

Form **990**

**Return of Organization Exempt From Income Tax**

OMB No. 1545-0047

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

**2021**

Department of the Treasury  
Internal Revenue Service

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

Open to Public Inspection

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

**A For the 2021 calendar year, or tax year beginning and ending**

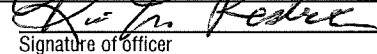
<b>B</b> Check if applicable: Address change Name change Initial return Final return/terminated Amended return Application pending	<b>C Name of organization</b> <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION</b>		<b>D Employer identification number</b> <b>95-3018799</b>
	Doing business as <b>TSC ALLIANCE</b>		<b>E Telephone number</b> <b>301-562-9890</b>
	Number and street (or P.O. box if mail is not delivered to street address) <b>8737 COLESVILLE ROAD</b>	Room/suite <b>400</b>	
	City or town, state or province, country, and ZIP or foreign postal code <b>SILVER SPRING, MD 20910</b>		<b>G Gross receipts \$</b> <b>9,061,703.</b>
<b>F Name and address of principal officer: KARI L. ROSBECK</b> <b>SAME AS C ABOVE</b>		<b>H(a) Is this a group return for subordinates? Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></b> <b>H(b) Are all subordinates included? Yes No</b> If "No," attach a list. See instructions	
<b>I Tax-exempt status:</b> <input checked="" type="checkbox"/> 501(c)(3) 501(c)( ) (insert no.) 4947(a)(1) or 527			
<b>J Website:</b> <b>WWW.TSCALLIANCE.ORG</b>			
<b>K Form of organization:</b> <input checked="" type="checkbox"/> Corporation Trust Association Other			<b>L Year of formation:</b> <b>1975</b> <b>M State of legal domicile:</b> <b>CA</b>

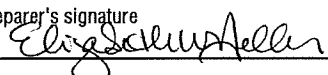
**Part I Summary**

<b>Activities &amp; Governance</b>	<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>29</b>
	<b>4</b> Number of independent voting members of the governing body (Part VI, line 1b)	<b>4</b> <b>29</b>
	<b>5</b> Total number of individuals employed in calendar year 2021 (Part V, line 2a)	<b>5</b> <b>22</b>
	<b>6</b> Total number of volunteers (estimate if necessary)	<b>6</b> <b>2234</b>
	<b>7 a</b> Total unrelated business revenue from Part VIII, column (C), line 12	<b>7a</b> <b>0.</b>
<b>b</b> Net unrelated business taxable income from Form 990-T, Part I, line 11	<b>7b</b> <b>0.</b>	
<b>Revenue</b>	<b>8</b> Contributions and grants (Part VIII, line 1h)	<b>Prior Year</b> <b>4,345,011.</b> <b>Current Year</b> <b>5,769,053.</b>
	<b>9</b> Program service revenue (Part VIII, line 2g)	<b>792,685.</b> <b>2,234,262.</b>
	<b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d)	<b>11,770.</b> <b>5,670.</b>
	<b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	<b>-21,302.</b> <b>1,007,002.</b>
	<b>12</b> Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	<b>5,128,164.</b> <b>9,015,987.</b>
	<b>Expenses</b>	<b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1-3)
<b>14</b> Benefits paid to or for members (Part IX, column (A), line 4)		<b>0.</b> <b>0.</b>
<b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		<b>2,382,792.</b> <b>2,455,940.</b>
<b>16 a</b> Professional fundraising fees (Part IX, column (A), line 11e)		<b>0.</b> <b>0.</b>
<b>b</b> Total fundraising expenses (Part IX, column (D), line 25)		<b>886,523.</b>
<b>17</b> Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		<b>2,353,610.</b> <b>3,465,386.</b>
<b>18</b> Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)		<b>5,422,190.</b> <b>6,869,562.</b>
<b>19</b> Revenue less expenses. Subtract line 18 from line 12	<b>-294,026.</b> <b>2,146,425.</b>	
<b>Net Assets or Fund Balances</b>	<b>20</b> Total assets (Part X, line 16)	<b>Beginning of Current Year</b> <b>11,657,873.</b> <b>End of Year</b> <b>14,046,866.</b>
	<b>21</b> Total liabilities (Part X, line 26)	<b>2,195,312.</b> <b>2,437,880.</b>
	<b>22</b> Net assets or fund balances. Subtract line 21 from line 20	<b>9,462,561.</b> <b>11,608,986.</b>

**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>		<b>4/12/22</b>
	Signature of officer	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 W. HELLER</b>	Preparer's signature 	Date <b>04/08/22</b>	Check if self-employed <input type="checkbox"/>	PTIN <b>P00397829</b>
	Firm's name <b>RSM US LLP</b>	Firm's EIN <b>42-0714325</b>		Phone no. <b>202-293-2200</b>	
	Firm's address <b>2021 L STREET NW, SUITE 400 WASHINGTON, DC 20036</b>				

May the IRS discuss this return with the preparer shown above? See instructions  Yes  No

