 5 by 0.035	<b>6</b>	
<b>7</b>	Recoveries of prior-year distributions	<b>7</b>	
<b>8</b>	<b>Minimum Asset Amount</b> (add line 7 to line 6)	<b>8</b>	
<b>Section C - Distributable Amount</b>			Current Year
<b>1</b>	Adjusted net income for prior year (from Section A, line 8, Column A)	<b>1</b>	
<b>2</b>	Enter 85% of line 1	<b>2</b>	
<b>3</b>	Minimum asset amount for prior year (from Section B, line 8, Column A)	<b>3</b>	
<b>4</b>	Enter greater of line 2 or line 3	<b>4</b>	
<b>5</b>	Income tax imposed in prior year	<b>5</b>	
<b>6</b>	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	<b>6</b>	
<b>7</b>	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)		

Part V

Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Section D - Distributions		Current Year
1	Amounts paid to supported organizations to accomplish exempt purposes	1
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2
3	Administrative expenses paid to accomplish exempt purposes of supported organizations	3
4	Amounts paid to acquire exempt-use assets	4
5	Qualified set-aside amounts (prior IRS approval required - provide details in Part VI)	5
6	Other distributions (describe in Part VI). See instructions	6
7	Total annual distributions. Add lines 1 through 6.	7
8	Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions	8
9	Distributable amount for 2020 from Section C, line 6	9
10	Line 8 amount divided by Line 9 amount	10

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2020	(iii) Distributable Amount for 2020
1	Distributable amount for 2020 from Section C, line 6		
2	Underdistributions, if any, for years prior to 2020 (reasonable cause required-- explain in Part VI). See instructions.		
3	Excess distributions carryover, if any, to 2020:		
a	From 2015. . . . .		
b	From 2016. . . . .		
c	From 2017. . . . .		
d	From 2018. . . . .		
e	From 2019. . . . .		
f	Total of lines 3a through e		
g	Applied to underdistributions of prior years		
h	Applied to 2020 distributable amount		
i	Carryover from 2015 not applied (see instructions)		
j	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.		
4	Distributions for 2020 from Section D, line 7: \$		
a	Applied to underdistributions of prior years		
b	Applied to 2020 distributable amount		
c	Remainder. Subtract lines 4a and 4b from line 4.		
5	Remaining underdistributions for years prior to 2020, if any. Subtract lines 3g and 4a from line 2. If the amount is greater than zero, explain in Part VI. See instructions.		
6	Remaining underdistributions for 2020. Subtract lines 3h and 4b from line 1. If the amount is greater than zero, explain in Part VI. See instructions.		
7	Excess distributions carryover to 2021. Add lines 3j and 4c.		
8	Breakdown of line 7:		
a	Excess from 2016. . . . .		
b	Excess from 2017. . . . .		
c	Excess from 2018. . . . .		
d	Excess from 2019. . . . .		
e	Excess from 2020. . . . .		

**Part VI** **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b; Part V, line 1; Part V, Section B, line 1e; Part V Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test

**990 Schedule A, Supplemental Information**

Return Reference	Explanation
SCHEDULE A, PART II, LINE 10, EXPLANATION OF OTHER INCOME:	INCOME FROM ACTIVITIES NOT REGULARLY CARRIED ON - 2016 AMOUNT: \$ 1,683. 2017 AMOUNT: \$ 642 . 2018 AMOUNT: \$ 1,243. 2019 AMOUNT: \$ 714. 2020 AMOUNT: \$ 0.

SCHEDULE C  
(Form 990 or 990-EZ)

Department of the Treasury  
Internal Revenue Service

Political Campaign and Lobbying Activities

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.

OMB No. 1545-0047

2020

Open to Public Inspection

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 the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
---	--

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?	<input type="checkbox"/> Yes <input type="checkbox"/> No
4a	Was a correction made?	<input type="checkbox"/> Yes <input type="checkbox"/> 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?	<input type="checkbox"/> Yes <input type="checkbox"/> 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> (The term "expenditures" means amounts paid or incurred.)	(a) Filing organization's totals	(b) Affiliated group totals												
<b>1a</b> Total lobbying expenditures to influence public opinion (grass roots lobbying) .....	895													
<b>b</b> Total lobbying expenditures to influence a legislative body (direct lobbying) .....	122,119													
<b>c</b> Total lobbying expenditures (add lines 1a and 1b) .....	123,014													
<b>d</b> Other exempt purpose expenditures .....	5,350,680													
<b>e</b> Total exempt purpose expenditures (add lines 1c and 1d) .....	5,473,694													
<b>f</b> Lobbying nontaxable amount. Enter the amount from the following table in both columns.	423,685													
<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 50%;">If the amount on line 1e, column (a) or (b) is:</th> <th style="width: 50%;">The lobbying nontaxable amount is:</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>	If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:	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.		
If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:													
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) .....	105,921													
<b>h</b> Subtract line 1g from line 1a. If zero or less, enter -0- .....	0													
<b>i</b> Subtract line 1f from line 1c. If zero or less, enter -0- .....	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 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.)**

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) Total
<b>2a</b> Lobbying nontaxable amount	416,065	450,555	445,393	423,685	1,735,698
<b>b</b> Lobbying ceiling amount (150% of line 2a, column(e))					2,603,547
<b>c</b> Total lobbying expenditures	146,199	149,340	165,226	123,014	583,779
<b>d</b> Grassroots nontaxable amount	104,016	112,639	111,348	105,921	433,924
<b>e</b> Grassroots ceiling amount (150% of line 2d, column (e))					650,886
<b>f</b> Grassroots lobbying expenditures	1,797	823	2,491	895	6,006

**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.

		(a)		(b)
		Yes	No	Amount
<b>1</b>	During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
<b>a</b>	Volunteers? .....			
<b>b</b>	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)? .....			
<b>c</b>	Media advertisements? .....			
<b>d</b>	Mailings to members, legislators, or the public? .....			
<b>e</b>	Publications, or published or broadcast statements? .....			
<b>f</b>	Grants to other organizations for lobbying purposes? .....			
<b>g</b>	Direct contact with legislators, their staffs, government officials, or a legislative body? .....			
<b>h</b>	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means? .....			
<b>i</b>	Other activities? .....			
<b>j</b>	Total. Add lines 1c through 1i .....			
<b>2a</b>	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)? .....			
<b>b</b>	If "Yes," enter the amount of any tax incurred under section 4912 .....			
<b>c</b>	If "Yes," enter the amount of any tax incurred by organization managers under section 4912 .....			
<b>d</b>	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).**

