

Form **990**

Department of the Treasury  
Internal Revenue Service

## Return of Organization Exempt From Income Tax

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.

OMB No. 1545-0047

**2018**

Open to Public Inspection

**A** For the **2018** calendar year, or tax year beginning and ending

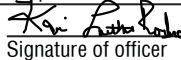
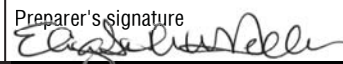
<b>B</b> Check if applicable:	<b>C</b> Name of organization <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.</b>	<b>D</b> Employer identification number <b>95-3018799</b>
Address change	Doing business as <b>TUBEROUS SCLEROSIS ALLIANCE</b>	<b>E</b> Telephone number <b>301-562-9890</b>
Name change	Number and street (or P.O. box if mail is not delivered to street address) Room/suite <b>801 ROEDER ROAD 750</b>	
Initial return	City or town, state or province, country, and ZIP or foreign postal code <b>SILVER SPRING, MD 20910</b>	<b>G</b> Gross receipts \$ <b>5,666,249.</b>
Final return/terminated	<b>F</b> Name and address of principal officer: <b>KARI L. ROSBECK</b> <b>SAME AS C ABOVE</b>	<b>H(a)</b> Is this a group return for subordinates? ..... <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
Amended return		<b>H(b)</b> Are all subordinates included? <b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/> If "No," attach a list. (see instructions)
Application pending	<b>I</b> Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) ( ) (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527	<b>H(c)</b> Group exemption number ▶
<b>J</b> Website: ▶ <b>WWW.TSALLIANCE.ORG</b>		<b>L</b> Year of formation: <b>1975</b> <b>M</b> State of legal domicile: <b>CA</b>
<b>K</b> Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶		

**Part I Summary**

<b>1</b>	Briefly describe the organization's mission or most significant activities: <b>FINDING A CURE FOR TUBEROUS SCLEROSIS COMPLEX WHILE IMPROVING THE LIVES OF THOSE AFFECTED.</b>		
<b>2</b>	Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
<b>3</b>	Number of voting members of the governing body (Part VI, line 1a)	<b>3</b>	<b>24</b>
<b>4</b>	Number of independent voting members of the governing body (Part VI, line 1b)	<b>4</b>	<b>24</b>
<b>5</b>	Total number of individuals employed in calendar year 2018 (Part V, line 2a)	<b>5</b>	<b>23</b>
<b>6</b>	Total number of volunteers (estimate if necessary)	<b>6</b>	<b>2947</b>
<b>7a</b>	Total unrelated business revenue from Part VIII, column (C), line 12	<b>7a</b>	<b>0.</b>
<b>7b</b>	Net unrelated business taxable income from Form 990-T, line 38	<b>7b</b>	<b>17,094.</b>
		<b>Prior Year</b>	<b>Current Year</b>
<b>8</b>	Contributions and grants (Part VIII, line 1h)	3,949,953.	4,105,376.
<b>9</b>	Program service revenue (Part VIII, line 2g)	824,241.	1,884,102.
<b>10</b>	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	10,221.	12,198.
<b>11</b>	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	-41,611.	-510,235.
<b>12</b>	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	4,742,804.	5,491,441.
<b>13</b>	Grants and similar amounts paid (Part IX, column (A), lines 1-3)	535,454.	464,190.
<b>14</b>	Benefits paid to or for members (Part IX, column (A), line 4)	0.	0.
<b>15</b>	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	1,809,048.	2,013,185.
<b>16a</b>	Professional fundraising fees (Part IX, column (A), line 11e)	0.	0.
<b>b</b>	Total fundraising expenses (Part IX, column (D), line 25) ▶ <b>765,251.</b>		
<b>17</b>	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	2,976,795.	3,391,158.
<b>18</b>	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	5,321,297.	5,868,533.
<b>19</b>	Revenue less expenses. Subtract line 18 from line 12	-578,493.	-377,092.
		<b>Beginning of Current Year</b>	<b>End of Year</b>
<b>20</b>	Total assets (Part X, line 16)	9,757,301.	9,281,566.
<b>21</b>	Total liabilities (Part X, line 26)	700,521.	601,878.
<b>22</b>	Net assets or fund balances. Subtract line 21 from line 20	9,056,780.	8,679,688.

**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.

<b>Sign Here</b>	 Signature of officer	4/5/19 Date	
	<b>KARI L. ROSBECK, PRESIDENT &amp; CEO</b> Type or print name and title		
<b>Paid Preparer Use Only</b>	Print/Type preparer's name <b>ELIZABETH HELLER</b>	Preparer's signature 	Date 4/5/2019
	Firm's name ▶ <b>TATE AND TRYON</b>	Firm's EIN ▶ <b>52-1855942</b>	Check if self-employed <input type="checkbox"/> PTIN <b>P00397829</b>
	Firm's address ▶ <b>2021 L STREET, NW SUITE 400 WASHINGTON, DC 20036</b>	Phone no. (202) <b>293-2200</b>	

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

Form **8879-EO**

# IRS e-file Signature Authorization for an Exempt Organization

OMB No. 1545-1878

For calendar year 2018, or fiscal year beginning \_\_\_\_\_, 2018, and ending \_\_\_\_\_, 20\_\_\_\_

# 2018

Department of the Treasury  
Internal Revenue Service

▶ **Do not send to the IRS. Keep for your records.**  
▶ **Go to [www.irs.gov/Form8879EO](http://www.irs.gov/Form8879EO) for the latest information.**

Name of exempt organization

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,  
INC.**

Employer identification number

**95-3018799**

Name and title of officer

**KARI L ROSBECK  
PRESIDENT AND CEO**

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

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

<b>1a</b> Form 990 check here ▶ <input checked="" type="checkbox"/>	<b>b Total revenue</b> , if any (Form 990, Part VIII, column (A), line 12) .....	<b>1b</b> <u>5,491,441.</u>
<b>2a</b> Form 990-EZ check here ▶ <input type="checkbox"/>	<b>b Total revenue</b> , if any (Form 990-EZ, line 9) .....	<b>2b</b> _____
<b>3a</b> Form 1120-POL check here ▶ <input type="checkbox"/>	<b>b Total tax</b> (Form 1120-POL, line 22) .....	<b>3b</b> _____
<b>4a</b> Form 990-PF check here ▶ <input type="checkbox"/>	<b>b Tax based on investment income</b> (Form 990-PF, Part VI, line 5) .....	<b>4b</b> _____
<b>5a</b> Form 8868 check here ▶ <input type="checkbox"/>	<b>b Balance Due</b> (Form 8868, line 3c) .....	<b>5b</b> _____

### Part II Declaration and Signature Authorization of Officer

Under penalties of perjury, I declare that I am an officer of the above organization and that I have examined a copy of the organization's 2018 electronic return and accompanying schedules and statements and to the best of my knowledge and belief, they are true, correct, and complete. I further declare that the amount in Part I above is the amount shown on the copy of the organization's electronic return. I consent to allow my intermediate service provider, transmitter, or electronic return originator (ERO) to send the organization's return to the IRS and to receive from the IRS (a) an acknowledgement of receipt or reason for rejection of the transmission, (b) the reason for any delay in processing the return or refund, and (c) the date of any refund. If applicable, I authorize the U.S. Treasury and its designated Financial Agent to initiate an electronic funds withdrawal (direct debit) entry to the financial institution account indicated in the tax preparation software for payment of the organization's federal taxes owed on this return, and the financial institution to debit the entry to this account. To revoke a payment, I must contact the U.S. Treasury Financial Agent at 1-888-353-4537 no later than 2 business days prior to the payment (settlement) date. I also authorize the financial institutions involved in the processing of the electronic payment of taxes to receive confidential information necessary to answer inquiries and resolve issues related to the payment. I have selected a personal identification number (PIN) as my signature for the organization's electronic return and, if applicable, the organization's consent to electronic funds withdrawal.

Officer's PIN: check one box only

I authorize **TATE AND TRYON** to enter my PIN **20910**  
ERO firm name Enter five numbers, but do not enter all zeros

as my signature on the organization's tax year 2018 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I also authorize the aforementioned ERO to enter my PIN on the return's disclosure consent screen.

As an officer of the organization, I will enter my PIN as my signature on the organization's tax year 2018 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I will enter my PIN on the return's disclosure consent screen.

Officer's signature ▶ *Kari Rosbeck* Date ▶ 4/4/19

### Part III Certification and Authentication

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

**52472820036**  
Do not enter all zeros

I certify that the above numeric entry is my PIN, which is my signature on the 2018 electronically filed return for the organization indicated above. I confirm that I am submitting this return in accordance with the requirements of Pub. 4163, Modernized e-File (MeF) Information for Authorized IRS e-file Providers for Business Returns.

ERO's signature ▶ *Eagle* Date ▶ 3/31/2019

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

LHA For Paperwork Reduction Act Notice, see instructions.

Form **8879-EO** (2018)

823051 10-26-18

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: THE NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC., D/B/A TUBEROUS SCLEROSIS 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 [X] No

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

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses.

4a (Code: ) (Expenses \$ 2,457,381. including grants of \$ 464,190. ) (Revenue \$ 1,884,102. ) 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 TS ALLIANCE RESEARCH PROGRAM FUNDS RESEARCH FOCUSED ON TSC PROPOSED BY RESEARCHERS AND ALIGNED WITH THE ORGANIZATION'S MISSION. THE TS ALLIANCE 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.

4b (Code: ) (Expenses \$ 1,537,888. including grants of \$ ) (Revenue \$ ) 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 2018 THE TS ALLIANCE FACILITATED 24,852 PEER-TO-PEER SUPPORTS FROM ADULT REGIONAL COORDINATORS, CLINIC AMBASSADORS, DEPENDENT ADULT TRANSITION RESOURCE COORDINATORS, EDUCATION PARENT MENTORS, AND COMMUNITY ALLIANCES THROUGH THE TSC CONNECT PROGRAM.

THE SUPPORT SERVICES DEPARTMENT ALSO PROVIDED DIRECT SUPPORT AND RESOURCES TO 4,083 INDIVIDUALS AND FAMILIES DEALING WITH TSC THROUGHOUT

4c (Code: ) (Expenses \$ 322,973. including grants of \$ ) (Revenue \$ ) 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 2018, THE TS ALLIANCE PRODUCED TWO ISSUES OF ITS NATIONAL MAGAZINE, PERSPECTIVE, WHICH IS MAILED TO APPROXIMATELY 14,000 CONSTITUENTS AS WELL AS POSTED ON THE WEBSITE. THE TS ALLIANCE'S WEBSITE INCREASES AWARENESS AND PROVIDES EXTENSIVE EDUCATION THROUGH AN AVERAGE OF MORE THAN 35,000 UNIQUE VISITORS EACH MONTH. THE TS ALLIANCE ALSO RELIES HEAVILY ON SOCIAL MEDIA TO EDUCATE CONSTITUENTS AND PROMOTE NEW RESOURCES AND EVENTS. ITS FACEBOOK GROUP BOASTS MORE THAN 9,200 MEMBERS, WHILE ITS TWITTER AND INSTAGRAM ACCOUNTS HAVE 2,000-PLUS AND 1,300-PLUS FOLLOWERS RESPECTIVELY.

4d Other program services (Describe in Schedule O.) (Expenses \$ 277,961. including grants of \$ ) (Revenue \$ )

4e Total program service expenses 4,596,203.