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: THE NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, D/B/A TSC ALLIANCE, IS DEDICATED TO FINDING A CURE FOR TUBEROUS SCLEROSIS COMPLEX WHILE IMPROVING THE LIVES OF THOSE AFFECTED.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? [ ] Yes [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. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code: ) (Expenses \$ 3,939,485. including grants of \$ 948,236. ) (Revenue \$ 3,190,730. ) RESEARCH PROGRAM STIMULATES AND SUPPORTS BASIC, TRANSLATIONAL, AND CLINICAL RESEARCH ON THE VARIOUS MANIFESTATIONS OF TUBEROUS SCLEROSIS COMPLEX (TSC) TO FURTHER THE DEVELOPMENT OF CLINICAL THERAPIES AND, ULTIMATELY, A CURE FOR TSC. DIRECTED BY STEVEN L. ROBERDS, PHD, CHIEF SCIENTIFIC OFFICER, THE TSC ALLIANCE RESEARCH PROGRAM BUILDS AND FOSTERS COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS BY COLLECTING AND DISTRIBUTING TSC NATURAL HISTORY DATA AND BIOSAMPLES, THROUGH COLLABORATIVE PRECLINICAL AND CLINICAL RESEARCH PROGRAMS, AND BY HOSTING BIENNIAL INTERNATIONAL TSC RESEARCH CONFERENCES.

SINCE 1984, THE TSC ALLIANCE HAS INVESTED \$31 MILLION INTO TSC RESEARCH PROJECTS THROUGH GRANTS AND CONTRACTS: \$19.5 MILLION IN RESEARCH GRANTS

4b (Code: ) (Expenses \$ 648,010. including grants of \$ 0. ) (Revenue \$ 183,500. ) 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 2021 THE TSC ALLIANCE FACILITATED 8,742 PEER-TO-PEER SUPPORTS FROM ADULT REGIONAL COORDINATORS (12 VOLUNTEERS IN 8 REGIONS NATIONWIDE), CLINIC AMBASSADORS (16 VOLUNTEERS IN 19 TSC CLINICS AND TSC CENTERS OF EXCELLENCE NATIONWIDE), DEPENDENT ADULT TRANSITION RESOURCE COORDINATORS (31 VOLUNTEERS IN 26 STATES AND PUERTO RICO), EDUCATION PARENT MENTORS (29 VOLUNTEERS IN 21 STATES), AND COMMUNITY ALLIANCE LEADERS (47 VOLUNTEERS IN 33 REGIONS ACROSS THE UNITED STATES) WITH

4c (Code: ) (Expenses \$ 524,283. including grants of \$ 0. ) (Revenue \$ 69,500. ) 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. ONE MAJOR PROJECT IN 2021 WAS CHANGING THE ORGANIZATION'S NAME TO TSC ALLIANCE, WHICH WAS FORMALLY ANNOUNCED SUNDAY, MAY 16.

DURING 2021, THE TSC ALLIANCE ALSO PRODUCED TWO ISSUES OF ITS NATIONAL MAGAZINE, PERSPECTIVE, WHICH IS MAILED TO APPROXIMATELY 17,900 CONSTITUENTS AS WELL AS POSTED ON THE WEBSITE. THE TSC ALLIANCE'S PODCAST SERIES, CALLED TSC NOW, PRODUCED 12 EPISODES WITH 2,186 DOWNLOADS. SIX ISSUES OF THE ELECTRONIC TSC MATTERS NEWSLETTER WERE DISTRIBUTED TO 1,340 SUBSCRIBERS. THE TSC ALLIANCE'S WEBSITE INCREASES

4d Other program services (Describe on Schedule O.) (Expenses \$ 353,569. including grants of \$ ) (Revenue \$ 34,070.)

4e Total program service expenses 5,465,347.

**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>1</b> X	
<b>2</b> Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? See instructions .....	<b>2</b> X	
<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>3</b>	X
<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>4</b> X	
<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 Rev. Proc. 98-19? <i>If "Yes," complete Schedule C, Part III</i> .....	<b>5</b>	X
<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>6</b>	X
<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>7</b>	X
<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>8</b>	X
<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>9</b>	X
<b>10</b> Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi endowments? <i>If "Yes," complete Schedule D, Part V</i> .....	<b>10</b> X	
<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>11a</b> X	
<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>11b</b>	X
<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>11c</b>	X
<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>11d</b> X	
<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>11e</b> X	
<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>11f</b>	X
<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>12a</b>	X
<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>12b</b> X	
<b>13</b> Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i> .....	<b>13</b>	X
<b>14a</b> Did the organization maintain an office, employees, or agents outside of the United States? .....	<b>14a</b>	X
<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>14b</b> X	
<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>15</b> X	
<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>16</b>	X
<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> See instructions .....	<b>17</b>	X
<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>18</b> X	
<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>19</b>	X
<b>20a</b> Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i> .....	<b>20a</b>	X
<b>b</b> If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? .....	<b>20b</b>	
<b>21</b> Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i> .....	<b>21</b> X	

**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 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part II</i> .....		X
<b>27</b> Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <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 the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions):		
<b>a</b> A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>b</b> A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>c</b> A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <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 on Schedule O for Part VI, lines 11b and 19? .....	X	

**Note:** All Form 990 filers are required to complete Schedule O

**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 on 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)

Table with columns for question number, question text, and Yes/No columns. Includes questions 2a through 17 regarding employee counts, tax returns, unrelated business income, foreign accounts, prohibited transactions, and charitable contributions.