	Yes	No
<b>1</b> Were substantially all (90% or more) dues received nondeductible by members? .....	<b>1</b>	
<b>2</b> Did the organization make only in-house lobbying expenditures of \$2,000 or less? .....	<b>2</b>	
<b>3</b> Did the organization agree to carry over lobbying and political expenditures from the prior year? .....	<b>3</b>	

**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."**

<b>1</b>	Dues, assessments and similar amounts from members .....	<b>1</b>	
<b>2</b>	Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).		
<b>a</b>	Current year .....	<b>2a</b>	
<b>b</b>	Carryover from last year .....	<b>2b</b>	
<b>c</b>	Total .....	<b>2c</b>	
<b>3</b>	Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues .	<b>3</b>	
<b>4</b>	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? .....	<b>4</b>	
<b>5</b>	Taxable amount of lobbying and political expenditures (see instructions) .....	<b>5</b>	

**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.

Return Reference	Explanation
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SCHEDULE D  
(Form 990)

Department of the Treasury  
Internal Revenue Service

Supplemental Financial Statements

► 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.  
► 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

2020

Open to Public Inspection

Name of the organization  
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number  
95-3018799

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.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year . . . . .		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year . . . . .		

5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? . . . . .

☐ Yes ☐ No

6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? . . . . .

☐ Yes ☐ No

Part II

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

1 Purpose(s) of conservation easements held by the organization (check all that apply).

☐ Preservation of land for public use (e.g., recreation or education)

☐ Preservation of an historically important land area

☐ Protection of natural habitat

☐ Preservation of a certified historic structure

☐ Preservation of open space

2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.

	Held at the End of the Year
a Total number of conservation easements . . . . .	2a
b Total acreage restricted by conservation easements . . . . .	2b
c Number of conservation easements on a certified historic structure included in (a) . . . . .	2c
d Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register . . . . .	2d

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ►

4 Number of states where property subject to conservation easement is located ►

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? . . . . .

☐ Yes ☐ No

6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ►

7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ► \$

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? . . . . .

☐ Yes ☐ No

9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

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.

1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items.

b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) Revenue included on Form 990, Part VIII, line 1 . . . . . ► \$

(ii) Assets included in Form 990, Part X . . . . . ► \$

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items:

a Revenue included on Form 990, Part VIII, line 1 . . . . . ► \$

b Assets included in Form 990, Part X . . . . . ► \$

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

Cat. No. 52283D Schedule D (Form 990) 2020

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:

c

Beginning balance . . . . .

d

Additions during the year . . . . .

e

Distributions during the year . . . . .

f

Ending balance . . . . .

	Amount
1c	
1d	
1e	
1f	

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 in 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
1a Beginning of year balance . . . . .	5,915,805	5,193,934	5,655,555	5,293,989	4,763,517
b Contributions . . . . .	54,645	78,962	82,346	92,635	58,749
c Net investment earnings, gains, and losses	416,431	959,121	-439,321	739,072	525,868
d Grants or scholarships . . . . .					
e Other expenditures for facilities and programs . . . . .	463,721	288,356	50,000	403,000	
f Administrative expenses . . . . .	29,639	27,856	54,646	67,141	54,145
g End of year balance . . . . .	5,893,521	5,915,805	5,193,934	5,655,555	5,293,989

2

Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

a

Board designated or quasi-endowment ▶ 85.080 %

b

Permanent endowment ▶ 14.920 %

c

Term 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:

(i) Unrelated organizations . . . . .

(ii) Related organizations . . . . .

b

If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R? . . . . .

	Yes	No
3a(i)		No
3a(ii)	Yes	
3b	Yes	

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
1a Land . . . . .				
b Buildings . . . . .				
c Leasehold improvements		449,272	30,632	418,640
d Equipment . . . . .		191,620	109,910	81,710
e Other . . . . .		94,712	84,695	10,017
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).) . . . ▶				510,367

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 (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives . . . . .		
(2) Closely-held equity interests . . . . .		
(3) Other _____		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
(I)		
Total. (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: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
Total. (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) INTEREST IN NET ASSETS OF AFFILIATE	5,893,521
(2) OPERATING LEASE RIGHT-OF-USE ASSET	833,830
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 15.) . . . . . ▶	6,727,351

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) DEFERRED RENT & LEASE INCENTIVE	1,336,433
(3) DUE TO AFFILIATE	1,175
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col.(B) line 25.) ▶	1,337,608

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.

<b>1</b>	Total revenue, gains, and other support per audited financial statements . . . . .	<b>1</b>	5,210,068
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
<b>a</b>	Net unrealized gains (losses) on investments . . . . .	<b>2a</b>	
<b>b</b>	Donated services and use of facilities . . . . .	<b>2b</b>	81,904
<b>c</b>	Recoveries of prior year grants . . . . .	<b>2c</b>	
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>	
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .	<b>2e</b>	81,904
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .	<b>3</b>	5,128,164
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line <b>1</b> :		
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>	
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>	
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .	<b>4c</b>	0
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.) . . . . .	<b>5</b>	5,128,164

**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.

<b>1</b>	Total expenses and losses per audited financial statements . . . . .	<b>1</b>	5,504,094
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
<b>a</b>	Donated services and use of facilities . . . . .	<b>2a</b>	81,904
<b>b</b>	Prior year adjustments . . . . .	<b>2b</b>	
<b>c</b>	Other losses . . . . .	<b>2c</b>	
<b>d</b>	Other (Describe in Part XIII.) . . . . .	<b>2d</b>	
<b>e</b>	Add lines <b>2a</b> through <b>2d</b> . . . . .	<b>2e</b>	81,904
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b> . . . . .	<b>3</b>	5,422,190
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line <b>1</b> :		
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b . . . . .	<b>4a</b>	
<b>b</b>	Other (Describe in Part XIII.) . . . . .	<b>4b</b>	
<b>c</b>	Add lines <b>4a</b> and <b>4b</b> . . . . .	<b>4c</b>	0
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.) . . . . .	<b>5</b>	5,422,190