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,  
INC.**

**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)? <i>If "Yes," complete Schedule A</i> .....	<b>X</b>	
<b>2</b> Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? .....	<b>X</b>	
<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? <i>If "Yes," complete Schedule C, Part I</i> .....		<b>X</b>
<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? <i>If "Yes," complete Schedule C, Part II</i> .....	<b>X</b>	
<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? <i>If "Yes," complete Schedule C, Part III</i> .....		<b>X</b>
<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? <i>If "Yes," complete Schedule D, Part I</i> .....		<b>X</b>
<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? <i>If "Yes," complete Schedule D, Part II</i> .....		<b>X</b>
<b>8</b> Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i> .....		<b>X</b>
<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? <i>If "Yes," complete Schedule D, Part IV</i> .....		<b>X</b>
<b>10</b> Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i> .....	<b>X</b>	
<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? <i>If "Yes," complete Schedule D, Part VI</i> .....	<b>X</b>	
<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? <i>If "Yes," complete Schedule D, Part VII</i> .....		<b>X</b>
<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? <i>If "Yes," complete Schedule D, Part VIII</i> .....		<b>X</b>
<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? <i>If "Yes," complete Schedule D, Part IX</i> .....	<b>X</b>	
<b>e</b> Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i> .....	<b>X</b>	
<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)? <i>If "Yes," complete Schedule D, Part X</i> .....		<b>X</b>
<b>12a</b> Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i> .....		<b>X</b>
<b>b</b> Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i> .....	<b>X</b>	
<b>13</b> Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i> .....		<b>X</b>
<b>14a</b> Did the organization maintain an office, employees, or agents outside of the United States? .....		<b>X</b>
<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? <i>If "Yes," complete Schedule F, Parts I and IV</i> .....	<b>X</b>	
<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? <i>If "Yes," complete Schedule F, Parts II and IV</i> .....	<b>X</b>	
<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? <i>If "Yes," complete Schedule F, Parts III and IV</i> .....		<b>X</b>
<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? <i>If "Yes," complete Schedule G, Part I</i> .....		<b>X</b>
<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? <i>If "Yes," complete Schedule G, Part II</i> .....	<b>X</b>	
<b>19</b> Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i> .....		<b>X</b>
<b>20a</b> Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i> .....		<b>X</b>
<b>b</b> If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? .....		
<b>21</b> Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i> .....	<b>X</b>	

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.

Form 990 (2018)

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

**Part V Statements Regarding Other IRS Filings and Tax Compliance**

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

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

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

		Yes	No
<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		
	2a		23
<b>b</b>	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	X	
	<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>3a</b>	Did the organization have unrelated business gross income of \$1,000 or more during the year?	X	
<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	X	
<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)?		X
<b>b</b>	If "Yes," enter the name of the foreign country: 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?		X
<b>b</b>	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
<b>c</b>	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		
<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?		X
<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>7</b>	<b>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?	X	
<b>b</b>	If "Yes," did the organization notify the donor of the value of the goods or services provided?	X	
<b>c</b>	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
<b>d</b>	If "Yes," indicate the number of Forms 8282 filed during the year		
	7d		
<b>e</b>	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		X
<b>f</b>	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		X
<b>g</b>	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
<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>8</b>	<b>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</b>	<b>Sponsoring organizations maintaining donor advised funds.</b>		
<b>a</b>	Did the sponsoring organization make any taxable distributions under section 4966?		
<b>b</b>	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		
<b>10</b>	<b>Section 501(c)(7) organizations.</b> Enter:		
<b>a</b>	Initiation fees and capital contributions included on Part VIII, line 12	10a	
<b>b</b>	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b	
<b>11</b>	<b>Section 501(c)(12) organizations.</b> Enter:		
<b>a</b>	Gross income from members or shareholders	11a	
<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.)	11b	
<b>12a</b>	<b>Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?	12a	
<b>b</b>	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b	
<b>13</b>	<b>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?	13a	
	<b>Note.</b> See the instructions for additional information the organization must report on Schedule O.		
<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	13b	
<b>c</b>	Enter the amount of reserves on hand	13c	
<b>14a</b>	Did the organization receive any payments for indoor tanning services during the tax year?		X
<b>b</b>	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O	14b	
<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?		X
	If "Yes," see instructions and file Form 4720, Schedule N.		
<b>16</b>	Is the organization an educational institution subject to the section 4968 excise tax on net investment income?		X
	If "Yes," complete Form 4720, Schedule O.		

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

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

**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 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>1a</b> 24		
<b>b</b>	Enter the number of voting members included in line 1a, above, who are independent		
	<b>1b</b> 24		
<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?		X
<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?		X
<b>4</b>	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		X
<b>5</b>	Did the organization become aware during the year of a significant diversion of the organization's assets?		X
<b>6</b>	Did the organization have members or stockholders?	X	
<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?	X	
<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?		X
<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?	X	
<b>b</b>	Each committee with authority to act on behalf of the governing body?	X	
<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		X

**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?	X	
<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?	X	
<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?	X	
<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	X	
<b>b</b>	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	X	
<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	X	
<b>13</b>	Did the organization have a written whistleblower policy?	X	
<b>14</b>	Did the organization have a written document retention and destruction policy?	X	
<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	X	
<b>b</b>	Other officers or key employees of the organization	X	
	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?		X
<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?		

**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**
- 18** Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A if applicable), 990, and 990-T (Section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.  
 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 - 301-562-9890**  
**801 ROEDER ROAD, STE. 750, SILVER SPRING, MD 20910**

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

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

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

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

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

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

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below 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			
(1) BETH DEAN CHAIR	5.00 0.00	X		X				0.	0.	0.
(2) CHRIS RUSSELL VICE CHAIR	5.00 0.00	X		X				0.	0.	0.
(3) TIM DILLS IMMEDIATE PAST CHAIR	5.00 0.00	X		X				0.	0.	0.
(4) CASSANDRA CARROLL SECRETARY	5.00 0.00	X		X				0.	0.	0.
(5) JIM MAGINN TREASURER	5.00 0.00	X		X				0.	0.	0.
(6) MARTINA BEBIN, MD, MPA BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(7) JOHN J BISSLER, MD BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(8) MICHAEL CAGGIANO BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(9) SARA CHIEFFO BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(10) DAVID COIT BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(11) MARGARET COX BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(12) PETER CRINO, MD, PHD BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(13) BONNIE HOGUE DUFFY BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(14) DAVID FITZMAURICE BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(15) ROB GRANDIA BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(16) TOM GWINN BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(17) DANA HOLINKA BOARD MEMBER	2.00 0.00	X						0.	0.	0.



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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below 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			
(18) LAURA S LUBBERS BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(19) BRENDAN D MANNING, PHD BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(20) DARREN MILES BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(21) ADOLFO ORIVE BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(22) REBECCA ANHANG PRICE BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(23) MATTHEW SIMONIAN BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(24) TARA ZIMMERMAN BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(25) KARI L ROSBECK PRESIDENT & CEO	54.00 1.00			X				186,994.	3,463.	31,736.
(26) RICHARD A GOLLUB CONTROLLER & CFO	47.00 3.00			X				138,939.	8,869.	30,755.
<b>1b Sub-total</b>								325,933.	12,332.	62,491.
<b>c Total from continuation sheets to Part VII, Section A</b>								409,862.	0.	56,869.
<b>d Total (add lines 1b and 1c)</b>								735,795.	12,332.	119,360.

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 **5**

	Yes	No
3 Did the organization list any former officer, director, or trustee, key employee, or highest compensated employee on line 1a? If "Yes," complete Schedule J for such individual		X
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? If "Yes," complete Schedule J for such individual	X	
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person		X

**Section B. Independent Contractors**

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

(A) Name and business address	(B) Description of services	(C) Compensation
PSYCHOGENICS INC. 20 GRAMERCY PARK SOUTH, NEW YORK, NY 10003	RESEARCH LAB SVCS	782,961.
PORSOLT S.A.S., Z.A. DE GLATIGNE, LEGENEST-SAINT-ISLE, FRANCE 53940	RESEARCH LAB SVCS	122,260.
CAVAROCCHI RUSCIO DENNIS & ASSOC LLC, 600 MARYLAND AVE SW, STE 835W, WASH, DC 20024	GOVERNMENT RELATIONS	116,914.

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 **3**

SEE PART VII, SECTION A CONTINUATION SHEETS

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**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	<b>1 a</b> Federated campaigns	<b>1a</b> 34,150.				
	<b>b</b> Membership dues	<b>1b</b> 8,144.				
	<b>c</b> Fundraising events	<b>1c</b> 1,558,687.				
	<b>d</b> Related organizations	<b>1d</b> 50,000.				
	<b>e</b> Government grants (contributions)	<b>1e</b>				
	<b>f</b> All other contributions, gifts, grants, and similar amounts not included above	<b>1f</b> 2,454,395.				
	<b>g</b> Noncash contributions included in lines 1a-1f: \$	56,905.				
	<b>h Total.</b> Add lines 1a-1f	▶ 4,105,376.				
Program Service Revenue	<b>2 a</b> <b>CONTRACT REVENUE</b>	<b>Business Code</b> 900099	1,126,302.	1,126,302.		
	<b>b</b> <b>CONFERENCE REVENUE</b>	900099	757,800.		757,800.	
	<b>c</b>					
	<b>d</b>					
	<b>e</b>					
	<b>f</b> All other program service revenue					
	<b>g Total.</b> Add lines 2a-2f	▶ 1,884,102.				
Other Revenue	<b>3</b> Investment income (including dividends, interest, and other similar amounts)	▶ 13,784.			13,784.	
	<b>4</b> Income from investment of tax-exempt bond proceeds	▶				
	<b>5</b> Royalties	▶				
	<b>6 a</b> Gross rents	(i) Real				
		(ii) Personal				
		<b>b</b> Less: rental expenses				
		<b>c</b> Rental income or (loss)				
	<b>d</b> Net rental income or (loss)	▶				
	<b>7 a</b> Gross amount from sales of assets other than inventory	(i) Securities	47,237.			
		(ii) Other				
		<b>b</b> Less: cost or other basis and sales expenses	48,823.			
		<b>c</b> Gain or (loss)	-1,586.			
	<b>d</b> Net gain or (loss)	▶ -1,586.			-1,586.	
	<b>8 a</b> Gross income from fundraising events (not including \$ 1,558,687. of contributions reported on line 1c). See Part IV, line 18	<b>a</b>	76,128.			
		<b>b</b> Less: direct expenses	125,985.			
<b>c</b> Net income or (loss) from fundraising events		▶ -49,857.			-49,857.	
<b>9 a</b> Gross income from gaming activities. See Part IV, line 19	<b>a</b>					
	<b>b</b> Less: direct expenses	<b>b</b>				
	<b>c</b> Net income or (loss) from gaming activities	▶				
<b>10 a</b> Gross sales of inventory, less returns and allowances	<b>a</b>					
	<b>b</b> Less: cost of goods sold	<b>b</b>				
	<b>c</b> Net income or (loss) from sales of inventory	▶				
Miscellaneous Revenue		<b>Business Code</b>				
11 a	<b>MISCELLANEOUS</b>	900099	1,243.		1,243.	
	<b>b</b> <b>CHANGE INT-ENDOWMENT</b>	900099	-461,621.		-461,621.	
	<b>c</b>					
	<b>d</b> All other revenue					
	<b>e Total.</b> Add lines 11a-11d	▶ -460,378.				
<b>12 Total revenue.</b> See instructions	▶ 5,491,441.	1,126,302.	0.	259,763.		

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INC.**

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**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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	389,085.	389,085.		
<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	75,105.	75,105.		
<b>4</b> Benefits paid to or for members				
<b>5</b> Compensation of current officers, directors, trustees, and key employees	647,517.	390,975.	116,386.	140,156.
<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	1,055,494.	639,990.	190,359.	225,145.
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	30,191.	18,306.	5,445.	6,440.
<b>9</b> Other employee benefits	163,661.	96,332.	28,819.	38,510.
<b>10</b> Payroll taxes	116,322.	68,468.	20,483.	27,371.
<b>11</b> Fees for services (non-employees):				
<b>a</b> Management				
<b>b</b> Legal	36,660.	24,376.	12,216.	68.
<b>c</b> Accounting	19,500.		19,500.	
<b>d</b> Lobbying	108,084.	108,084.		
<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 Sch O.)	156,635.	84,446.	16,062.	56,127.
<b>12</b> Advertising and promotion				
<b>13</b> Office expenses	284,230.	126,962.	21,949.	135,319.
<b>14</b> Information technology	181,771.	121,958.	28,225.	31,588.
<b>15</b> Royalties				
<b>16</b> Occupancy	97,207.	57,361.	16,886.	22,960.
<b>17</b> Travel	316,693.	281,538.	4,256.	30,899.
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials				
<b>19</b> Conferences, conventions, and meetings	646,435.	630,084.	5,900.	10,451.
<b>20</b> Interest				
<b>21</b> Payments to affiliates				
<b>22</b> Depreciation, depletion, and amortization	79,410.	61,394.	5,234.	12,782.
<b>23</b> Insurance	7,917.	4,676.	1,383.	1,858.
<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> <b>PRECLINICAL CONSORTIUM</b>	1,007,978.	1,007,978.		
<b>b</b> <b>NATURAL HISTORY DATABAS</b>	170,893.	170,893.		
<b>c</b> <b>BIOSAMPLE REPOSITORY</b>	164,328.	164,328.		
<b>d</b> <b>DUES AND SUBSCRIPTIONS</b>	56,969.	23,021.	11,632.	22,316.
<b>e</b> All other expenses	56,448.	50,843.	2,344.	3,261.
<b>25</b> Total functional expenses. Add lines 1 through 24e	5,868,533.	4,596,203.	507,079.	765,251.
<b>26</b> Joint costs. 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)	73,440.	36,720.	0.	36,720.