**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 on 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 on Schedule O.		
	1a 29		
<b>b</b>	Enter the number of voting members included on line 1a, above, who are independent		
	1b 29		
<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, 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 on 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 on 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 on 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 on 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 on Schedule O)
- 19** Describe on 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**  
**8737 COLESVILLE ROAD, 400, 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 the 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, Form 1099-MISC, and/or box 1 of Form 1099-NEC) 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. See the instructions for the order in which to list the persons above.

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

(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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(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) STEVEN L. ROBERDS CHIEF SCIENTIFIC OFFICER	45.00 0.00				X			228,854.	0.	26,998.
(2) KARI L. ROSBECK PRESIDENT & CEO	54.00 1.00			X				214,608.	3,974.	33,232.
(3) RICHARD GOLLUB CFO	47.00 3.00			X				156,734.	10,004.	32,878.
(4) DEAN RAGER-AGUIAR DIRECTOR, PRECLINICAL RESEARCH	45.00 0.00				X			163,695.	0.	32,110.
(5) LISA M. MOSS SR. DIRECTOR, DONOR RELATIONS	45.00 0.00					X		109,646.	0.	26,893.
(6) JAYE D. ISHAM VP, COMMUNICATIONS STRATEGY	45.00 0.00					X		121,765.	0.	4,244.
(7) ASHLEY POUNDERS DIRECTOR, MEDICAL AFFAIRS	45.00 0.00					X		101,208.	0.	11,671.
(8) APRIL COOPER DIRECTOR, COMMUNITY PROGRAMS	45.00 0.00					X		108,589.	0.	3,418.
(9) PETER CRINO, MD, PHD CHAIR	5.00 0.00	X		X				0.	0.	0.
(10) WILLIAM JOSEPH VICE CHAIR	5.00 1.00	X		X				0.	0.	0.
(11) CHRIS RUSSELL IMMEDIATE PAST CHAIR	5.00 0.00	X		X				0.	0.	0.
(12) LAURA MARKS SECRETARY	5.00 0.00	X		X				0.	0.	0.
(13) PAUL WAXLAX TREASURER	5.00 1.00	X		X				0.	0.	0.
(14) DEREK BAUER BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(15) JULIE BLUM BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(16) MATT BOLGER BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(17) EDWARD BURKHALTER BOARD MEMBER	2.00 0.00	X						0.	0.	0.

**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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(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) MARK CARROLL BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(19) SARAH CHIEFFO BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(20) DAVID COIT BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(21) MARGARET COX BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(22) TIMOTHY DILLS BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(23) BONNIE HOGUE DUFFY BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(24) TANJALA GIPSON BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(25) STEVEN GOLDSTEIN BOARD MEMBER	2.00 0.00	X						0.	0.	0.
(26) ROBERT GRANDIA BOARD MEMBER	2.00 0.00	X						0.	0.	0.
<b>1b Subtotal</b>								1,205,099.	13,978.	171,444.
<b>c Total from continuation sheets to Part VII, Section A</b>								0.	0.	0.
<b>d Total (add lines 1b and 1c)</b>								1,205,099.	13,978.	171,444.

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 **8**

	Yes	No
3 Did the organization list any former officer, director, 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 SERVICES	1,564,533.
VAN ANDEL RESEARCH INSTITUTE, 333 BOSTWICK AVE. NE, GRAND RAPIDS, MI 49503	LABORATORY SERVICES	227,915.
CAVAROCCHI RUSCIO DENNIS AND ASSOCIATES 600 MARYLAND AVE. SW, WASHINGTON, DC 20024	GOVERNMENT RELATIONS	112,980.