**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.

Return Reference	Explanation
See Additional Data Table	

**Part XIII** Supplemental Information *(continued)*

Return Reference	Explanation

**Additional Data**

**Software ID:**  
**Software Version:**  
**EIN:** 95-3018799  
**Name:** NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

**Supplemental Information**

Return Reference	Explanation
PART V, LINE 4:	THE ALLIANCE'S ENDOWMENTS CONSIST OF TWO FUNDS ESTABLISHED FOR DIFFERENT PURPOSES. THE ALLIANCE'S ENDOWMENT INCLUDE ONE TRADITIONAL DONOR-RESTRICTED ENDOWMENT FUNDS AND ONE BOARD-DESIGNATED ENDOWMENT FUND. THE BOARD-DESIGNATED ENDOWMENT FUND SOLELY CONSISTS OF THE ENDOWMENT FUND'S UNRESTRICTED NET ASSET BALANCE.

SCHEDULE F  
(Form 990)

Department of the Treasury  
Internal Revenue Service

Statement of Activities Outside the United States

▶ Complete if the organization answered "Yes" to 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.

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization  
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number  
95-3018799

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 Activites 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 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
See Add'l Data					
3a Sub-total . . . . .	0	0			111,726
b Total from continuation sheets to Part I . . . . .	0	0			0
c Totals (add lines 3a and 3b)	0	0			111,726

**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.

<b>1</b>	<b>(a)</b> Name of organization	<b>(b)</b> IRS code section and EIN (if applicable)	<b>(c)</b> Region	<b>(d)</b> Purpose of grant	<b>(e)</b> Amount of cash grant	<b>(f)</b> Manner of cash disbursement	<b>(g)</b> Amount of noncash assistance	<b>(h)</b> Description of noncash assistance	<b>(i)</b> Method of valuation (book, FMV, appraisal, other)
			MIDDLE EAST AND NORTH AFRICA	RESEARCH ON TUBEROUS SCLEROSIS COMPLEX	18,750	WIRE			
			EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM	PROGRAMMATIC SUPPORT	34,032	WIRE			

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 . . . . . **0**

3 Enter total number of other organizations or entities . . . . . **2**



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

[illegible]

**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.

**990 Schedule F, Supplemental Information**

Return Reference	Explanation
PART I, LINE 2:	GRANTEE ORGANIZATIONS ARE EXPECTED TO FILE ANNUAL PROGRESS REPORTS TO OUTLINED GRANT GOALS AND MILESTONES. THESE REPORTS ARE REVIEWED BY A COMMITTEE OF PEERS. THIS COMMITTEE MAKES DETERMINATIONS BASED ON QUALITY OF WORK TO GOALS AND IF THE GRANTEE WILL CONTINUE TO RECEIVE FUNDING. A FINAL WRITTEN AND FINANCIAL REPORT IS REQUIRED OF ALL GRANTEES.

**990 Schedule F, Supplemental Information**

Return Reference	Explanation
PART III ACCOUNTING METHOD:	

**Additional Data**

**Software ID:**  
**Software Version:**  
**EIN:** 95-3018799  
**Name:** NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

**Form 990 Schedule F Part I - Activities Outside The United States**

(a) Region	(b) Number of offices in the region	(c) Number of employees or agents in region	(d) Activities conducted in region (by type) (i.e., fundraising, program services, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for region
EUROPE (INCLUDING ICELAND & GREENLAND)	0	0	GRANTMAKING		34,032
MIDDLE EAST AND NORTH AFRICA	0	0	GRANTMAKING		18,750

**Form 990 Schedule F Part I - Activities Outside The United States**

(a) Region	(b) Number of offices in the region	(c) Number of employees or agents in region	(d) Activities conducted in region (by type) (i.e., fundraising, program services, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for region
EUROPE (INCLUDING ICELAND & GREENLAND)	0	0	PROGRAM SERVICE ACTIVITIES	PRECLINICAL RESEARCH STUDIES	58,944



**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.

Revenue		(a) Event #1 <b>VIRTUAL WALKS</b> (event type)	(b) Event #2 <b>COMEDY FOR A CURE</b> (event type)	(c) Other events <b>9</b> (total number)	(d) Total events (add col. (a) through col. (c))
	<b>1</b> Gross receipts . . . . .	660,000	179,147	406,278	1,245,425
	<b>2</b> Less: Contributions . . . . .	626,454	175,292	391,193	1,192,939
	<b>3</b> Gross income (line 1 minus line 2) . . . . .	33,546	3,855	15,085	52,486
Direct Expenses	<b>4</b> Cash prizes . . . . .				
	<b>5</b> Noncash prizes . . . . .	33,308	756	4,129	38,193
	<b>6</b> Rent/facility costs . . . . .			8,091	8,091
	<b>7</b> Food and beverages . . . . .	58	137	2,739	2,934
	<b>8</b> Entertainment . . . . .	180	1,979	127	2,286
	<b>9</b> Other direct expenses . . . . .				
	<b>10</b> Direct expense summary. Add lines 4 through 9 in column (d) . . . . . ►				51,504
	<b>11</b> Net income summary. Subtract line 10 from line 3, column (d) . . . . . ►				982

**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.

Revenue		(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 _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <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: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_



<b>11</b>	Does the organization conduct gaming activities with nonmembers?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>12</b>	Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>13</b>	Indicate the percentage of gaming activity conducted in:		
<b>a</b>	The organization's facility	<b>13a</b>	%
<b>b</b>	An outside facility	<b>13b</b>	%
<b>14</b>	Enter the name and address of the person who prepares the organization's gaming/special events books and records:		
	Name ► .....		
	Address ► .....		
<b>15a</b>	Does the organization have a contract with a third party from whom the organization receives gaming revenue?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>b</b>	If "Yes," enter the amount of gaming revenue received by the organization ► \$ ..... and the amount of gaming revenue retained by the third party ► \$ .....		
<b>c</b>	If "Yes," enter name and address of the third party:		
	Name ► .....		
	Address ► .....		
<b>16</b>	Gaming manager information:		
	Name ► .....		
	Gaming manager compensation ► \$ .....		
	Description of services provided ► .....		
	<input type="checkbox"/> Director/officer	<input type="checkbox"/> Employee	<input type="checkbox"/> Independent contractor
<b>17</b>	Mandatory distributions:		
<b>a</b>	Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?		<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>b</b>	Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ► \$ .....		