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**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash - non-interest-bearing .....	1,079,000.	<b>1</b>	785,107.
	<b>2</b> Savings and temporary cash investments .....	1,231,098.	<b>2</b>	1,469,865.
	<b>3</b> Pledges and grants receivable, net .....	989,299.	<b>3</b>	1,249,706.
	<b>4</b> Accounts receivable, net .....	278,373.	<b>4</b>	158,782.
	<b>5</b> Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L .....		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instr). Complete Part II of Sch L .....		<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 .....	344,133.	<b>9</b>	263,093.
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....	<b>10a</b> 430,481.		
	<b>b</b> Less: accumulated depreciation .....	<b>10b</b> 261,135.	186,001.	<b>10c</b> 169,346.
	<b>11</b> Investments - publicly traded securities .....	10,970.	<b>11</b>	65.
	<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 .....	5,638,427.	<b>15</b>	5,185,602.
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 34) .....	9,757,301.	<b>16</b>	9,281,566.	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses .....	472,644.	<b>17</b>	452,001.
	<b>18</b> Grants payable .....		<b>18</b>	
	<b>19</b> Deferred revenue .....	167,293.	<b>19</b>	114,499.
	<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 current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L .....		<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 .....	60,584.	<b>25</b>	35,378.
	<b>26 Total liabilities.</b> Add lines 17 through 25 .....	700,521.	<b>26</b>	601,878.
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.</b>			
	<b>27</b> Unrestricted net assets .....	5,975,949.	<b>27</b>	5,024,877.
	<b>28</b> Temporarily restricted net assets .....	2,201,387.	<b>28</b>	0.
	<b>29</b> Permanently restricted net assets .....	879,444.	<b>29</b>	3,654,811.
	<b>Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34.</b>			
	<b>30</b> Capital stock or trust principal, or current funds .....		<b>30</b>	
	<b>31</b> Paid-in or capital surplus, or land, building, or equipment fund .....		<b>31</b>	
	<b>32</b> Retained earnings, endowment, accumulated income, or other funds .....		<b>32</b>	
<b>33</b> Total net assets or fund balances .....	9,056,780.	<b>33</b>	8,679,688.	
<b>34</b> Total liabilities and net assets/fund balances .....	9,757,301.	<b>34</b>	9,281,566.	

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**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,  
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**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>	5,491,441.
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	5,868,533.
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	-377,092.
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	<b>4</b>	9,056,780.
<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 33, column (B))	<b>10</b>	8,679,688.

**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		<b>X</b>
<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	<b>X</b>	
<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.	<b>X</b>	
<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? _____		<b>X</b>
<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 _____		

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NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,

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

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

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....	3124386.	3514873.	4517826.	3949953.	4105376.	19212414.
<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 Total.</b> Add lines 1 through 3 .....	3124386.	3514873.	4517826.	3949953.	4105376.	19212414.
<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) .....						3185510.
<b>6 Public support.</b> Subtract line 5 from line 4.						16026904.

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(f) Total
<b>7</b> Amounts from line 4 .....	3124386.	3514873.	4517826.	3949953.	4105376.	19212414.
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....	13,455.	16,038.	15,431.	10,393.	13,784.	69,101.
<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.) .....	9,351.	1,401.	1,683.	642.	1,243.	14,320.
<b>11 Total support.</b> Add lines 7 through 10						19340325.
<b>12</b> Gross receipts from related activities, etc. (see instructions) .....					12	6,113,224.
<b>13 First five 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>14</b> Public support percentage for 2018 (line 6, column (f) divided by line 11, column (f)) .....	<b>14</b>	82.87 %
<b>15</b> Public support percentage from 2017 Schedule A, Part II, line 14 .....	<b>15</b>	84.54 %
<b>16a 33 1/3% support test - 2018.</b> If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization .....	▶ <input checked="" type="checkbox"/>	
<b>b 33 1/3% support test - 2017.</b> 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 <b>stop here.</b> The organization qualifies as a publicly supported organization .....	▶ <input type="checkbox"/>	
<b>17a 10% -facts-and-circumstances test - 2018.</b> 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 <b>stop here.</b> Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization .....	▶ <input type="checkbox"/>	
<b>b 10% -facts-and-circumstances test - 2017.</b> 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 <b>stop here.</b> Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization .....	▶ <input type="checkbox"/>	
<b>18 Private foundation.</b> If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions .....	▶ <input type="checkbox"/>	



**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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) 2018	(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.)						

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

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

<b>15</b> Public support percentage for 2018 (line 8, column (f), divided by line 13, column (f)) .....	<b>15</b>	%
<b>16</b> Public support percentage from 2017 Schedule A, Part III, line 15 .....	<b>16</b>	%

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

<b>17</b> Investment income percentage for 2018 (line 10c, column (f), divided by line 13, column (f)) .....	<b>17</b>	%
<b>18</b> Investment income percentage from 2017 Schedule A, Part III, line 17 .....	<b>18</b>	%

**19a 33 1/3% support tests - 2018.** 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 - 2017.** 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 in line 12 on Part I. If you checked 12a of Part I, complete Sections A and B. If you checked 12b of Part I, complete Sections A and C. If you checked 12c of Part I, complete Sections A, D, and E. If you checked 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 Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i>		
<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 Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
<b>3a</b> Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer (b) and (c) below.</i>		
<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 Part VI when and how the organization made the determination.</i>		
<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 Part VI what controls the organization put in place to ensure such use.</i>		
<b>4a</b> Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>		
<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 Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i>		
<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 Part VI 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>5a</b> Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI, 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>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>c Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
<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 Part VI.</i>		
<b>7</b> Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as 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>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>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 Part VI.</i>		
<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 Part VI.</i>		
<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 Part VI.</i>		
<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 10b below.</i>		
<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>		

**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 (b) and (c) below, the governing body of a supported organization?		
<b>b</b> A family member of a person described in (a) above?		
<b>c</b> A 35% controlled entity of a person described in (a) or (b) above? <i>If "Yes" to a, b, or c, provide detail in Part VI.</i>		

**Section B. Type I Supporting Organizations**

	Yes	No
<b>1</b> Did the 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 (2), 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 (a) and (b) 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 (a) 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 (a) and (b) 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>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>		

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,

Schedule A (Form 990 or 990-EZ) 2018 INC.

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**Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations**

1  Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI.) **See instructions.** All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	1	
2	Recoveries of prior-year distributions	2	
3	Other gross income (see instructions)	3	
4	Add lines 1 through 3	4	
5	Depreciation and depletion	5	
6	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)	6	
7	Other expenses (see instructions)	7	
8	<b>Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4)	8	

Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	<b>Total</b> (add lines 1a, 1b, and 1c)	1d	
e	<b>Discount</b> claimed for blockage or other factors (explain in detail in <b>Part VI</b> ):		
2	Acquisition indebtedness applicable to non-exempt-use assets	2	
3	Subtract line 2 from line 1d	3	
4	Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, see instructions)	4	
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6	Multiply line 5 by .035	6	
7	Recoveries of prior-year distributions	7	
8	<b>Minimum Asset Amount</b> (add line 7 to line 6)	8	

Section C - Distributable Amount		(A) Prior Year	Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1	
2	Enter 85% of line 1	2	
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3	
4	Enter greater of line 2 or line 3	4	
5	Income tax imposed in prior year	5	
6	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	6	
7	<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).		

Schedule A (Form 990 or 990-EZ) 2018

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,

Schedule A (Form 990 or 990-EZ) 2018 INC.

95-3018799 Page 7

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

Section D - Distributions	Current Year
<b>1</b> Amounts paid to supported organizations to accomplish exempt purposes	
<b>2</b> Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
<b>3</b> Administrative expenses paid to accomplish exempt purposes of supported organizations	
<b>4</b> Amounts paid to acquire exempt-use assets	
<b>5</b> Qualified set-aside amounts (prior IRS approval required)	
<b>6</b> Other distributions (describe in <b>Part VI</b> ). See instructions.	
<b>7 Total annual distributions.</b> Add lines 1 through 6.	
<b>8</b> Distributions to attentive supported organizations to which the organization is responsive (provide details in <b>Part VI</b> ). See instructions.	
<b>9</b> Distributable amount for 2018 from Section C, line 6	
<b>10</b> Line 8 amount divided by line 9 amount	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2018	(iii) Distributable Amount for 2018
<b>1</b> Distributable amount for 2018 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2018 (reasonable cause required- explain in <b>Part VI</b> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2018			
<b>a</b> From 2013			
<b>b</b> From 2014			
<b>c</b> From 2015			
<b>d</b> From 2016			
<b>e</b> From 2017			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2018 distributable amount			
<b>i</b> Carryover from 2013 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
<b>4</b> Distributions for 2018 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2018 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from 4.			
<b>5</b> Remaining underdistributions for years prior to 2018, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>6</b> Remaining underdistributions for 2018. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>7 Excess distributions carryover to 2019.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2014			
<b>b</b> Excess from 2015			
<b>c</b> Excess from 2016			
<b>d</b> Excess from 2017			
<b>e</b> Excess from 2018			

Schedule A (Form 990 or 990-EZ) 2018

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,

Schedule A (Form 990 or 990-EZ) 2018 INC.

95-3018799 Page 8

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.)

SCHEDULE A, PART II, LINE 10, EXPLANATION FOR OTHER INCOME:

INCOME FROM ACTIVITIES NOT REGULARLY CARRIED ON

2014 AMOUNT: \$ 9,351.

2015 AMOUNT: \$ 1,401.

2016 AMOUNT: \$ 1,683.

2017 AMOUNT: \$ 642.

2018 AMOUNT: \$ 1,243.

Multiple horizontal lines for providing additional information.

**Schedule B**

(Form 990, 990-EZ, or 990-PF)

Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

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

OMB No. 1545-0047

**2018**

Name of the organization

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,  
INC.**

Employer identification number

**95-3018799**

Organization type (check one):

**Filers of:**

**Section:**

Form 990 or 990-EZ

501(c)( 3 ) (enter number) organization

4947(a)(1) nonexempt charitable trust **not** treated as a private foundation

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

4947(a)(1) nonexempt charitable trust treated as a private foundation

501(c)(3) taxable private foundation

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

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

**General Rule**

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

**Special Rules**

For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of **(1)** \$5,000; or **(2)** 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year ..... ▶ \$ \_\_\_\_\_

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

Name of organization <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.</b>	Employer identification number <b>95-3018799</b>
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**Part I Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>1</u>	 <hr/> <hr/> <hr/>	\$ <u>900,000.</u>	Person <input checked="" type="checkbox"/> Payroll Noncash (Complete Part II for noncash contributions.)
<u>2</u>	 <hr/> <hr/> <hr/>	\$ <u>110,000.</u>	Person <input type="checkbox"/> Payroll <input checked="" type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
<u>3</u>	 <hr/> <hr/> <hr/>	\$ <u>119,000.</u>	Person <input type="checkbox"/> Payroll <input checked="" type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
<u>4</u>	 <hr/> <hr/> <hr/>	\$ <u>125,000.</u>	Person <input type="checkbox"/> Payroll <input checked="" type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
<u>5</u>	 <hr/> <hr/> <hr/>	\$ <u>100,000.</u>	Person <input type="checkbox"/> Payroll <input checked="" type="checkbox"/> Noncash (Complete Part II for noncash contributions.)
<u>6</u>	 <hr/> <hr/> <hr/>	\$ <u>115,000.</u>	Person <input type="checkbox"/> Payroll <input checked="" type="checkbox"/> Noncash (Complete Part II for noncash contributions.)