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





**Part VIII Statement of Revenue**

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

			(A)	(B)	(C)	(D)	
			Total revenue	Related or exempt function revenue	Unrelated business revenue	Revenue excluded from tax under sections 512 - 514	
Contributions, Gifts, Grants and Other Similar Amounts	<b>1 a</b> Federated campaigns	<b>1a</b>	50,596.				
	<b>b</b> Membership dues	<b>1b</b>	4,132.				
	<b>c</b> Fundraising events	<b>1c</b>	955,330.				
	<b>d</b> Related organizations	<b>1d</b>	226,000.				
	<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>	4,532,995.				
	<b>g</b> Noncash contributions included in lines 1a-1f	<b>1g</b>	\$ 285,267.				
	<b>h Total.</b> Add lines 1a-1f			5,769,053.			
Program Service Revenue	<b>2 a</b> CONTRACT REVENUE	<b>Business Code</b>					
		900099	2,120,485.	2,120,485.			
	<b>b</b> CONFERENCE REVENUE	900099	113,777.	113,777.			
	<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			2,234,262.				
Other Revenue	<b>3</b> Investment income (including dividends, interest, and other similar amounts)		3,809.			3,809.	
	<b>4</b> Income from investment of tax-exempt bond proceeds						
	<b>5</b> Royalties						
	<b>6 a</b> Gross rents	<b>6a</b>	(i) Real				
			(ii) Personal				
	<b>b</b> Less: rental expenses	<b>6b</b>					
	<b>c</b> Rental income or (loss)	<b>6c</b>					
	<b>d</b> Net rental income or (loss)						
	<b>7 a</b> Gross amount from sales of assets other than inventory	<b>7a</b>	(i) Securities	1,861.			
			(ii) Other				
	<b>b</b> Less: cost or other basis and sales expenses	<b>7b</b>	0.				
	<b>c</b> Gain or (loss)	<b>7c</b>	1,861.				
<b>d</b> Net gain or (loss)			1,861.		1,861.		
<b>8 a</b> Gross income from fundraising events (not including \$ 955,330. of contributions reported on line 1c). See Part IV, line 18	<b>8a</b>		234,482.				
		<b>b</b> Less: direct expenses	<b>8b</b>	45,716.			
		<b>c</b> Net income or (loss) from fundraising events			188,766.		188,766.
<b>9 a</b> Gross income from gaming activities. See Part IV, line 19	<b>9a</b>						
		<b>b</b> Less: direct expenses	<b>9b</b>				
		<b>c</b> Net income or (loss) from gaming activities					
<b>10 a</b> Gross sales of inventory, less returns and allowances	<b>10a</b>						
		<b>b</b> Less: cost of goods sold	<b>10b</b>				
		<b>c</b> Net income or (loss) from sales of inventory					
Miscellaneous Revenue	<b>11 a</b> CHANGE INT-ENDOWMENT	<b>Business Code</b>					
		900099	818,236.			818,236.	
	<b>b</b>						
	<b>c</b>						
	<b>d</b> All other revenue						
<b>e Total.</b> Add lines 11a-11d			818,236.				
<b>12 Total revenue.</b> See instructions			9,015,987.	2,234,262.	0.	1012672.	

**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 ...	833,329.	833,329.		
<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 .....	114,907.	114,907.		
<b>4</b> Benefits paid to or for members .....				
<b>5</b> Compensation of current officers, directors, trustees, and key employees .....	797,701.	489,000.	223,016.	85,685.
<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 .....	1,242,312.	792,478.	103,838.	345,996.
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
<b>9</b> Other employee benefits .....	275,780.	173,018.	38,279.	64,483.
<b>10</b> Payroll taxes .....	140,147.	87,925.	19,453.	32,769.
<b>11</b> Fees for services (nonemployees):				
<b>a</b> Management .....				
<b>b</b> Legal .....	38,838.	25,875.	10,766.	2,197.
<b>c</b> Accounting .....	26,179.		26,179.	
<b>d</b> Lobbying .....	112,980.	112,980.		
<b>e</b> Professional fundraising services. See Part IV, line 17				
<b>f</b> Investment management fees .....				
<b>g</b> Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Sch O.)	369,033.	228,093.	16,900.	124,040.
<b>12</b> Advertising and promotion .....	24,836.	24,608.		228.
<b>13</b> Office expenses .....	256,679.	140,716.	8,501.	107,462.
<b>14</b> Information technology .....	172,599.	90,501.	20,808.	61,290.
<b>15</b> Royalties .....				
<b>16</b> Occupancy .....	128,139.	80,284.	17,669.	30,186.
<b>17</b> Travel .....	13,890.	8,415.	1,692.	3,783.
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials ...				
<b>19</b> Conferences, conventions, and meetings .....	76,847.	76,630.	55.	162.
<b>20</b> Interest .....				
<b>21</b> Payments to affiliates .....				
<b>22</b> Depreciation, depletion, and amortization .....	73,200.	50,381.	6,465.	16,354.
<b>23</b> Insurance .....	11,222.	7,040.	1,558.	2,624.
<b>24</b> Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on 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>	1,824,180.	1,824,180.		
<b>b</b> <b>NHD BIOSAMPLE REPOSIT</b>	266,285.	266,285.		
<b>c</b> <b>DUES AND SUBSCRIPTIONS</b>	48,878.	29,979.	12,767.	6,132.
<b>d</b> <b>MISCELLANEOUS EXPENSES</b>	8,527.	3,443.	3,848.	1,236.
<b>e</b> All other expenses _____	13,074.	5,280.	5,898.	1,896.
<b>25</b> <b>Total functional expenses.</b> Add lines 1 through 24e	6,869,562.	5,465,347.	517,692.	886,523.
<b>26</b> <b>Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				
Check here <input checked="" type="checkbox"/> if following SOP 98-2 (ASC 958-720)	33,150.	16,575.	0.	16,575.