**Part IV Supplemental Information.** Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.

Return Reference	Explanation
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Note: To capture the full content of this document, please select landscape mode (11" x 8.5") when printing.

Schedule I  
(Form 990)

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

2020

Open to Public  
Inspection

Department of the  
Treasury  
Internal Revenue Service

Name of the organization  
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number

95-3018799

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.

(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) See Additional Data							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							

- 2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table . . . . . ▶ 13
- 3 Enter total number of other organizations listed in the line 1 table . . . . . ▶ 0

**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)					
(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.

Return Reference	Explanation
PART I, LINE 2:	THE TSC ALLIANCE HAS FUNDED MORE THAN \$27.7 MILLION IN RESEARCH ON TSC SINCE 1984. DIRECTED BY STEVEN L. ROBERDS, PH.D, CHIEF SCIENTIFIC OFFICER, THE TSC ALLIANCE RESEARCH GRANTS PROGRAM FUNDS RESEARCH FOCUSED ON TSC WITH PRIORITIES SET BY THE RESEARCHERS TOGETHER WITH THE TSC ALLIANCE. COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS ARE ENCOURAGED AND FOSTERED, AND THE TSC ALLIANCE IS WORKING TO INCREASE FUNDING FOR RESEARCH ON TSC. THROUGH THE TSC ALLIANCE RESEARCH GRANTS PROGRAM, APPLICATIONS CAN BE SUBMITTED FOR: POSTDOCTORAL FELLOWSHIPS AND TSC RESEARCH GRANTS. GRANTS ARE REVIEWED IN A THREE-STEP PROCESS: 1. A GRANT REVIEW COMMITTEE COMPOSED OF INDIVIDUALS KNOWLEDGEABLE ABOUT THE CLINICAL AND BASIC COMPONENTS OF TSC AS WELL AS CONSUMERS REVIEW ALL GRANT APPLICATIONS FOR SCIENTIFIC MERIT, RELEVANCY TO THE FUNDING PRIORITIES OF THE ORGANIZATION AND WITH A FOCUS ON UNDERSTANDING THE MECHANISMS OF TSC AND/OR THE DEVELOPMENT OF TREATMENTS AND THERAPIES FOR THE MANIFESTATIONS OF THE DISEASE. 2. THE SCIENCE AND MEDICAL COMMITTEE OF THE BOARD OF DIRECTORS THEN REVIEWS THE GRANT REVIEW COMMITTEE'S CONCLUSIONS AND MAKES FUNDING RECOMMENDATIONS TO THE BOARD OF DIRECTORS. 3. THE BOARD OF DIRECTORS THEN REVIEWS THE RECOMMENDATIONS OF THE SCIENCE AND MEDICAL COMMITTEE AND MAKES FINAL APPROVAL FOR THE FUNDING OF GRANTS.

Additional Data

Software ID:  
Software Version:  
EIN: 95-3018799  
Name: NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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 non-cash assistance	(h) Purpose of grant or assistance
BRIGHAM & WOMAN'S HOSPITAL 75 SAINT FRANCIS STREET BOSTON, MA 02115	04-2312909	501(C)(3)	55,436				RESEARCH GRANTS
UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER 5323 HARRY HINES BLVD DALLAS, TX 75287	75-6002868	501(C)(3)	56,250				RESEARCH GRANTS

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(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 non-cash assistance	(h) Purpose of grant or assistance
YALE UNIVERSITY POBOX 1873 NEW HAVEN, CT 06508	06-0646973	501(C)(3)	56,011				RESEARCH GRANTS
AMERICAN THORACIC SOCIETY 25 BROADWAY 18TH FLOOR NEW YORK, NY 10004	06-1548706	501(C)(3)	5,500				RESEARCH GRANTS

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(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 non-cash assistance	(h) Purpose of grant or assistance
CHILDREN'S HOSPITAL MEDICAL CENTER SPONSORED PRGS ACTG ML 4900 3333 BURNET AVE CINCINNATI, OH 45229	31-0833936	501(C)(3)	50,000				CLINICAL RESEARCH GRANTS
NATIONAL ORGANIZATION FOR RARE DISORDERS 55 KENOSIA AVENUE DANBURY, CT 06810	13-3223946	501(C)(3)	65,000				TSC TRAVEL AND LODGING ASSISTANCE PROGRAM

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(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 non-cash assistance	(h) Purpose of grant or assistance
NORTHWESTERN UNIVERSITY 7TH FLOOR RUBLOFF BUILDING CHICAGO, IL 60611	36-2167818	501(C)(3)	75,001				RESEARCH GRANTS
CHILDREN'S HOSPITAL CORPORATION 300 LONGWOOD AVENUE BOSTON, MA 02115	04-2774441	501(C)(3)	150,001				RESEARCH GRANTS

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(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 non-cash assistance	(h) Purpose of grant or assistance
BOSTON CHILDREN'S HOSPITAL 300 LONGWOOD AVENUE BOSTON, MA 02115	04-2774441	501(C)(3)	57,409				CLINICAL RESEARCH GRANT
UNIVERSITY OF CALIFORNIA BERKELEY 1608 FOURTH ST STE 220 BERKELEY, CA 94710	94-6002123	501(C)(3)	9,375				RESEARCH GRANT



Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(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 non-cash assistance	(h) Purpose of grant or assistance
UNIVERSITY OF ALABAMA 1720 2ND AVE SOUTH AB990 BIRMINGHAM, AL 35294	63-6005396	501(C)(3)	15,533				CLINICAL RESEARCH GRANT
UNIVERSITY OF TENNESSEE HEALTH SCIENCE CTR 910 MADISON AVE STE 823 MEMPHIS, TN 38103	62-6001636	501(C)(3)	18,511				RESEARCH GRANT