Name of organization <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.</b>	Employer identification number <b>95-3018799</b>
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**Part I Contributors** (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	<hr/> <hr/> <hr/>	\$ 100,000.	Person <input checked="" type="checkbox"/> Payroll Noncash (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/>	\$ _____	Person Payroll Noncash (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/>	\$ _____	Person Payroll Noncash (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/>	\$ _____	Person Payroll Noncash (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/>	\$ _____	Person Payroll Noncash (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/>	\$ _____	Person Payroll Noncash (Complete Part II for noncash contributions.)
_____	<hr/> <hr/> <hr/>	\$ _____	Person Payroll Noncash (Complete Part II for noncash contributions.)

Name of organization <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.</b>	Employer identification number <b>95-3018799</b>
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**Part II Noncash Property** (see instructions). Use duplicate copies of Part II if additional space is needed.

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		\$ _____	_____
		\$ _____	_____
		\$ _____	_____
		\$ _____	_____
		\$ _____	_____
		\$ _____	_____
		\$ _____	_____

Name of organization <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.</b>	Employer identification number <b>95-3018799</b>
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**Part III** Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of **\$1,000 or less** for the year. (Enter this info. once.) ▶ \$ \_\_\_\_\_  
Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
<b>(e) Transfer of gift</b>			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
<b>(e) Transfer of gift</b>			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
<b>(e) Transfer of gift</b>			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
<b>(e) Transfer of gift</b>			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	
<b>(e) Transfer of gift</b>			
Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee	

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

**Political Campaign and Lobbying Activities**

OMB No. 1545-0047

**2018**

Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

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.

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

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

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

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

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

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

Name of organization <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.</b>	Employer identification number <b>95-3018799</b>
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**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.
- 2 Political campaign activity expenditures ..... ► \$ \_\_\_\_\_
- 3 Volunteer hours for political campaign activities .....

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

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

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

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

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

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Schedule C (Form 990 or 990-EZ) 2018

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,

**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.

Limits on Lobbying Expenditures (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)	823.													
<b>b</b>	Total lobbying expenditures to influence a legislative body (direct lobbying)	148,517.													
<b>c</b>	Total lobbying expenditures (add lines 1a and 1b)	149,340.													
<b>d</b>	Other exempt purpose expenditures	5,861,759.													
<b>e</b>	Total exempt purpose expenditures (add lines 1c and 1d)	6,011,099.													
<b>f</b>	Lobbying nontaxable amount. Enter the amount from the following table in both columns.	450,555.													
<table border="1"> <thead> <tr> <th>If the amount on line 1e, column (a) or (b) is:</th> <th>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)	112,639.													
<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"/> Yes <input type="checkbox"/> No												

**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) 2015	(b) 2016	(c) 2017	(d) 2018	(e) Total
<b>2a</b> Lobbying nontaxable amount	364,719.	394,622.	416,065.	450,555.	1,625,961.
<b>b</b> Lobbying ceiling amount (150% of line 2a, column(e))					2,438,942.
<b>c</b> Total lobbying expenditures	126,441.	145,927.	146,199.	149,340.	567,907.
<b>d</b> Grassroots nontaxable amount	91,180.	98,656.	104,016.	112,639.	406,491.
<b>e</b> Grassroots ceiling amount (150% of line 2d, column (e))					609,737.
<b>f</b> Grassroots lobbying expenditures	5,047.	986.	1,797.	823.	8,653.

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,

**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)).**

	(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 campaign activity 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.

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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 for instructions and the latest information.

OMB No. 1545-0047

2018

Open to Public Inspection

Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.

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.

Table with 2 columns: (a) Donor advised funds, (b) Funds and other accounts. Rows include: 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?, 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?

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

Table with 2 columns: Held at the End of the Tax Year. Rows include: 1 Purpose(s) of conservation easements held by the organization (check all that apply), 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, 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?, 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)?, 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.

Table with 2 columns: Revenue, Assets. Rows include: 1a If the organization elected, as permitted under SFAS 116 (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. 1b If the organization elected, as permitted under SFAS 116 (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 SFAS 116 (ASC 958) relating to these items: a Revenue included on Form 990, Part VIII, line 1, b Assets included in Form 990, Part X.

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

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

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

- 1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?  Yes  No
- b If "Yes," explain the arrangement in Part XIII and complete the following table:
- |                                 | Amount |
|---------------------------------|--------|
| c Beginning balance             | 1c     |
| d Additions during the year     | 1d     |
| e Distributions during the year | 1e     |
| f Ending balance                | 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 on Part XIII

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	5,655,555.	5,293,989.	4,763,517.	5,061,299.	4,994,766.
b Contributions		92,635.	58,749.	29,940.	47,153.
c Net investment earnings, gains, and losses	-439,321.	739,072.	525,868.	93,294.	179,553.
d Grants or scholarships					
e Other expenditures for facilities and programs	50,000.	403,000.		202,000.	97,500.
f Administrative expenses	54,646.	67,141.	54,145.	32,428.	62,673.
g End of year balance	5,111,588.	5,655,555.	5,293,989.	4,950,105.	5,061,299.

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment  84.34 %
  - b Permanent endowment  15.66 %
  - c Temporarily restricted endowment  \_\_\_\_\_ %
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- |  | Yes | No |
|--|-----|----|
| (i) unrelated organizations  |     | X  |
| (ii) related organizations   | X   |    |
| b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R? <input checked="" type="checkbox"/> | X   |    |
- 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		156,545.	128,781.	27,764.
d Equipment		155,880.	54,742.	101,138.
e Other		118,056.	77,612.	40,444.
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)				169,346.



**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,  
INC.**

Schedule D (Form 990) 2018

95-3018799 Page **3**

**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 .....		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
<b>Total.</b> (Col. (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)		
<b>Total.</b> (Col. (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 AFFI	5,193,934.
(2) DUE FROM AFFILIATE	-8,332.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 15.) ▶	5,185,602.

**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.

(a) Description of liability	(b) Book value
(1) Federal income taxes	
(2) DEFERRED RENT & LEASE INCENTIVE	35,378.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	35,378.

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

Schedule D (Form 990) 2018

**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.

1	Total revenue, gains, and other support per audited financial statements		1	5,507,752.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a		
b	Donated services and use of facilities	2b	16,311.	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d	2e		16,311.
3	Subtract line 2e from line 1	3		5,491,441.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c		0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5		5,491,441.

**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.

1	Total expenses and losses per audited financial statements		1	5,884,844.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	16,311.	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d	2e		16,311.
3	Subtract line 2e from line 1	3		5,868,533.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c		0.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)	5		5,868,533.

**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.

**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.

**PART V, LINE 1C:**

VOLATILITY OF THE FINANCIAL MARKETS IN 2018 NEGATIVELY IMPACTED THE MARKET VALUE OF MUTUAL FUND INVESTMENTS HELD BY THE TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FUND (A SEPARATE SUPPORTING ORGANIZATION TO THE NATIONAL TUBEROUS SCLEROSIS ASSOC., INC.). INCLUDED IN THE (\$439,321) OF NET



**SCHEDULE F  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Statement of Activities Outside the United States**

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

▶ Attach to Form 990.

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

OMB No. 1545-0047

**2018**

Open to Public Inspection

Name of the organization  
**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.**

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

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
EUROPE (INCLUDING ICELAND & GREENLAND)	0	0	GRANTMAKING		73,105.
MIDDLE EAST AND NORTH AFRICA	0	0	GRANTMAKING		2,000.
EUROPE (INCLUDING ICELAND & GREENLAND)	0	0	PROGRAM SERVICE ACTIVITIES	PRECLINICAL RESEARCH STUDIES	122,260.
<b>3 a Subtotal</b> .....	0	0			197,365.
<b>b Total from continuation sheets to Part I</b> .....	0	0			0.
<b>c Totals</b> (add lines 3a and 3b) .....	0	0			197,365.

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,  
INC.

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

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		EUROPE/ICELAND/GREENLAND	PROGRAMMATIC SUPPORT	10,000.	WIRE	0.		CASH
		EUROPE (INCLUDING ICELAND & GREENLAND)	RESEARCH ON TSC	44,105.	WIRE	0.		CASH
		EUROPE (INCLUDING ICELAND & GREENLAND)	RESEARCH ON TSC	19,000.	WIRE	0.		CASH

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 ..... 1

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



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.

**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.





NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,

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

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events (add col. (a) through col. (c))	
		WALKS (event type)	COMEDY FOR A CURE (event type)	11 (total number)		
Revenue	1	Gross receipts	940,123.	264,046.	430,646.	1,634,815.
	2	Less: Contributions	880,123.	251,435.	427,129.	1,558,687.
	3	Gross income (line 1 minus line 2)	60,000.	12,611.	3,517.	76,128.
Direct Expenses	4	Cash prizes				
	5	Noncash prizes	41,943.	7.	5,255.	47,205.
	6	Rent/facility costs	18,695.	14,007.	973.	33,675.
	7	Food and beverages	4,575.	32,181.	1,639.	38,395.
	8	Entertainment	4,251.	1,500.	943.	6,694.
	9	Other direct expenses			16.	16.
	10	Direct expense summary. Add lines 4 through 9 in column (d)				125,985.
11	Net income summary. Subtract line 10 from line 3, column (d)				-49,857.	

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

		(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
Revenue	1	Gross revenue			
	2	Cash prizes			
Direct Expenses	3	Noncash prizes			
	4	Rent/facility costs			
	5	Other direct expenses			
6	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	
7	Direct expense summary. Add lines 2 through 5 in column (d)				
8	Net gaming income summary. Subtract line 7 from line 1, column (d)				

9 Enter the state(s) in which the organization conducts gaming activities: \_\_\_\_\_

a Is the organization licensed to conduct gaming activities in each of these states?  Yes  No

b If "No," explain: \_\_\_\_\_

10a Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year?  Yes  No

b If "Yes," explain: \_\_\_\_\_





**SCHEDULE I  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Grants and Other Assistance to Organizations,  
Governments, and Individuals in the United States**  
Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

▶ **Attach to Form 990.**

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

OMB No. 1545-0047

**2018**

**Open to Public  
Inspection**

Name of the organization **NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,  
INC.**

**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.

<b>1 (a)</b> Name and address of organization or government	<b>(b)</b> EIN	<b>(c)</b> IRC section (if applicable)	<b>(d)</b> Amount of cash grant	<b>(e)</b> Amount of non-cash assistance	<b>(f)</b> Method of valuation (book, FMV, appraisal, other)	<b>(g)</b> Description of noncash assistance	<b>(h)</b> Purpose of grant or assistance
BRIGHAM & WOMAN'S HOSPITAL 75 ST. FRANCIS STREET BOSTON , MA 02115	04-2312909	501 (C)(3)	143,750.	0.			RESEARCH GRANTS
UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER - 5323 HARRY HINES BLVD. - DALLAS, TX 75287	75-6002868	501 (C)(3)	75,000.	0.			RESEARCH GRANTS
UT HEALTH SCIENCE CENTER AT HOUSTON - 7000 FANNIN, UCT 1000 - HOUSTON , TX 77030	74-1761309	501 (C)(3)	10,313.	0.			RESEARCH GRANTS
WAYNE STATE UNIVERSITY 5057 WOODWARD STE. 13202 DETROIT, MI 48202	38-6028429	501 (C)(3)	50,000.	0.			RESEARCH GRANTS
YALE UNIVERSITY P.O.BOX 1873 NEW HAVEN , CT 06508	06-0646973	501 (C)(3)	18,522.	0.			RESEARCH GRANTS
WEILL MEDICAL COLLEGE OF CORNELL UNIVERSITY - 575 LEXINGTON AVE. 9TH FLOOR - NEW YORK, NY 10022	13-1623978	501 (C)(3)	21,000.	0.			RESEARCH GRANTS

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ..... ▶ **8.**
- 3** Enter total number of other organizations listed in the line 1 table ..... ▶ **0.**

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

**Schedule I (Form 990) (2018)**



NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,  
INC.