**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 .....	1,097,500.	<b>1</b>	1,459,324.
	<b>2</b> Savings and temporary cash investments .....	1,238,876.	<b>2</b>	1,242,438.
	<b>3</b> Pledges and grants receivable, net .....	1,578,285.	<b>3</b>	2,698,495.
	<b>4</b> Accounts receivable, net .....	113,491.	<b>4</b>	99,173.
	<b>5</b> Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons .....		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B) .....		<b>6</b>	
	<b>7</b> Notes and loans receivable, net .....		<b>7</b>	
	<b>8</b> Inventories for sale or use .....		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges .....	392,003.	<b>9</b>	620,148.
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....	<b>10a</b> 719,159.		
	<b>b</b> Less: accumulated depreciation .....	<b>10b</b> 281,990.	510,367.	<b>10c</b> 437,169.
	<b>11</b> Investments - publicly traded securities .....		<b>11</b>	
	<b>12</b> Investments - other securities. See Part IV, line 11 .....		<b>12</b>	
	<b>13</b> Investments - program-related. See Part IV, line 11 .....		<b>13</b>	
	<b>14</b> Intangible assets .....		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11 .....	6,727,351.	<b>15</b>	7,490,119.
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33) .....	11,657,873.	<b>16</b>	14,046,866.	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses .....	435,478.	<b>17</b>	472,049.
	<b>18</b> Grants payable .....		<b>18</b>	
	<b>19</b> Deferred revenue .....	422,226.	<b>19</b>	676,798.
	<b>20</b> Tax-exempt bond liabilities .....		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D .....		<b>21</b>	
	<b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons .....		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties .....		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties .....		<b>24</b>	
	<b>25</b> Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D .....	1,337,608.	<b>25</b>	1,289,033.
	<b>26 Total liabilities.</b> Add lines 17 through 25 .....	2,195,312.	<b>26</b>	2,437,880.
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions .....	5,954,477.	<b>27</b>	6,580,605.
	<b>28</b> Net assets with donor restrictions .....	3,508,084.	<b>28</b>	5,028,381.
	<b>Organizations that do not follow FASB ASC 958, check here</b> <input type="checkbox"/> <b>and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds .....		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building, or equipment fund .....		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds .....		<b>31</b>	
	<b>32</b> Total net assets or fund balances .....	9,462,561.	<b>32</b>	11,608,986.
<b>33</b> Total liabilities and net assets/fund balances .....	11,657,873.	<b>33</b>	14,046,866.	

**Part XI Reconciliation of Net Assets**

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	9,015,987.
2	Total expenses (must equal Part IX, column (A), line 25)	2	6,869,562.
3	Revenue less expenses. Subtract line 2 from line 1	3	2,146,425.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	9,462,561.
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	11,608,986.

**Part XII Financial Statements and Reporting**

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

- 1 Accounting method used to prepare the Form 990:  Cash  Accrual  Other \_\_\_\_\_  
If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.
- 2a 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:  
 Separate basis  Consolidated basis  Both consolidated and separate basis
- 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:  
 Separate basis  Consolidated basis  Both consolidated and separate basis
- c 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 on Schedule O.
- 3a 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 If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits .....

	Yes	No
2a		X
2b	X	
2c	X	
3a		X
3b		



**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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....	3949953.	4105376.	5527543.	4345011.	5769053.	23696936.
<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 .....	3949953.	4105376.	5527543.	4345011.	5769053.	23696936.
<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) .....						3559289.
<b>6 Public support.</b> Subtract line 5 from line 4.						20137647.

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
<b>7</b> Amounts from line 4 .....	3949953.	4105376.	5527543.	4345011.	5769053.	23696936.
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....	10,393.	13,784.	27,444.	11,188.	3,809.	66,618.
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on .....						
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....	642.	1,243.	714.			2,599.
<b>11 Total support.</b> Add lines 7 through 10						23766153.
<b>12</b> Gross receipts from related activities, etc. (see instructions) .....					12	10,327,170.
<b>13 First 5 years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and <b>stop here</b> .....						<input type="checkbox"/>

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

<b>14</b> Public support percentage for 2021 (line 6, column (f), divided by line 11, column (f)) .....	<b>14</b>	84.73	%
<b>15</b> Public support percentage from 2020 Schedule A, Part II, line 14 .....	<b>15</b>	84.30	%
<b>16a 33 1/3% support test - 2021.</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 - 2020.</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 - 2021.</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 - 2020.</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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(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 on 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 5 years.** If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here**

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

<b>15</b> Public support percentage for 2021 (line 8, column (f), divided by line 13, column (f)) .....	<b>15</b>	%
<b>16</b> Public support percentage from 2020 Schedule A, Part III, line 15 .....	<b>16</b>	%

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

<b>17</b> Investment income percentage for <b>2021</b> (line 10c, column (f), divided by line 13, column (f)) .....	<b>17</b>	%
<b>18</b> Investment income percentage from <b>2020</b> Schedule A, Part III, line 17 .....	<b>18</b>	%