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(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 non-cash assistance	(h) Purpose of grant or assistance
VANDERBILT UNIVERSITY 1161 21ST AVE SOUTH NASHVILLE, TN 37232	35-2528741	501(C)(3)	9,375				RESEARCH GRANT

Schedule J  
(Form 990)

Department of the Treasury  
Internal Revenue Service

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

2020

Open to Public Inspection

Name of the organization  
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number  
95-3018799

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 type="checkbox"/> First-class or charter travel	<input type="checkbox"/> Housing allowance or residence for personal use		
<input type="checkbox"/> Travel for companions	<input type="checkbox"/> Payments for business use of personal residence		
<input type="checkbox"/> Tax idemnification and gross-up payments	<input type="checkbox"/> Health or social club dues or initiation fees		
<input type="checkbox"/> Discretionary spending account	<input type="checkbox"/> Personal services (e.g., 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		<b>1b</b>	
<b>2</b> Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, officers, including the CEO/Executive Director, regarding the items checked on Line 1a?		<b>2</b>	
<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 checked="" type="checkbox"/> Compensation committee	<input type="checkbox"/> Written employment contract		
<input type="checkbox"/> Independent compensation consultant	<input checked="" type="checkbox"/> Compensation survey or study		
<input checked="" type="checkbox"/> Form 990 of other organizations	<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?		<b>4a</b>	No
<b>b</b> Participate in, or receive payment from, a supplemental nonqualified retirement plan?		<b>4b</b>	No
<b>c</b> Participate in, or receive payment from, an equity-based compensation arrangement?		<b>4c</b>	No
If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.			
<b>Only 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?		<b>5a</b>	Yes
<b>b</b> Any related organization?		<b>5b</b>	No
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?		<b>6a</b>	Yes
<b>b</b> Any related organization?		<b>6b</b>	No
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 in lines 5 and 6? If "Yes," describe in Part III.		<b>7</b>	No
<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.		<b>8</b>	No
<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)?		<b>9</b>	

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 are not 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.

[illegible]

**Part III**   **Supplemental Information**

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

Return Reference	Explanation
PART I, LINE 5	KARI LUTHER ROSBECK, RICHARD GOLLUB, STEVE ROBERDS, DEAN AGUIAR, JAYE ISHAM, LISA MOSS AND APRIL COOPER ALL HAVE INCENTIVE COMPENSATION EQUAL TO A PERCENTAGE OF THEIR SALARIES BASED ON KEY PERFORMANCE OBJECTIVES AS ESTABLISHED BY THE COMPENSATION COMMITTEE.
PART I, LINE 6	KARI LUTHER ROSBECK, RICHARD GOLLUB, STEVE ROBERDS, DEAN AGUIAR, JAYE ISHAM, LISA MOSS AND APRIL COOPER ALL HAVE INCENTIVE COMPENSATION EQUAL TO A PERCENTAGE OF THEIR SALARIES BASED ON KEY PERFORMANCE OBJECTIVES AS ESTABLISHED BY THE COMPENSATION COMMITTEE.

SCHEDULE M  
(Form 990)

Department of the Treasury  
Internal Revenue Service

Noncash Contributions

►Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.  
► Attach to Form 990.  
►Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization  
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number  
95-3018799

Part I

Types of Property

	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1 Art—Works of art . . . . .				
2 Art—Historical treasures . . . . .				
3 Art—Fractional interests . . . . .				
4 Books and publications . . . . .				
5 Clothing and household goods . . . . .	X		422	FMV
6 Cars and other vehicles . . . . .				
7 Boats and planes . . . . .				
8 Intellectual property . . . . .				
9 Securities—Publicly traded . . . . .	X	6	87,545	FMV
10 Securities—Closely held stock . . . . .				
11 Securities—Partnership, LLC, or trust interests . . . . .				
12 Securities—Miscellaneous . . . . .				
13 Qualified conservation contribution—Historic structures . . . . .				
14 Qualified conservation contribution—Other . . . . .				
15 Real estate—Residential . . . . .				
16 Real estate—Commercial . . . . .				
17 Real estate—Other . . . . .				
18 Collectibles . . . . .				
19 Food inventory . . . . .	X	2	3,060	FMV
20 Drugs and medical supplies . . . . .				
21 Taxidermy . . . . .				
22 Historical artifacts . . . . .				
23 Scientific specimens . . . . .				
24 Archeological artifacts . . . . .				
25 Other ► ( )				
26 Other ► ( )				
27 Other ► ( )				
28 Other ► ( )				

29

Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, Donee Acknowledgement

29

0

30a

During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least three years from the date of the initial contribution, and which isn't required to be used for exempt purposes for the entire holding period?

30a

Yes

No

b

If "Yes," describe the arrangement in Part II.

31

Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions?

31

Yes

No

32a

Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?

32a

Yes

No

b

If "Yes," describe in Part II.

33

If the organization didn't report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II.

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

Cat. No. 51227J

Schedule M (Form 990) (2020)

**Part II** **Supplemental Information.** Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.

Return Reference	Explanation
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efile GRAPHIC print - DO NOT PROCESS		As Filed Data -	DLN: 93493102006101
<b>SCHEDULE O</b> (Form 990 or 990-EZ)	<b>Supplemental Information to Form 990 or 990-EZ</b> 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 <u><a href="http://www.irs.gov/Form990">www.irs.gov/Form990</a></u> for the latest information.		OMB No. 1545-0047
			<b>2020</b>
Department of the Treasury Internal Revenue Service			<b>Open to Public Inspection</b>
Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION		Employer identification number  95-3018799	