**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 non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance

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

**PART I, LINE 2:**

THE TS ALLIANCE HAS FUNDED MORE THAN \$20.7 MILLION IN RESEARCH ON TSC SINCE 1984. DIRECTED BY STEVEN L. ROBERDS, PH.D, CHIEF SCIENTIFIC OFFICER, THE TS ALLIANCE RESEARCH GRANTS PROGRAM FUNDS RESEARCH FOCUSED ON TSC WITH PRIORITIES SET BY THE RESEARCHERS TOGETHER WITH THE TS ALLIANCE. COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS ARE ENCOURAGED AND FOSTERED, AND THE TS ALLIANCE IS WORKING TO INCREASE FUNDING FOR RESEARCH ON TSC. THROUGH THE TS ALLIANCE RESEARCH GRANTS PROGRAM, APPLICATIONS CAN BE SUBMITTED FOR: POSTDOCTORAL FELLOWSHIPS AND TSC RESEARCH GRANTS.

**Part IV** Supplemental Information

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 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.



**SCHEDULE J  
(Form 990)**

**Compensation Information**

OMB No. 1545-0047

**2018**

Open to Public Inspection

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.

Department of the Treasury  
Internal Revenue Service

Name of the organization **NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.** Employer identification number **95-3018799**

**Part I Questions Regarding Compensation**

**1a** 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 indemnification 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 (such as maid, chauffeur, chef) |

**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 .....

**2** Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a? .....

**3** 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 |

**4** 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:

- a** Receive a severance payment or change-of-control payment? .....
- b** Participate in, or receive payment from, a supplemental nonqualified retirement plan? .....
- c** Participate in, or receive payment from, an equity-based compensation arrangement? .....
- If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

**Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.**

**5** 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:

- a** The organization? .....
- b** Any related organization? .....
- If "Yes" on line 5a or 5b, describe in Part III.

**6** 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:

- a** The organization? .....
- b** Any related organization? .....
- If "Yes" on line 6a or 6b, describe in Part III.

**7** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III .....

**8** 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 .....

**9** If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)? .....

	Yes	No
<b>1b</b>		
<b>2</b>		
<b>4a</b>		<input checked="" type="checkbox"/>
<b>4b</b>		<input checked="" type="checkbox"/>
<b>4c</b>		<input checked="" type="checkbox"/>
<b>5a</b>	<input checked="" type="checkbox"/>	
<b>5b</b>		<input checked="" type="checkbox"/>
<b>6a</b>	<input checked="" type="checkbox"/>	
<b>6b</b>		<input checked="" type="checkbox"/>
<b>7</b>		<input checked="" type="checkbox"/>
<b>8</b>		<input checked="" type="checkbox"/>
<b>9</b>		

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

Schedule J (Form 990) 2018

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,  
INC.

95-3018799

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

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

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

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation in column (B) reported as deferred on prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
(1) KARI L ROSBECK PRESIDENT & CEO	(i)	169,536.	17,328.	130.	5,848.	31,043.	223,885.	0.
	(ii)	3,140.	321.	2.	108.	575.	4,146.	0.
(2) RICHARD A GOLLUB CONTROLLER & CFO	(i)	125,314.	13,267.	358.	4,382.	30,017.	173,338.	0.
	(ii)	7,999.	847.	23.	280.	1,916.	11,065.	0.
(3) STEVEN L ROBERDS CHIEF SCIENTIFIC OFFICER	(i)	180,565.	19,143.	133.	6,228.	29,013.	235,082.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							

**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.

PART I, LINE 5:

KARI LUTHER ROSBECK, RICHARD GOLLUB, STEVE ROBERDS, JAYE ISHAM AND LISA

MOSS 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, JAYE ISHAM AND LISA

MOSS 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)**

**Noncash Contributions**

OMB No. 1545-0047

**2018**

Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

- ▶ 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 instructions and the latest information.

Name of the organization **NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.** 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				
6 Cars and other vehicles				
7 Boats and planes				
8 Intellectual property				
9 Securities - Publicly traded	X	5	47,237.	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				
20 Drugs and medical supplies				
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ▶ (SPORTING EVEN)	X	1	9,170.	FMV
26 Other ▶ (FIDGET SPINNE)	X	1	250.	FMV
27 Other ▶ (KEYCHAINS)	X	1	248.	FMV
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**

	Yes	No
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?		X
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?		X
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?		X
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.		



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

Department of the Treasury  
Internal Revenue Service

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

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

▶ Attach to Form 990 or 990-EZ.

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

OMB No. 1545-0047

**2018**

Open to Public  
Inspection

Name of the organization	<b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.</b>	Employer identification number	<b>95-3018799</b>
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**FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:**

THE TS ALLIANCE HAS FUNDED MORE THAN \$20.7 MILLION IN RESEARCH GRANTS ON TSC SINCE 1984. THROUGH THE TS ALLIANCE RESEARCH GRANTS PROGRAM, APPLICATIONS CAN BE SUBMITTED FOR POSTDOCTORAL FELLOWSHIPS AND RESEARCH GRANTS. GRANTS ARE REVIEWED IN A THREE-STEP PROCESS: (1) ALL GRANT APPLICATIONS ARE REVIEWED BY A COMMITTEE COMPRISED OF SCIENTISTS KNOWLEDGEABLE ABOUT THE TOPIC AREA FOR SCIENTIFIC MERIT AND OF ADULTS OR PARENTS 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 TS 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.

A TOTAL OF 12 RESEARCH AWARDS WERE FUNDED DURING 2018. THE BOARD OF DIRECTORS APPROVED FUNDING TO BEGIN IN 2018 FOR FOUR MAJOR RESEARCH PROJECTS: (1) DR. YOU FENG (BRIGHAM AND WOMEN'S HOSPITAL) TO STUDY DYSREGULATED PHOSPHATIDYLCHOLINE METABOLISM IN TSC AND LAM PATHOGENESIS AND THERAPY; (2) DR. CHRISTINE OCHOA ESCAMILLA (UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL SCHOOL) FOR A POSTDOCTORAL FELLOWSHIP TO STUDY NEURAL CIRCUITS UNDERLYING AUTISM-RELATED BEHAVIORS IN TSC; (3) DR. ANGELIQUE BORDEY (YALE UNIVERSITY) TO STUDY NON-CELL AUTONOMOUS EFFECTS IN TSC BRAIN MALFORMATIONS; AND (4) DR. ALAN DOMBKOWSKI (WAYNE STATE UNIVERSITY) TO STUDY THE ROLE OF EXOSOMES IN EPILEPSY OF TSC. THE TS

ALLIANCE ALSO FUNDED FOUR SEED GRANTS IN RESPONSE TO A CALL FOR

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

Schedule O (Form 990 or 990-EZ) (2018)

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PROPOSALS TO UTILIZE BIOSAMPLES AND DATA IN THE TSC BIOSAMPLE

REPOITORY AND NATURAL HISTORY DATABASE: (1) DR. LAURA FARACH

(UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT HOUSTON) FOR DEVELOPING A

GENETIC RISK PREDICTION MODEL FOR EPILEPSY IN PATIENTS WITH TSC; (2)

DR. HILAIRE LAM (BRIGHAM AND WOMEN'S HOSPITAL) TO STUDY MITOCHONDRIAL

DNA HETEROPLASMY IN THE PATHOGENESIS AND THERAPY OF TSC; (3) DR. JOANA

MARQUES (UNIVERSITY OF PORTO FACULTY OF MEDICINE) TO STUDY EPIGENETIC

AND TRANSCRIPTIONAL ANALYSIS OF TSC2 IN LEUKOCYTE DNA FROM TSC

PATIENTS; AND (4) DR. JANE YU (UNIVERSITY OF CINCINNATI) FOR

QUANTIFICATION OF PLASMA LEVELS OF SPHINGOLIPIDS AND CERAMIDES IN

PATIENTS WITH TSC. ALSO IN 2018, WE CONTINUED TO SUPPORT FOUR RESEARCH

GRANTS AWARDED IN PREVIOUS YEARS: (1) DR. HENG-JIA LIU (BRIGHAM AND

WOMEN'S HOSPITAL) FOR A POSTDOCTORAL FELLOWSHIP TO STUDY T-CELL

DYSFUNCTION IN TSC; (2) DR. PETER TSAI (UNIVERSITY OF TEXAS

SOUTHWESTERN MEDICAL CENTER) TO STUDY THE IMPACT OF CEREBELLAR-MEDIAL

PREFRONTAL CORTICAL CIRCUITS IN TSC; (3) DR. BRENDAN MANNING (HARVARD

SCHOOL OF PUBLIC HEALTH) TO STUDY THE REPURPOSING OF INHIBITORS OF

PURINE SYNTHESIS FOR TSC TREATMENT; AND (4) DR. MARK THOMAS AND

ROSEMARY EKONG (UNIVERSITY COLLEGE LONDON) TO CURATE ADDITIONAL

MUTATIONS IN TSC1 AND TSC2 GENES AND MAKE THEM OPENLY AVAILABLE TO THE

PUBLIC IN A DATABASE THAT IS HIGHLY UTILIZED BY GENETIC RESEARCHERS IN

TSC.

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. AS OF DECEMBER 2018, 2,179 PEOPLE WITH TSC WERE

ENROLLED IN THE PROJECT FROM AMONG 18 U.S.-BASED SITES. THE TS ALLIANCE

PROVIDES FUNDING TO PARTICIPATING CLINICS TO PERFORM DATA ENTRY,

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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 2018, THE TS ALLIANCE INVESTED \$170,893 IN THE TSC NATURAL HISTORY DATABASE, INCLUDING SUB-PROJECTS ON TAND, EPILEPSY, RENAL ANGIOMYOLIPOMAS, AND SUBEPYNDYMAL GIANT CELL ASTROCYTOMAS TO ADDRESS DETAILED QUESTIONS ABOUT THESE LIFE-THREATENING MANIFESTATIONS OF TSC. A CONTRACT WITH NOVARTIS EXECUTED IN NOVEMBER 2012 PROVIDED TS ALLIANCE WITH FUNDING TO ENHANCE AND GROW THE DEPTH OF DATA IN THE TSC NATURAL HISTORY DATABASE THROUGH 2018.

THE TSC BIOSAMPLE REPOSITORY IS A TS ALLIANCE-DIRECTED PROJECT INITIATED IN 2014 THAT WILL IMPACT RESEARCH OVER THE NEXT TEN YEARS OR MORE. HIGH-QUALITY BIOSAMPLES SUCH AS BLOOD, DNA, AND TISSUES LINKED TO DETAILED CLINICAL DATA ARE REQUIRED FOR RESEARCHERS TO UNDERSTAND WHY TSC IS SO DIFFERENT FROM PERSON TO PERSON. THE TS ALLIANCE'S SCIENCE AND MEDICAL COMMITTEE IDENTIFIED THIS AS A GAP THAT CAN ONLY BE FILLED EFFECTIVELY WITH LEADERSHIP OF THE TS ALLIANCE, GUIDED BY A STEERING COMMITTEE OF CLINICIANS AND RESEARCHERS. THE TSC BIOSAMPLE REPOSITORY ENDED 2018 WITH 756 BIOSAMPLES: 524 BLOOD, BUCCAL CELL, OR TISSUE SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE TSC NATURAL HISTORY DATABASE, AND AN ADDITIONAL 232 SAMPLES FROM THE RARE DISEASE CLINICAL RESEARCH NETWORK'S DEVELOPMENTAL SYNAPTOPATHIES CONSORTIUM AND THE PREVENTING EPILEPSY USING VIGABATRIN IN INFANTS WITH TUBEROUS SCLEROSIS COMPLEX (PREVENT) CLINICAL TRIAL. SAMPLES IN THE REPOSITORY ARE LINKED TO DETAILED CLINICAL DATA IN OUR EXISTING TSC NATURAL HISTORY DATABASE AND ARE AVAILABLE TO QUALIFIED RESEARCHERS WORLDWIDE. SAMPLES ARE HOUSED AT AND DISTRIBUTED FROM THE VAN ANDEL INSTITUTE IN GRAND RAPIDS,



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MICHIGAN, UNDER CONTROL OF THE TS ALLIANCE.