**19a 33 1/3% support tests - 2021.** 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 - 2020.** 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 box 12a, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, 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 lines 3b and 3c 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 box 12a or 12b in Part I, answer lines 4b and 4c 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 lines 5b and 5c 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).</i>		
<b>8</b> Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? <i>If "Yes," complete Part I of Schedule L (Form 990).</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 on 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 on 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 line 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 on lines 11b and 11c below, the governing body of a supported organization?		
<b>b</b> A family member of a person described on line 11a above?		
<b>c</b> A 35% controlled entity of a person described on line 11a or 11b above? <i>If "Yes" to line 11a, 11b, or 11c, provide detail in Part VI.</i>		
<b>11a</b>		
<b>11b</b>		
<b>11c</b>		

**Section B. Type I Supporting Organizations**

	Yes	No
<b>1</b> Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, 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 officers, 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>		
<b>1</b>		
<b>2</b>		

**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>		
<b>1</b>		

**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 on line 2, above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		
<b>1</b>		
<b>2</b>		
<b>3</b>		

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

**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 ( <i>explain in detail in Part VI</i> ):		
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 0.015 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 0.035.	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			Current Year
1	Adjusted net income for prior year (from Section A, line 8, column A)	1	
2	Enter 0.85 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).		

**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>1</b>
<b>2</b>	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	<b>2</b>
<b>3</b>	Administrative expenses paid to accomplish exempt purposes of supported organizations	<b>3</b>
<b>4</b>	Amounts paid to acquire exempt-use assets	<b>4</b>
<b>5</b>	Qualified set-aside amounts (prior IRS approval required - <i>provide details in Part VI</i> )	<b>5</b>
<b>6</b>	Other distributions ( <i>describe in Part VI</i> ). See instructions.	<b>6</b>
<b>7</b>	<b>Total annual distributions.</b> Add lines 1 through 6.	<b>7</b>
<b>8</b>	Distributions to attentive supported organizations to which the organization is responsive ( <i>provide details in Part VI</i> ). See instructions.	<b>8</b>
<b>9</b>	Distributable amount for 2021 from Section C, line 6	<b>9</b>
<b>10</b>	Line 8 amount divided by line 9 amount	<b>10</b>

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2021	(iii) Distributable Amount for 2021
<b>1</b> Distributable amount for 2021 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2021 (reasonable cause required - <i>explain in Part VI</i> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2021			
<b>a</b> From 2016			
<b>b</b> From 2017			
<b>c</b> From 2018			
<b>d</b> From 2019			
<b>e</b> From 2020			
<b>f</b> <b>Total</b> of lines 3a through 3e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2021 distributable amount			
<b>i</b> Carryover from 2016 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2021 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2021 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2021, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
<b>6</b> Remaining underdistributions for 2021. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
<b>7</b> <b>Excess distributions carryover to 2022.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2017			
<b>b</b> Excess from 2018			
<b>c</b> Excess from 2019			
<b>d</b> Excess from 2020			
<b>e</b> Excess from 2021			

**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

2017 AMOUNT: \$ 642.

2018 AMOUNT: \$ 1,243.

2019 AMOUNT: \$ 714.

**Schedule B**  
**(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

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

OMB No. 1545-0047

**2021**

Name of the organization

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION**

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), 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), 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).

Name of organization  <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION</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>380,595.</u>	Person <input checked="" type="checkbox"/> Payroll Noncash (Complete Part II for noncash contributions.)
<u>2</u>	 <hr/> <hr/> <hr/>	\$ <u>393,572.</u>	Person <input checked="" type="checkbox"/> Payroll Noncash (Complete Part II for noncash contributions.)
<u>3</u>	 <hr/> <hr/> <hr/>	\$ <u>174,554.</u>	Person <input checked="" type="checkbox"/> Payroll Noncash (Complete Part II for noncash contributions.)
<u>4</u>	 <hr/> <hr/> <hr/>	\$ <u>333,817.</u>	Person <input checked="" type="checkbox"/> Payroll Noncash (Complete Part II for noncash contributions.)
<u>5</u>	 <hr/> <hr/> <hr/>	\$ <u>1,357,344.</u>	Person <input checked="" type="checkbox"/> Payroll Noncash (Complete Part II for noncash contributions.)
<u>6</u>	 <hr/> <hr/> <hr/>	\$ <u>226,000.</u>	Person <input checked="" type="checkbox"/> Payroll Noncash (Complete Part II for noncash contributions.)

Name of organization  <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION</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/>	\$ 150,000.	Person <input checked="" type="checkbox"/> Payroll Noncash (Complete Part II for noncash contributions.)
8	<hr/> <hr/> <hr/>	\$ 137,000.	Person <input checked="" type="checkbox"/> Payroll Noncash (Complete Part II for noncash contributions.)
9	<hr/> <hr/> <hr/>	\$ 125,500.	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.)



Name of organization  <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION</b>	Employer identification number  <b>95-3018799</b>
--	---

**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</b>	Employer identification number  <b>95-3018799</b>
--	---

**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

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

**SCHEDULE C**  
**(Form 990)**

**Political Campaign and Lobbying Activities**

OMB No. 1545-0047

**2021**

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</b>	Employer identification number <b>95-3018799</b>
--	---

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

- 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV.
- 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-.