# 990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART III, LINE 4A (CONT'D):	<p>IN 2012, THE TSC ALLIANCE HELPED CREATE THE TSC CLINICAL RESEARCH CONSORTIUM IN PARTNERSHIP WITH INVESTIGATORS RUNNING CLINICAL STUDIES TO ENSURE CLINICAL RESEARCH IN TSC IS AS EFFICIENT AND EFFECTIVE AS POSSIBLE. SINCE THEN, TSC CLINICAL RESEARCH CONSORTIUM INVESTIGATORS HAVE BEEN AWARDED MORE THAN \$35 MILLION BY THE NATIONAL INSTITUTES OF HEALTH (NIH) THROUGH COMPETITIVE GRANT PROCESSES. TSC ALLIANCE PERSONNEL SERVE ON THE LEADERSHIP TEAM FOR THE CONSORTIUM, ACTIVELY TRACK ENROLLMENT, AND RAISE COMMUNITY AWARENESS TO HELP IDENTIFY POTENTIAL PARTICIPANTS FOR CLINICAL STUDIES. TSC ALLIANCE ALSO PROVIDES SUPPLEMENTAL FINANCIAL SUPPORT TO ACCELERATE OR EXPAND NIH-FUNDED STUDIES. THE PREVENT TRIAL - PREVENTING EPILEPSY USING VIGABATRIN IN INFANTS WITH TSC - IS THE FIRST PREVENTATIVE TRIAL IN THE UNITED STATES FOR ANY FORM OF EPILEPSY AND HAS COMPLETED ENROLLMENT OF 86 PARTICIPANTS. WE EXPECT THE FIRST RESULTS IN DECEMBER 2021 AND FINAL RESULTS IN LATE 2022 OR EARLY 2023. THIS TRIAL BUILDS DIRECTLY UPON THE CLINICAL RESEARCH CONSORTIUM'S FIRST CLINICAL STUDY, WHICH IDENTIFIED SPECIFIC EEG CHANGES IN INFANTS WITH TSC PRIOR TO THE ONSET OF SEIZURES. IN THE PREVENT TRIAL, INFANTS WITH TSC RECEIVE REGULAR EEG MONITORING, AND THOSE WHO DEVELOP EEG ABNORMALITIES ARE PLACED ON EITHER VIGABATRIN OR PLACEBO. ANY INFANT WHO SUBSEQUENTLY DEVELOPS CLINICAL SEIZURES IS IMMEDIATELY PLACED ON STANDARD TREATMENT. THIS TRIAL WILL DETERMINE WHETHER TREATMENT WITH VIGABATRIN PRIOR TO THE ONSET OF CLINICAL SEIZURES IN TSC IS BENEFICIAL TO CHILDREN'S DEVELOPMENTAL AND NEUROLOGIC OUTCOMES. MORE DETAILS ABOUT THIS STUDY ARE ONLINE AT <a href="http://WWW.CLINICALTRIALS.GOV/CT2/SHOW/NCT02849457">WWW.CLINICALTRIALS.GOV/CT2/SHOW/NCT02849457</a>. IMMEDIATELY AFTER THE PREVENT TRIAL ENROLLMENT COMPLETED, A SIMILAR CLINICAL TRIAL BEGAN ENROLLING NEWBORNS WITH TSC UTILIZING A SIMILAR PROTOCOL BUT TESTING THE EFFECTS OF SIROLIMUS INSTEAD OF VIGABATRIN. THE STOPPING TSC ONSET AND PROGRESSION 2 (STOP-2) TRIAL OPENED AT CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER, AND THE TSC ALLIANCE IS CONTRIBUTING \$200,000 TO ENABLE THE TRIAL TO BE EXPANDED TO ADDITIONAL SITES ACROSS THE COUNTRY IN 2021. TSC ALLIANCE IS ALSO PROVIDING SUPPLEMENTAL FUNDING AND COLLECTING BLOOD SAMPLES FOR THE DEVELOPMENTAL SYNAPTOPATHIES CONORTIUM (DSC), AN NIH-FUNDED PROJECT THAT INCLUDES STUDIES OF TSC AND THE RELATED RARE DISORDERS PHELAN-MCDERMID SYNDROME AND PTEN HAMARTOMA SYNDROME. THESE THREE RARE DISEASES SEEM TO AFFECT CERTAIN SHARED PATHWAYS INFLUENCING THE DEVELOPMENT OF BRAIN CONNECTIONS, OR SYNAPSES. RESEARCHERS IN THIS STUDY ARE TRYING TO FIND EARLIER SIGNS OF AUTISM SPECTRUM DISORDER (ASD) AND INTELLECTUAL DISABILITY (ID) TO GAIN A BETTER UNDERSTANDING OF ASD/ID IN INDIVIDUALS WITH TSC AND ENABLE EFFECTIVE TREATMENTS AND INTERVENTIONS FOR ASD/ID TO BE FOUND. THE DSC WAS RENEWED LAST YEAR FOR A SECOND 5-YEAR FUNDING PERIOD. TSC ALLIANCE FUNDS A PORTION OF CLINICAL RESEARCH COORDINATORS' SALARIES AT 5 SITES AND WILL BEGIN FUNDING A 2-YEAR CLINICAL FELLOWSHIP IN TS</p>

**990 Schedule O, Supplemental Information**

Return Reference	Explanation
FORM 990, PART III, LINE 4A (CONT'D):	<p>C BEGINNING 2021. IN ADDITION TO SPECIFIC COLLABORATIVE PROJECTS DETAILED ABOVE, THE TSC ALLIANCE STIMULATES COLLABORATION AND INNOVATION THROUGH CONVENING EXPERTS AND STAKEHOLDERS WITHIN AND OUTSIDE THE TSC FIELD. THE FIRST INNOVATION WORKSHOP WAS HELD IN 2020 AND FOCUSED ON NEWBORN SCREENING. THIS WORKSHOP'S GOALS INCLUDED: DEFINE THE CRITICAL PATH - OR RATE-LIMITING STEPS - OF DEVELOPING A SCREENING ASSAY TO ENABLE NOMINATION OF TSC TO THE RECOMMENDED UNIFORM SCREENING PANEL; SPECIFY THE IMMEDIATE NEXT STEPS NEEDED ALONG THE CRITICAL PATH; RECOMMEND COMPONENTS OF A FUNDING OPPORTUNITY ANNOUNCEMENT TO ELICIT THE BEST IDEAS AND APPLICANTS TO IMPLEMENT THOSE NEXT STEPS; AND ENABLE TSC ALLIANCE TO FUND THE MOST MERITORIOUS APPLICATIONS WITHIN 100 DAYS AFTER THE WORKSHOP. ORIGINALLY, THE TSC ALLIANCE HAD PLANNED TO HOST AN IN-PERSON WORKSHOP TO BE HELD IN EARLY JUNE. HOWEVER, DUE TO THE NOVEL CORONAVIRUS PANDEMIC, THE INNOVATION WORKSHOP WAS RE-IMAGINED AS A SERIES OF VIRTUAL MEETINGS PUNCTUATED BY ONLINE DISCUSSION USING THE PLATFORM POWERNODDLE. THE FINAL CUMULATIVE DISCUSSION WILL TAKE PLACE IN EARLY JANUARY 2021 AND WILL BE FOLLOWED BY AN FOA IN THE FIRST QUARTER OF 2021.</p>