THE TS ALLIANCE LAUNCHED THE TSC PRECLINICAL CONSORTIUM IN 2015, WHICH ENABLES PRIORITIZATION OF CANDIDATE TREATMENTS BASED ON COMPARING HEAD-TO-HEAD DATA USING CONSISTENT ANIMAL MODELS AND RIGOROUS TESTING PROCEDURES. THE TS ALLIANCE IS IDEALLY POSITIONED TO DRIVE THIS COLLABORATION - WITH INPUT FROM ACADEMIC, REGULATORY, AND INDUSTRY STAKEHOLDERS - BY MAINTAINING CONSTANT FOCUS ON THE NEEDS OF PEOPLE WITH TSC. TO DRIVE THIS PROJECT FURTHER IN 2019 AND BEYOND, THE TS ALLIANCE IN NOVEMBER 2018 HIRED DEAN J. AGUIAR, PHD, AS THE DIRECTOR OF PRECLINICAL RESEARCH. DEAN HAS MORE THAN 17 YEARS OF RESEARCH AND DEVELOPMENT (R&D) LEADERSHIP IN BIOPHARMACEUTICAL AND MEDICAL DEVICE INDUSTRIES, LEADING TEAMS AND TECHNOLOGIES FROM DISCOVERY TO INVESTIGATIONAL NEW DRUG (IND) AND INVESTIGATIONAL DEVICE EXEMPTION (IDE), A PRE-REQUISITE FOR CLINICAL TRIAL EVALUATION. THE TS 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 TS 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. THE CONSORTIUM BEGAN RUNNING EPILEPSY EXPERIMENTS IN AUGUST 2016 AT PSYCHOGENICS, A CONTRACT RESEARCH ORGANIZATION. TUMOR EXPERIMENTS BEGAN IN AUGUST 2017 AT PORSOLT, ANOTHER CONTRACT RESEARCH ORGANIZATION. THREE PHARMACEUTICAL COMPANIES JOINED THE PRECLINICAL CONSORTIUM IN 2018, BRINGING THE TOTAL SINCE INCEPTION TO NINE INDUSTRY PARTNERS, SEVEN OF WHOM REMAIN ACTIVE MEMBERS. THE TSC PRECLINICAL RESEARCH CONSORTIUM RAN 12 STUDIES TO TEST 10 COMPOUNDS IN 2018, COMPARED TO 10

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STUDIES AND 8 COMPOUNDS IN 2017. SOME OF THE CONSORTIUM'S RESULTS WERE SHARED BY PIQR AT THE EPILEPSY PIPELINE CONFERENCE AND BY DR. ANGELIQUE BORDEY AT THE AMERICAN EPILEPSY SOCIETY ANNUAL MEETING.

THIS DESCRIPTION IS CONTINUED ON LINE 4D.

FORM 990, PART III, LINE 4B, PROGRAM SERVICE ACCOMPLISHMENTS:

2018. THE VICE PRESIDENT, SUPPORT SERVICES AND EDUCATION PARENT MENTORS ATTENDED 83 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. THROUGH COLLABORATIONS WITH THE PARENT TRAINING AND INFORMATION CENTERS IN 2018, 4,473 FREE PARENT TRAININGS/WEBINARS ON EDUCATIONAL ADVOCACY WERE OFFERED TO FAMILIES IN 36 STATES DEALING WITH EDUCATIONAL ISSUES FOR THEIR CHILDREN. IN ADDITION, 110 SCHOOL SYSTEMS WERE OFFERED THE SUPPORT OF THE EDUCATOR MENTOR PROGRAM IN 2018. THERE WERE 12 SCHOOL SYSTEMS PROVIDED TRAINING ON "TSC 101" FOR SCHOOL DISTRICTS IN AN EFFORT TO HELP THEM UNDERSTAND THE COMPLEXITIES OF TSC AND LEARNING.

THROUGH A NETWORK OF 37 VOLUNTEER BRANCHES OF THE ORGANIZATION, CALLED COMMUNITY ALLIANCES, LOCAL EDUCATION AND SUPPORT GROUP MEETINGS WERE HELD THROUGHOUT THE COUNTRY EDUCATING AND SUPPORTING 1,500 FAMILIES/INDIVIDUALS LIVING WITH TSC. THE COMMUNITY PROGRAMS TEAM WAS DEVELOPED IN 2018 WHEN THE COMMUNITY ALLIANCES WERE DIVIDED INTO THREE REGIONS, WITH A COMMUNITY PROGRAMS MANAGER ASSIGNED TO EACH REGION TO MANAGE THE DAY-TO-DAY ACTIVITIES WITHIN THEIR COMMUNITIES. IN 2018, 16

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OF 75 LEADERSHIP POSITIONS (37 COMMUNITY ALLIANCE CHAIRS AND 38 WALK CHAIRS) WERE FILLED, AND THREE REMAINED OPEN AS OF DECEMBER 31, 2018.

THE 2018 WORLD TSC CONFERENCE WAS CO-HOSTED BY THE TS ALLIANCE AND TUBEROUS SCLEROSIS COMPLEX INTERNATIONAL IN DALLAS, TEXAS FROM JULY 26-29, 2018. THIS EVENT DREW 933 TOTAL ATTENDEES FROM 26 COUNTRIES. NINETY-NINE SCHOLARSHIPS WERE AWARDED TO ASSIST FAMILIES/INDIVIDUALS WITH THE COST. THE SUCCESS OF THIS EVENT IS DO TO BOTH THE IN-PERSON AND ONLINE PARTICIPATION. THE CONFERENCE CONSISTED OF FOUR EDUCATIONAL TRACKS: PEDIATRIC, TRANSITION, ADULT, AND SPECIALTY. IN ADDITION, THERE WERE CONCURRENTLY RUN GROUP SESSIONS (4) AND MEET-THE-EXPERT SESSIONS (2). GROUP SESSIONS PROVIDED A CONVERSATIONAL FORUM TO DISCUSS TOPICS RELEVANT TO A SMALLER POPULATION OF THOSE AFFECTED BY TSC (E.G.: WOMEN'S HEALTH ISSUES). MEET-THE-EXPERT SESSIONS PROVIDED A QUESTION-AND-ANSWER FORMAT WITH SIX EXPERTS PER SESSION PARTICIPATING FROM VARIOUS SPECIALTIES. GENERAL SESSIONS TOPICS WERE SELECTED BASED ON HOT TOPICS THAT ARE APPLICABLE TO THE MAJORITY OF TSC INDIVIDUALS AND FAMILIES AND INTERNATIONAL RELEVANCE.

GLOBAL OUTREACH WORKS TO ADDRESS UNMET NEEDS WITHIN THE GLOBAL TSC COMMUNITY. THE PROGRAM PROVIDES THE OPPORTUNITY FOR THE TS 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 TS ALLIANCE TO FACILITATE LOCAL CONNECTIONS FOR INDIVIDUALS AND FAMILIES AFFECTED BY TSC, AND RAISE REVENUE AND AWARENESS WHILE SUPPORTING THE MISSION OF THE ORGANIZATION. IN 2018, THE TS ALLIANCE SIGNED A GLOBAL AGREEMENT WITH THE TS ALLIANCE OF INDIA. THE TS ALLIANCE NOW HAS SIX

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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.

FORM 990, PART III, LINE 4C, PROGRAM SERVICE ACCOMPLISHMENTS:

TO INCREASE PUBLIC AWARENESS, THE TS ALLIANCE ONCE AGAIN PARTICIPATED IN TSC GLOBAL AWARENESS DAY ON MAY 15 AS WELL AS TSC AWARENESS MONTH THROUGHOUT MAY; A TSC GLOBAL AWARENESS DAY NEWS RELEASE GARNERED 15.7 MILLION IMPRESSIONS. THE TS ALLIANCE AGAIN HEAVILY PROMOTED INFANTILE SPASMS AWARENESS WEEK, DECEMBER 1 TO 7. THIS AWARENESS CAMPAIGN INCLUDED TARGETED SOCIAL MEDIA OUTREACH AND A SATELLITE RADIO TOUR, WHICH GAINED COVERAGE REACHING A POTENTIAL OF 1.8 MILLION. ADDITIONAL NEWS RELEASES REACHED ANOTHER 76.1 MILLION. EDUCATIONAL SESSION VIDEOS FROM THE ORGANIZATION'S 2018 WORLD TSC CONFERENCE WERE VIEWED 4,510 TIMES.

FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:

GOVERNMENT RELATIONS FOCUSES ON EDUCATING MEMBERS OF CONGRESS ABOUT TSC TO FURTHER TSC RESEARCH, AWARENESS AND CLINICAL CARE. THE ANNUAL TS ALLIANCE MARCH ON CAPITOL HILL TO ADVOCATE FOR FEDERAL FUNDING FOR THE TUBEROUS SCLEROSIS COMPLEX RESEARCH PROGRAM (TSCR) AT THE DEPARTMENT OF DEFENSE'S (DOD) CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP) TOOK PLACE IN EARLY MARCH 2018. MORE THAN 100 MEMBERS OF THE TSC COMMUNITY PARTICIPATED AND ASKED THEIR SENATORS AND REPRESENTATIVES TO SIGN ONTO DEAR COLLEAGUE LETTERS IN SUPPORT OF THE TSCR. 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

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CASE FOR CONTINUED FUNDING. IN THE HOUSE, 200 DEMOCRATIC AND REPUBLICAN REPRESENTATIVES SIGNED A BIPARTISAN DEAR COLLEAGUE LETTER OF SUPPORT FROM REPRESENTATIVES DAVE LOEBSACK (D-IA) AND ILEANA ROS-LEHTINEN (R-FL). THE SENATE LETTER WAS SPONSORED BY SENATORS CHRIS MURPHY (D-CT) AND JOHNNY ISAKSON (R-GA) AND ENDED WITH 29 SIGNATURES. IN FY2019, THE TSC RESEARCH PROGRAM AT THE CDMRP RECEIVED A \$6 MILLION APPROPRIATION, BRINGING THE CUMULATIVE FUNDING TO \$83 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

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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 TSCRIP.

EXPENSES \$ 149,340. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

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 TS ALLIANCE PARTICIPATED IN AND PRESENTED AT 38 PROFESSIONAL MEETINGS INCLUDING: AMERICAN THORACIC SOCIETY AND THE ATS LEADERSHIP SUMMIT; SOCIETY FOR NEUROSCIENCE; GLOBAL GENES; NINDS ANTIEPILEPTOGENESIS AND DISEASE MODIFICATION WORKSHOP; THE EPILEPSY PIPELINE CONFERENCE; TWO HEALTH RESEARCH ALLIANCE MEMBERS MEETINGS; INTERNATIONAL SOCIETY FOR AUTISM RESEARCH; RESEARCH ROUNDTABLE IN EPILEPSY; ASSOCIATION OF CLINICAL RESEARCH PROFESSIONALS; INTERNATIONAL RESEARCH CONFERENCE ON TSC (JAPAN); ICARE (INTERAGENCY COLLABORATIVE TO ADVANCE RESEARCH IN EPILEPSY); NINDS NONPROFIT FORUM; FDA CDER PUBLIC WORKSHOP: DRAFT GUIDANCE RELATING TO PATIENT EXPERIENCE; WORLD ORPHAN DRUG CONGRESS; NORD ORPHAN PRODUCTS AND BREAKTHROUGH SUMMIT; OPEN RESEARCH FUNDERS GROUP; NCATS RARE DISEASES CLINICAL RESEARCH NETWORK (RDCRN) MEETING; PARTNERS AGAINST MORTALITY IN EPILEPSY (PAME); DRUG INFORMATION ASSOCIATION ANNUAL MEETING; BIO INTERNATIONAL CONVENTION; BIO PATIENT HEALTH AND ADVOCACY SUMMIT; THE ARC NATIONAL CONVENTION; INFANTILE SPASMS ACTION NETWORK; AMERICAN ACADEMY OF PEDIATRICS; THE

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LAM FOUNDATION'S RARE LUNG DISEASES CONFERENCE AND LAMPOSIUM; INTERNATIONAL AUTISM CONFERENCE PATHWAYS TO AN INCLUSIVE LIFE IN MUMBAI, INDIA; 7 REUNION NACIONAL DE ESCLEROSIS TUBEROSA; CBI RARE DISEASE INNOVATION SUMMIT; 2018 WORLD TSC CONFERENCE; AND NONPROFIT FUNDER-RESEARCH FORUM. IN ADDITION, AT THE AMERICAN EPILEPSY SOCIETY MEETING THE TS ALLIANCE PRESENTED IN THE DISCOVERY CENTER AND THE POSTER SESSION, AND HOSTED MORE THAN 100 GUESTS AT A RECEPTION FOR TSC RESEARCHERS. AT THE CONFERENCE THE TS ALLIANCE ALSO PARTICIPATED IN A SPECIAL INTEREST GROUP MEETING ON TSC.