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

- A** Check  if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).
- B** Check  if the filing organization checked box A and "limited control" provisions apply.

<b>Limits on Lobbying Expenditures</b> (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals												
<b>1a</b>	Total lobbying expenditures to influence public opinion (grassroots lobbying) .....	1,127.													
<b>b</b>	Total lobbying expenditures to influence a legislative body (direct lobbying) .....	153,012.													
<b>c</b>	Total lobbying expenditures (add lines 1a and 1b) .....	154,139.													
<b>d</b>	Other exempt purpose expenditures .....	6,795,167.													
<b>e</b>	Total exempt purpose expenditures (add lines 1c and 1d) .....	6,949,306.													
<b>f</b>	Lobbying nontaxable amount. Enter the amount from the following table in both columns.	497,465.													
<table border="1" style="width: 100%;"> <thead> <tr> <th style="width: 50%;">If the amount on line 1e, column (a) or (b) is:</th> <th style="width: 50%;">The lobbying nontaxable amount is:</th> </tr> </thead> <tbody> <tr> <td>Not over \$500,000</td> <td>20% of the amount on line 1e.</td> </tr> <tr> <td>Over \$500,000 but not over \$1,000,000</td> <td>\$100,000 plus 15% of the excess over \$500,000.</td> </tr> <tr> <td>Over \$1,000,000 but not over \$1,500,000</td> <td>\$175,000 plus 10% of the excess over \$1,000,000.</td> </tr> <tr> <td>Over \$1,500,000 but not over \$17,000,000</td> <td>\$225,000 plus 5% of the excess over \$1,500,000.</td> </tr> <tr> <td>Over \$17,000,000</td> <td>\$1,000,000.</td> </tr> </tbody> </table>		If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:	Not over \$500,000	20% of the amount on line 1e.	Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.	Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.	Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.	Over \$17,000,000	\$1,000,000.		
If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:														
Not over \$500,000	20% of the amount on line 1e.														
Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.														
Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.														
Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.														
Over \$17,000,000	\$1,000,000.														
<b>g</b>	Grassroots nontaxable amount (enter 25% of line 1f) .....	124,366.													
<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.)

<b>Lobbying Expenditures During 4-Year Averaging Period</b>					
Calendar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) Total
<b>2a</b> Lobbying nontaxable amount	450,555.	445,393.	423,685.	497,465.	1,817,098.
<b>b</b> Lobbying ceiling amount (150% of line 2a, column(e))					2,725,647.
<b>c</b> Total lobbying expenditures	149,340.	165,226.	123,014.	154,139.	591,719.
<b>d</b> Grassroots nontaxable amount	112,639.	111,348.	105,921.	124,366.	454,274.
<b>e</b> Grassroots ceiling amount (150% of line 2d, column (e))					681,411.
<b>f</b> Grassroots lobbying expenditures	823.	2,491.	895.	1,127.	5,336.

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

2021

Open to Public Inspection

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

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

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? (Yes/No), 6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? (Yes/No)

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

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 (2a Total number of conservation easements, 2b Total acreage restricted by conservation easements, 2c Number of conservation easements on a certified historic structure included in (a), 2d Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register), 3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year, 4 Number of states where property subject to conservation easement is located, 5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? (Yes/No), 6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year, 7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year, 8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? (Yes/No), 9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

Table with 2 columns: Revenue, Assets. Rows include: 1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items. b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items: (i) Revenue included on Form 990, Part VIII, line 1, (ii) Assets included in Form 990, Part X, 2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items: a Revenue included on Form 990, Part VIII, line 1, b Assets included in Form 990, Part X

**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 make 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 program
  - 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	5,893,521.	5,915,805.	5,193,934.	5,655,555.	5,293,989.
b Contributions	132,476.	54,645.	78,962.	82,346.	92,635.
c Net investment earnings, gains, and losses	1,053,588.	416,431.	959,121.	-439,321.	739,072.
d Grants or scholarships					
e Other expenditures for facilities and programs	333,813.	463,721.	288,356.	50,000.	403,000.
f Administrative expenses	34,024.	29,639.	27,856.	54,646.	67,141.
g End of year balance	6,711,748.	5,893,521.	5,915,805.	5,193,934.	5,655,555.

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment  84.5600 %
  - b Permanent endowment  13.1000 %
  - c Term endowment  2.3400 %
- 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?
- 4 Describe in Part XIII the intended uses of the organization's endowment funds.

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

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements		449,272.	71,475.	377,797.
d Equipment		189,615.	134,797.	54,818.
e Other		80,272.	75,718.	4,554.
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)				437,169.

**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 AFFILIATE	6,711,748.
(2) OPERATING LEASE RIGHT-OF-USE ASSET	778,371.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 15.) ▶	7,490,119.