## 990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION A, LINE 6	MEMBERSHIP IS AVAILABLE TO ANY PERSON WHO SUBSCRIBES TO THE PURPOSES AND OBJECTIVES OF THE CORPORATION, WITHOUT REGARD TO RACE, RELIGION, GENDER, SEXUAL ORIENTATION, AGE, COLOR, NATIONAL ORIGIN OR MENTAL OR PHYSICAL HANDICAP OR DISABILITY. THERE SHALL BE NO LIMIT TO THE NUMBER OF MEMBERS IN THE CORPORATION. 1) THERE MAY BE ONE OR MORE CLASSES OF MEMBERSHIP AS DETERMINED BY THE BOARD. 2) MEMBERSHIP IS NOT TRANSFERABLE OR ASSIGNABLE.

## 990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION A, LINE 7A	THE TSC ALLIANCE IS A MEMBERSHIP-BASED ORGANIZATION, WHICH MEANS MEMBERS HELP ELECT THE BOARD OF DIRECTORS. THE TSC ALLIANCE MEMBERSHIP PROGRAM ALLOWED INDIVIDUALS TO STATE THEIR INTENT TO BE A MEMBER FOR THE PURPOSE OF GOVERNANCE. THERE WERE NO LEVELS TO MEMBERSHIP IN 2020. ANYONE CAN BE A MEMBER AT NO COST.

## 990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 11B	THE FORM 990 IS REVIEWED, IN DETAIL, BY THE BOARD OF DIRECTORS' AUDIT COMMITTEE. RECOMMENDATIONS ARE MADE BY THE COMMITTEE MEMBERS FOR ANY CHANGES/EDITS/ADDITIONS. AFTER THOSE HAVE BEEN INCORPORATED, THE AUDIT COMMITTEE VOTES WHETHER TO APPROVE AND THEN FORWARD THE 990 TO THE FINANCE AND EXECUTIVE COMMITTEES. THE FINANCE AND EXECUTIVE COMMITTEES PERFORM THE FINAL REVIEW AND THEN VOTE WHETHER TO APPROVE ON BEHALF OF THE BOARD OF DIRECTORS. A COPY OF THE APPROVED 990 IS SHARED WITH THE ENTIRE BOARD PRIOR TO ITS FILING WITH THE IRS.

**990 Schedule O, Supplemental Information**

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 12C	<p>ANNUALLY EACH MEMBER OF THE BOARD OF DIRECTORS WILL RECEIVE NOTICE OF THE ORGANIZATION'S CONFLICT OF INTEREST STATEMENT. EACH MEMBER WILL BE PROVIDED WITH A STATEMENT TO MAKE DISCLOSURE OF ANY POTENTIAL CONFLICT OF INTEREST. IF DURING THE COURSE OF THE YEAR A POTENTIAL CONFLICT OF INTEREST ARISES THAT HAS NOT PREVIOUSLY BEEN DISCLOSED, THE BOARD MEMBER WILL MAKE WRITTEN NOTICE OF A POTENTIAL CONFLICT OF INTEREST AND RECUSE HIMSELF OR HERSELF FROM ANY DISCUSSIONS AND VOTES IN CONNECTION WITH THE ISSUE IDENTIFIED. ANY TIME A MEMBER IS RECUSED FROM DISCUSSION ON AN ISSUE, THE MINUTES OF COMMITTEE MEETING AND BOARD MEETING WILL DULY RECORD SUCH ACTIONS. THE FOLLOWING POTENTIAL CONFLICTS OF INTEREST WERE DISCLOSED FOR 2020: BOARD MEMBER MUSTAFA SAHIN, PH.D., M.D., IS EMPLOYED AT BOSTON CHILDREN'S HOSPITAL, WHICH RECEIVED \$132,409 IN GRANTS AND \$13,935 IN FEES FOR SERVICES FOR PARTICIPATION IN THE TSC NATURAL HISTORY DATABASE. BOARD MEMBER DARCY KRUEGER, MD, MPA, IS EMPLOYED AT THE CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER, WHICH RECEIVED A \$50,000 GRANT PAYMENT FOR HIS WORK ON STOP-2 AND \$26,335 IN FEES FOR SERVICES FOR PARTICIPATION IN THE TSC NATURAL HISTORY DATABASE.</p>

**990 Schedule O, Supplemental Information**

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 15	THE COMPENSATION COMMITTEE REVIEWS AND APPROVES THE SALARIES OF THE PRESIDENT/CEO, CHIEF SCIENTIFIC OFFICER, CONTROLLER & CFO, AND ANY EMPLOYEE APPEARING ON THE FORM 990, IN ACCORDANCE WITH THE TSC ALLIANCE BYLAWS. SUCH REVIEW AND APPROVAL OCCURS INITIALLY UPON HIRING, UPON ANNUAL REVIEWS AND WHENEVER MODIFIED. THE ORGANIZATION'S EXECUTIVE REMUNERATION HAS BEEN STRUCTURED TO ENSURE THAT IT: IS REASONABLE; PROVIDES A COMPETITIVE COMPENSATION PROGRAM TO RETAIN, ATTRACT AND REWARD KEY EMPLOYEES AND ACHIEVES CLEAR ALIGNMENT BETWEEN TOTAL REMUNERATION AND DELIVERED BUSINESS AND PERSONAL PERFORMANCE OVER THE SHORT AND LONG-TERMS. THE COMPENSATION IS REVIEWED BY THE COMPENSATION COMMITTEE TO ENSURE: - COMPARABILITY, - PROPER REVIEW, AND - SUBSTANTIATION IN SETTING THE COMPENSATION.