IN ADDITION, THE VICE PRESIDENT, SUPPORT SERVICES CONTINUES TO COLLABORATE WITH NATIONAL EDUCATIONAL NETWORKS, INCLUDING THE ARC USA, PARENT TRAINING INFORMATION CENTERS ACROSS THE COUNTRY AND THE ASSOCIATION FOR MIDDLE LEVEL EDUCATION.

EXPENSES \$ 128,621. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

LINE 4A, RESEARCH PROGRAM CONTINUED:

THE TS ALLIANCE CONTINUED TO BE A KEY PART OF THE TSC CLINICAL RESEARCH CONSORTIUM ALTHOUGH ONLY A SMALL AMOUNT OF TS ALLIANCE FINANCIAL SUPPORT WAS REQUIRED BECAUSE OF THE CONSORTIUM'S SUCCESS IN OBTAINING NIH FUNDING. HOWEVER, IN 2018 THE TS ALLIANCE CONTINUED ITS FUNDING OF DR. MUSTAFA SAHIN (BOSTON CHILDREN'S HOSPITAL) FOR ADMINISTRATIVE CORE SUPPORT FOR DEVELOPMENTAL SYNAPTOPATHIES ASSOCIATED WITH TSC, PTEN AND SHANK3 MUTATIONS. NOW CONSISTING OF TEN SITES WITH ANOTHER FIVE SITES TO BE ADDED IN EARLY 2019, THE CONSORTIUM HAS RECEIVED \$29 MILLION IN COMPETITIVE GRANT FUNDING FROM THE NATIONAL INSTITUTES OF HEALTH (NIH) TO SUPPORT CLINICAL STUDIES IN TSC. THE CLINICAL RESEARCH CONSORTIUM IS

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MAKING HISTORY WITH THE PREVENT TRIAL - PREVENTING EPILEPSY USING VIGABATRIN IN INFANTS WITH TUBEROUS SCLEROSIS COMPLEX. PREVENT IS THE FIRST PREVENTATIVE TRIAL FOR ANY FORM OF EPILEPSY IN THE US AND EXPECTS TO COMPLETE ENROLLING PARTICIPANTS IN DECEMBER 2019. THE PREVENT TRIAL BUILDS DIRECTLY UPON THE CONSORTIUM'S FIRST CLINICAL STUDY FROM WHICH INTERIM RESULTS HAVE BEEN PUBLISHED ([WWW.NCBI.NLM.NIH.GOV/PUBMED/26498039](http://WWW.NCBI.NLM.NIH.GOV/PUBMED/26498039)) SHOWING THAT ALL INFANTS WHO DEVELOPED ABNORMAL ACTIVITY ON EEGS WENT ON TO DEVELOP SEIZURES. 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. THE TS ALLIANCE'S CHIEF SCIENTIFIC OFFICER SERVES ON THE CONSORTIUM'S LEADERSHIP TEAM.

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.

FORM 990, PART VI, SECTION A, LINE 7A:

THE TS ALLIANCE IS A MEMBERSHIP-BASED ORGANIZATION, WHICH MEANS MEMBERS HELP ELECT THE BOARD OF DIRECTORS. THE TS ALLIANCE MEMBERSHIP PROGRAM



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ALLOWED INDIVIDUALS TO STATE THEIR INTENT TO BE A MEMBER FOR THE PURPOSE OF GOVERNANCE. THERE WERE NO LEVELS TO MEMBERSHIP IN 2018. ANYONE CAN BE A MEMBER AT NO COST.

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.

FORM 990, PART VI, SECTION B, LINE 12C:

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 2018:

BOARD MEMBER BRENDAN MANNING, PH.D., IS EMPLOYED AT HARVARD COLLEGE, WHICH

Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.	Employer identification number 95-3018799
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RECEIVED A \$50,000 ROTHBERG COURAGE AWARD GRANT TO STUDY TO STUDY THE REPURPOSING OF CLINICALLY APPROVED IMMUNOSUPPRESSANTS AS A SAFE AND EFFECTIVE TREATMENT FOR TSC.

BOARD MEMBER MARTINA BEBIN, MD, MPA, IS EMPLOYED AT THE UNIVERSITY OF ALABAMA AT BIRMINGHAM, WHICH RECEIVED \$11,495 FOR HER WORK ON THE TSC NATURAL HISTORY DATABASE.

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 TUBEROUS SCLEROSIS 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.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:

Name of the organization <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.</b>	Employer identification number <b>95-3018799</b>
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**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, WV, WI**

**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

**2018**

Open to Public Inspection

Name of the organization **NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.** 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
TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FD - 52-1926919, 801 ROEDER ROAD, STE 750, SILVER SPRING, MD 20910	SUPPORT ORG	MARYLAND	501(C)(3)	LINE 12B, II	N/A		X

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

Schedule R (Form 990) 2018

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,

**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

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION,  
INC.**

**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 (i) interest, (ii) annuities, (iii) royalties, or (iv) rent from a controlled entity .....		X
<b>b</b> Gift, grant, or capital contribution to related organization(s) .....		X
<b>c</b> Gift, grant, or capital contribution from related organization(s) .....	X	
<b>d</b> Loans or loan guarantees to or for related organization(s) .....		X
<b>e</b> Loans or loan guarantees by related organization(s) .....		X
<b>f</b> Dividends from related organization(s) .....		X
<b>g</b> Sale of assets to related organization(s) .....		X
<b>h</b> Purchase of assets from related organization(s) .....		X
<b>i</b> Exchange of assets with related organization(s) .....		X
<b>j</b> Lease of facilities, equipment, or other assets to related organization(s) .....		X
<b>k</b> Lease of facilities, equipment, or other assets from related organization(s) .....		X
<b>l</b> Performance of services or membership or fundraising solicitations for related organization(s) .....		X
<b>m</b> Performance of services or membership or fundraising solicitations by related organization(s) .....		X
<b>n</b> Sharing of facilities, equipment, mailing lists, or other assets with related organization(s) .....	X	
<b>o</b> Sharing of paid employees with related organization(s) .....	X	
<b>p</b> Reimbursement paid to related organization(s) for expenses .....		X
<b>q</b> Reimbursement paid by related organization(s) for expenses .....		X
<b>r</b> Other transfer of cash or property to related organization(s) .....		X
<b>s</b> Other transfer of cash or property from related organization(s) .....		X

**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> TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FUND	C	50,000.	CASH
<b>(2)</b>			
<b>(3)</b>			
<b>(4)</b>			
<b>(5)</b>			
<b>(6)</b>			







Form **990-T**

**Exempt Organization Business Income Tax Return**  
**(and proxy tax under section 6033(e))**

OMB No. 1545-0687

**2018**

For calendar year 2018 or other tax year beginning \_\_\_\_\_, and ending \_\_\_\_\_

▶ Go to [www.irs.gov/Form990T](http://www.irs.gov/Form990T) for instructions and the latest information.

▶ Do not enter SSN numbers on this form as it may be made public if your organization is a 501(c)(3).

Department of the Treasury  
Internal Revenue Service

Open to Public Inspection for  
501(c)(3) Organizations Only

<b>A</b> Check box if address changed		Name of organization ( <input type="checkbox"/> Check box if name changed and see instructions.) <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.</b>	D Employer identification number (Employees' trust, see instructions.) <b>95-3018799</b>
<b>B</b> Exempt under section	Print or Type	Number, street, and room or suite no. If a P.O. box, see instructions. <b>801 ROEDER ROAD, NO. 750</b>	E Unrelated business activity code (See instructions.) <b>900099</b>
<input checked="" type="checkbox"/> 501(c)(3)		City or town, state or province, country, and ZIP or foreign postal code <b>SILVER SPRING, MD 20910</b>	
408(e) 220(e) 408A 530(a) 529(a)			

<b>C</b> Book value of all assets at end of year <b>9,743,187.</b>	F Group exemption number (See instructions.) ▶	G Check organization type ▶ <input checked="" type="checkbox"/> 501(c) corporation	501(c) trust      401(a) trust      Other trust
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**H** Enter the number of the organization's unrelated trades or businesses. ▶ **1** Describe the only (or first) unrelated trade or business here ▶ **TAXABLE FRINGE BENEFITS**. If only one, complete Parts I-V. If more than one, describe the first in the blank space at the end of the previous sentence, complete Parts I and II, complete a Schedule M for each additional trade or business, then complete Parts III-V.

**I** During the tax year, was the corporation a subsidiary in an affiliated group or a parent-subsidiary controlled group? ..... ▶ Yes  No

If "Yes," enter the name and identifying number of the parent corporation. ▶

**J** The books are in care of ▶ **THE ORGANIZATION** Telephone number ▶ **301-562-9890**

Part I Unrelated Trade or Business Income	(A) Income	(B) Expenses	(C) Net
<b>1a</b> Gross receipts or sales			
<b>b</b> Less returns and allowances			
<b>c</b> Balance	<b>1c</b>		
<b>2</b> Cost of goods sold (Schedule A, line 7)	<b>2</b>		
<b>3</b> Gross profit. Subtract line 2 from line 1c	<b>3</b>		
<b>4a</b> Capital gain net income (attach Schedule D)	<b>4a</b>		
<b>b</b> Net gain (loss) (Form 4797, Part II, line 17) (attach Form 4797)	<b>4b</b>		
<b>c</b> Capital loss deduction for trusts	<b>4c</b>		
<b>5</b> Income (loss) from a partnership or an S corporation (attach statement)	<b>5</b>		
<b>6</b> Rent income (Schedule C)	<b>6</b>		
<b>7</b> Unrelated debt-financed income (Schedule E)	<b>7</b>		
<b>8</b> Interest, annuities, royalties, and rents from a controlled organization (Schedule F)	<b>8</b>		
<b>9</b> Investment income of a section 501(c)(7), (9), or (17) organization (Schedule G)	<b>9</b>		
<b>10</b> Exploited exempt activity income (Schedule I)	<b>10</b>		
<b>11</b> Advertising income (Schedule J)	<b>11</b>		
<b>12</b> Other income (See instructions; attach schedule)	<b>12</b>		
<b>13 Total.</b> Combine lines 3 through 12	<b>13</b>	<b>0.</b>	

**Part II Deductions Not Taken Elsewhere** (See instructions for limitations on deductions.)  
 (Except for contributions, deductions must be directly connected with the unrelated business income.)