# 990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION C, LINE 19	ALL GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY AND FINANCIAL STATEMENTS ARE AVAILABLE UPON WRITTEN REQUEST.



SCHEDULE R  
(Form 990)

Department of the Treasury  
Internal Revenue Service

Related Organizations and Unrelated Partnerships

▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 33, 34, 35b, 36, or 37.  
▶ 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

2020

Open to Public Inspection

Name of the organization  
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number  
95-3018799

Part I Identification of Disregarded Entities. Complete if the organization answered "Yes" on Form 990, Part IV, line 33.

(a) Name, address, and EIN (if applicable) of disregarded entity	(b) Primary activity	(c) Legal domicile (state or foreign country)	(d) Total income	(e) End-of-year assets	(f) Direct controlling entity

Part II Identification of Related Tax-Exempt Organizations. Complete if the organization answered "Yes" on Form 990, Part IV, line 34 because it had one or more related tax-exempt organizations during the tax year.

(a) Name, address, and EIN of related organization	(b) Primary activity	(c) Legal domicile (state or foreign country)	(d) Exempt Code section	(e) Public charity status (if section 501(c)(3))	(f) Direct controlling entity	(g) Section 512(b)(13) controlled entity?	
						Yes	No
(1)TSC ALLIANCE ENDOWMENT FUND INC 8737 COLESVILLE ROAD SUITE 400  SILVER SPRING, MD 20910 52-1926919	SUPPORT ORG	MD	501(C)(3)	LINE 12B, II	N/A		No

**Part III Identification of Related Organizations Taxable as a Partnership.** Complete if the organization answered "Yes" on Form 990, Part IV, line 34, because it had one or more related organizations treated as a partnership during the tax year.

(a) Name, address, and EIN of related organization	(b) Primary activity	(c) Legal domicile (state or foreign country)	(d) Direct controlling entity	(e) Predominant income(related, unrelated, excluded from tax under sections 512- 514)	(f) Share of total income	(g) Share of end-of-year assets	(h) Disproportionate allocations?		(i) Code V-UBI amount in box 20 of Schedule K-1 (Form 1065)	(j) General or managing partner?		(k) Percentage ownership
							Yes	No		Yes	No	

**Part IV Identification of Related Organizations Taxable as a Corporation or Trust.** Complete if the organization answered "Yes" on Form 990, Part IV, line 34 because it had one or more related organizations treated as a corporation or trust during the tax year.

(a) Name, address, and EIN of related organization	(b) Primary activity	(c) Legal domicile (state or foreign country)	(d) Direct controlling entity	(e) Type of entity (C corp, S corp, or trust)	(f) Share of total income	(g) Share of end-of- year assets	(h) Percentage ownership	(i) Section 512(b) (13) controlled entity?	
								Yes	No

**Part V Transactions With Related Organizations.** Complete if the organization answered "Yes" on Form 990, Part IV, line 34, 35b, or 36.**Note.** Complete line 1 if any entity is listed in Parts II, III, or IV of this schedule.**1** During the tax year, did the organization engage in any of the following transactions with one or more related organizations listed in Parts II-IV?

	Yes	No
<b>a</b> Receipt of <b>(i)</b> interest, <b>(ii)</b> annuities, <b>(iii)</b> royalties, or <b>(iv)</b> rent from a controlled entity . . . . .	<b>1a</b>	No
<b>b</b> Gift, grant, or capital contribution to related organization(s) . . . . .	<b>1b</b>	No
<b>c</b> Gift, grant, or capital contribution from related organization(s) . . . . .	<b>1c</b> Yes	
<b>d</b> Loans or loan guarantees to or for related organization(s) . . . . .	<b>1d</b>	No
<b>e</b> Loans or loan guarantees by related organization(s) . . . . .	<b>1e</b>	No
<b>f</b> Dividends from related organization(s) . . . . .	<b>1f</b>	No
<b>g</b> Sale of assets to related organization(s) . . . . .	<b>1g</b>	No
<b>h</b> Purchase of assets from related organization(s) . . . . .	<b>1h</b>	No
<b>i</b> Exchange of assets with related organization(s) . . . . .	<b>1i</b>	No
<b>j</b> Lease of facilities, equipment, or other assets to related organization(s) . . . . .	<b>1j</b>	No
<b>k</b> Lease of facilities, equipment, or other assets from related organization(s) . . . . .	<b>1k</b>	No
<b>l</b> Performance of services or membership or fundraising solicitations for related organization(s) . . . . .	<b>1l</b>	No
<b>m</b> Performance of services or membership or fundraising solicitations by related organization(s) . . . . .	<b>1m</b>	No
<b>n</b> Sharing of facilities, equipment, mailing lists, or other assets with related organization(s) . . . . .	<b>1n</b> Yes	
<b>o</b> Sharing of paid employees with related organization(s) . . . . .	<b>1o</b> Yes	
<b>p</b> Reimbursement paid to related organization(s) for expenses . . . . .	<b>1p</b>	No
<b>q</b> Reimbursement paid by related organization(s) for expenses . . . . .	<b>1q</b>	No
<b>r</b> Other transfer of cash or property to related organization(s) . . . . .	<b>1r</b>	No
<b>s</b> Other transfer of cash or property from related organization(s) . . . . .	<b>1s</b>	No

**2** If the answer to any of the above is "Yes," see the instructions for information on who must complete this line, including covered relationships and transaction thresholds.

(a) Name of related organization	(b) Transaction type (a-s)	(c) Amount involved	(d) Method of determining amount involved
<b>(1)</b> TSC ALLIANCE ENDOWMENT FUND INC	C	330,875	CASH

Provide the following information for each entity taxed as a partnership through which the organization conducted more than five percent of its activities (measured by total assets or gross revenue) that was not a related organization. See instructions regarding exclusion for certain investment partnerships.

[illegible]

**Part VII**   **Supplemental Information**

Provide additional information for responses to questions on Schedule R. (see instructions).