<b>14</b> Compensation of officers, directors, and trustees (Schedule K)	<b>14</b>	
<b>15</b> Salaries and wages	<b>15</b>	
<b>16</b> Repairs and maintenance	<b>16</b>	
<b>17</b> Bad debts	<b>17</b>	
<b>18</b> Interest (attach schedule) (see instructions)	<b>18</b>	
<b>19</b> Taxes and licenses	<b>19</b>	
<b>20</b> Charitable contributions (See instructions for limitation rules)	<b>20</b>	
<b>21</b> Depreciation (attach Form 4562)	<b>21</b>	
<b>22</b> Less depreciation claimed on Schedule A and elsewhere on return	<b>22a</b>	<b>22b</b>
<b>23</b> Depletion	<b>23</b>	
<b>24</b> Contributions to deferred compensation plans	<b>24</b>	
<b>25</b> Employee benefit programs	<b>25</b>	
<b>26</b> Excess exempt expenses (Schedule I)	<b>26</b>	
<b>27</b> Excess readership costs (Schedule J)	<b>27</b>	
<b>28</b> Other deductions (attach schedule)	<b>28</b>	
<b>29 Total deductions.</b> Add lines 14 through 28	<b>29</b>	<b>0.</b>
<b>30</b> Unrelated business taxable income before net operating loss deduction. Subtract line 29 from line 13	<b>30</b>	<b>0.</b>
<b>31</b> Deduction for net operating loss arising in tax years beginning on or after January 1, 2018 (see instructions)	<b>31</b>	
<b>32</b> Unrelated business taxable income. Subtract line 31 from line 30	<b>32</b>	<b>0.</b>

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, INC.

Form 990-T (2018)

95-3018799

Page 2

<b>Part III Total Unrelated Business Taxable Income</b>	
33	Total of unrelated business taxable income computed from all unrelated trades or businesses (see instructions) ..... 0.
34	Amounts paid for disallowed fringes ..... 18,094.
35	Deduction for net operating loss arising in tax years beginning before January 1, 2018 (see instructions) .....
36	Total of unrelated business taxable income before specific deduction. Subtract line 35 from the sum of lines 33 and 34 ..... 18,094.
37	Specific deduction (Generally \$1,000, but see line 37 instructions for exceptions) ..... 1,000.
38	<b>Unrelated business taxable income.</b> Subtract line 37 from line 36. If line 37 is greater than line 36, enter the smaller of zero or line 36 ..... 17,094.

<b>Part IV Tax Computation</b>	
39	<b>Organizations Taxable as Corporations.</b> Multiply line 38 by 21% (0.21) ..... 3,590.
40	<b>Trusts Taxable at Trust Rates.</b> See instructions for tax computation. Income tax on the amount on line 38 from: Tax rate schedule or Schedule D (Form 1041) .....
41	<b>Proxy tax.</b> See instructions .....
42	Alternative minimum tax (trusts only) .....
43	<b>Tax on Noncompliant Facility Income.</b> See instructions .....
44	<b>Total.</b> Add lines 41, 42, and 43 to line 39 or 40, whichever applies ..... 3,590.

<b>Part V Tax and Payments</b>	
45a	Foreign tax credit (corporations attach Form 1118; trusts attach Form 1116) ..... 45a
b	Other credits (see instructions) ..... 45b
c	General business credit. Attach Form 3800 ..... 45c
d	Credit for prior year minimum tax (attach Form 8801 or 8827) ..... 45d
e	<b>Total credits.</b> Add lines 45a through 45d ..... 45e
46	Subtract line 45e from line 44 ..... 3,590.
47	Other taxes. Check if from: Form 4255 <input type="checkbox"/> Form 8611 <input type="checkbox"/> Form 8697 <input type="checkbox"/> Form 8866 <input type="checkbox"/> Other (attach schedule) ..... 47
48	<b>Total tax.</b> Add lines 46 and 47 (see instructions) ..... 3,590.
49	2018 net 965 tax liability paid from Form 965-A or Form 965-B, Part II, column (k), line 2 ..... 0.
50a	Payments: A 2017 overpayment credited to 2018 ..... 50a
b	2018 estimated tax payments ..... 3,900.
c	Tax deposited with Form 8868 ..... 50c
d	Foreign organizations: Tax paid or withheld at source (see instructions) ..... 50d
e	Backup withholding (see instructions) ..... 50e
f	Credit for small employer health insurance premiums (attach Form 8941) ..... 50f
g	Other credits, adjustments, and payments: Form 2439 _____ Other _____ Total ..... 50g
51	<b>Total payments.</b> Add lines 50a through 50g ..... 3,900.
52	Estimated tax penalty (see instructions). Check if Form 2220 is attached ..... 52
53	<b>Tax due.</b> If line 51 is less than the total of lines 48, 49, and 52, enter amount owed ..... 53
54	<b>Overpayment.</b> If line 51 is larger than the total of lines 48, 49, and 52, enter amount overpaid ..... 310.
55	Enter the amount of line 54 you want: <b>Credited to 2019 estimated tax</b> 310.   <b>Refunded</b> ..... 0.

<b>Part VI Statements Regarding Certain Activities and Other Information</b> (see instructions)		Yes	No
56	At any time during the 2018 calendar year, did the organization have an interest in or a signature or other authority over a financial account (bank, securities, or other) in a foreign country? If "Yes," the organization may have to file FinCEN Form 114, Report of Foreign Bank and Financial Accounts. If "Yes," enter the name of the foreign country here ..... X		X
57	During the tax year, did the organization receive a distribution from, or was it the grantor of, or transferor to, a foreign trust? ..... X If "Yes," see instructions for other forms the organization may have to file.		X
58	Enter the amount of tax-exempt interest received or accrued during the tax year ..... \$		

**Sign Here** 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 taxpayer) is based on all information of which preparer has any knowledge.

Signature of officer: *Kari L. ...* Date: 4/5/19 Title: PRESIDENT & CEO

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

<b>Paid Preparer Use Only</b>	Print/Type preparer's name	Preparer's signature	Date	Check if self-employed	PTIN
	ELIZABETH HELLER	<i>Elizabeth Heller</i>	4/5/2019		P00397829
	Firm's name ▶ TATE AND TRYON	Firm's EIN ▶ 52-1855942		2021 L STREET, NW SUITE 400	
Firm's address ▶ WASHINGTON, DC 20036			Phone no. (202) 293-2200		

**Schedule A - Cost of Goods Sold.** Enter method of inventory valuation ► **N/A**

1	Inventory at beginning of year .....	1		6	Inventory at end of year .....	6			
2	Purchases .....	2			7	<b>Cost of goods sold.</b> Subtract line 6 from line 5. Enter here and in Part I, line 2 .....	7		
3	Cost of labor .....	3			8	Do the rules of section 263A (with respect to property produced or acquired for resale) apply to the organization? .....		Yes	No
4a	Additional section 263A costs (attach schedule) .....	4a							
b	Other costs (attach schedule) .....	4b							
5	<b>Total.</b> Add lines 1 through 4b .....	5							

**Schedule C - Rent Income (From Real Property and Personal Property Leased With Real Property)**

(see instructions)

1. Description of property

(1)	
(2)	
(3)	
(4)	

2. Rent received or accrued

(a) From personal property (if the percentage of rent for personal property is more than 10% but not more than 50%)	(b) From real and personal property (if the percentage of rent for personal property exceeds 50% or if the rent is based on profit or income)	3(a) Deductions directly connected with the income in columns 2(a) and 2(b) (attach schedule)
(1)		
(2)		
(3)		
(4)		
Total	0.	Total

(c) **Total income.** Add totals of columns 2(a) and 2(b). Enter here and on page 1, Part I, line 6, column (A) .....

(b) **Total deductions.** Enter here and on page 1, Part I, line 6, column (B) ... 0.

**Schedule E - Unrelated Debt-Financed Income** (see instructions)

1. Description of debt-financed property	2. Gross income from or allocable to debt-financed property	3. Deductions directly connected with or allocable to debt-financed property		
		(a) Straight line depreciation (attach schedule)	(b) Other deductions (attach schedule)	
(1)				
(2)				
(3)				
(4)				
4. Amount of average acquisition debt on or allocable to debt-financed property (attach schedule)	5. Average adjusted basis of or allocable to debt-financed property (attach schedule)	6. Column 4 divided by column 5	7. Gross income reportable (column 2 x column 6)	8. Allocable deductions (column 6 x total of columns 3(a) and 3(b))
(1)		%		
(2)		%		
(3)		%		
(4)		%		
<b>Totals</b> .....		Enter here and on page 1, Part I, line 7, column (A). 0.		Enter here and on page 1, Part I, line 7, column (B). 0.
<b>Total dividends-received deductions</b> included in column 8 .....				0.

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**Schedule F - Interest, Annuities, Royalties, and Rents From Controlled Organizations** (see instructions)

1. Name of controlled organization	2. Employer identification number	Exempt Controlled Organizations			
		3. Net unrelated income (loss) (see instructions)	4. Total of specified payments made	5. Part of column 4 that is included in the controlling organization's gross income	6. Deductions directly connected with income in column 5
(1)					
(2)					
(3)					
(4)					

**Nonexempt Controlled Organizations**

7. Taxable income	8. Net unrelated income (loss) (see instructions)	9. Total of specified payments made	10. Part of column 9 that is included in the controlling organization's gross income	11. Deductions directly connected with income in column 10
(1)				
(2)				
(3)				
(4)				
			Add columns 5 and 10. Enter here and on page 1, Part I, line 8, column (A).	Add columns 6 and 11. Enter here and on page 1, Part I, line 8, column (B).
<b>Totals</b>			0.	0.

**Schedule G - Investment Income of a Section 501(c)(7), (9), or (17) Organization** (see instructions)

1. Description of income	2. Amount of income	3. Deductions directly connected (attach schedule)	4. Set-asides (attach schedule)	5. Total deductions and set-asides (col. 3 plus col. 4)
(1)				
(2)				
(3)				
(4)				
		Enter here and on page 1, Part I, line 9, column (A).		Enter here and on page 1, Part I, line 9, column (B).
<b>Totals</b>		0.		0.

**Schedule I - Exploited Exempt Activity Income, Other Than Advertising Income** (see instructions)

1. Description of exploited activity	2. Gross unrelated business income from trade or business	3. Expenses directly connected with production of unrelated business income	4. Net income (loss) from unrelated trade or business (column 2 minus column 3). If a gain, compute cols. 5 through 7.	5. Gross income from activity that is not unrelated business income	6. Expenses attributable to column 5	7. Excess exempt expenses (column 6 minus column 5, but not more than column 4).
(1)						
(2)						
(3)						
(4)						
		Enter here and on page 1, Part I, line 10, col. (A).	Enter here and on page 1, Part I, line 10, col. (B).			Enter here and on page 1, Part II, line 26.
<b>Totals</b>		0.	0.			0.

**Schedule J - Advertising Income** (see instructions)

**Part I Income From Periodicals Reported on a Consolidated Basis**

1. Name of periodical	2. Gross advertising income	3. Direct advertising costs	4. Advertising gain or (loss) (col. 2 minus col. 3). If a gain, compute cols. 5 through 7.	5. Circulation income	6. Readership costs	7. Excess readership costs (column 6 minus column 5, but not more than column 4).
(1)						
(2)						
(3)						
(4)						
<b>Totals</b> (carry to Part II, line (5))		0.	0.			0.

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**Part II** **Income From Periodicals Reported on a Separate Basis** (For each periodical listed in Part II, fill in columns 2 through 7 on a line-by-line basis.)

1. Name of periodical	2. Gross advertising income	3. Direct advertising costs	4. Advertising gain or (loss) (col. 2 minus col. 3). If a gain, compute cols. 5 through 7.	5. Circulation income	6. Readership costs	7. Excess readership costs (column 6 minus column 5, but not more than column 4).
(1)						
(2)						
(3)						
(4)						
<b>Totals from Part I</b> .....	<b>0.</b>	<b>0.</b>				<b>0.</b>
<b>Totals, Part II (lines 1-5)</b> .....	Enter here and on page 1, Part I, line 11, col. (A). <b>0.</b>	Enter here and on page 1, Part I, line 11, col. (B). <b>0.</b>				Enter here and on page 1, Part II, line 27. <b>0.</b>

**Schedule K - Compensation of Officers, Directors, and Trustees** (see instructions)

1. Name	2. Title	3. Percent of time devoted to business	4. Compensation attributable to unrelated business
(1)		%	
(2)		%	
(3)		%	
(4)		%	
<b>Total.</b> Enter here and on page 1, Part II, line 14 .....			<b>0.</b>

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