**Part X Other Liabilities.**

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

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2) DEFERRED RENT & LEASE INCENTIVE	1,285,691.
(3) DUE TO AFFILIATE	3,342.
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	1,289,033.

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 FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII ...



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

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

<b>1</b>	Total revenue, gains, and other support per audited financial statements		<b>1</b>	9,050,015.
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
<b>a</b>	Net unrealized gains (losses) on investments	<b>2a</b>		
<b>b</b>	Donated services and use of facilities	<b>2b</b>	34,028.	
<b>c</b>	Recoveries of prior year grants	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.)	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b>		<b>2e</b>	34,028.
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b>		<b>3</b>	9,015,987.
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.)	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b>		<b>4c</b>	0.
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.)		<b>5</b>	9,015,987.

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

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

<b>1</b>	Total expenses and losses per audited financial statements		<b>1</b>	6,903,590.
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
<b>a</b>	Donated services and use of facilities	<b>2a</b>	34,028.	
<b>b</b>	Prior year adjustments	<b>2b</b>		
<b>c</b>	Other losses	<b>2c</b>		
<b>d</b>	Other (Describe in Part XIII.)	<b>2d</b>		
<b>e</b>	Add lines <b>2a</b> through <b>2d</b>		<b>2e</b>	34,028.
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b>		<b>3</b>	6,869,562.
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b	<b>4a</b>		
<b>b</b>	Other (Describe in Part XIII.)	<b>4b</b>		
<b>c</b>	Add lines <b>4a</b> and <b>4b</b>		<b>4c</b>	0.
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.)		<b>5</b>	6,869,562.

**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.

**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

**2021**

Open to Public  
Inspection

Name of the organization <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION</b>	Employer identification number <b>95-3018799</b>
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**Part I General Information on Activities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

- 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**
- For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- 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		19,907.
MIDDLE EAST AND NORTH AFRICA	0	0	GRANTMAKING		75,000.
EUROPE (INCLUDING ICELAND & GREENLAND)	0	0	PROGRAM SERVICE ACTIVITIES	PRECLINICAL RESEARCH STUDIES	4,177.
NORTH AMERICA	0	0	GRANTMAKING		20,000.
<b>3 a</b> Subtotal .....	0	0			119,084.
<b>b</b> Total from continuation sheets to Part I .....	0	0			0.
<b>c Totals</b> (add lines 3a and 3b) .....	0	0			119,084.

**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)
		MIDDLE EAST AND NORTH AFRICA	RESEARCH ON TUBEROUS SCLEROSIS COMPLEX	75,000.	WIRE	0.		
		EUROPE (INCLUDING ICELAND & GREENLAND)	PROGRAMMATIC SUPPORT	19,907.	WIRE	0.		
		NORTH AMERICA	GRANTMAKING	20,000.	CHECK	0.		

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter ..... **0**

3 Enter total number of other organizations or entities ..... **1**



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.



**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))	
		VIRTUAL WALKS (event type)	COMEDY FOR A CURE (event type)	7 (total number)		
Revenue	1	Gross receipts	806,174.	142,870.	240,768.	1,189,812.
	2	Less: Contributions	650,809.	100,282.	204,239.	955,330.
	3	Gross income (line 1 minus line 2)	155,365.	42,588.	36,529.	234,482.
Direct Expenses	4	Cash prizes				
	5	Noncash prizes	20,365.	1,093.	2,313.	23,771.
	6	Rent/facility costs	154.	15,891.	4,500.	20,545.
	7	Food and beverages				
	8	Entertainment		1,400.		1,400.
	9	Other direct expenses				
	10	Direct expense summary. Add lines 4 through 9 in column (d)				
11	Net income summary. Subtract line 10 from line 3, column (d)					188,766.

**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				
Direct Expenses	2	Cash prizes				
	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

**2021**

**Open to Public  
Inspection**

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

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

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

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

<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 noncash 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 & WOMEN'S HOSPITAL 75 FRANCIS STREET BOSTON , MA 02115	04-2312909	501(C)(3)	109,963.	0.			RESEARCH GRANTS
UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER - 5323 HARRY HINES BLVD. - DALLAS, TX 75287	75-6002868	501(C)(3)	18,750.	0.			RESEARCH GRANTS
NATIONAL ORGANIZATION FOR RARE DISORDERS - 55 KENOSIA AVENUE - DANBURY, CT 06810	13-3223946	501(C)(3)	225,000.	0.			TSC TRAVEL AND LODGING ASSISTANCE PROGRAM
NORTHWESTERN UNIVERSITY 7TH FLOOR, RUBLOFF BUILDING CHICAGO, IL 60611	36-2167818	501(C)(3)	56,250.	0.			RESEARCH GRANTS
CHILDREN'S HOSPITAL CORPORATION 300 LONGWOOD AVENUE BOSTON , MA 02115	04-2774441	501(C)(3)	112,500.	0.			RESEARCH GRANTS
UNIVERSITY OF CALIFORNIA BERKELEY 1608 FOURTH ST, STE. 220 BERKELEY, CA 94710	94-6002123	501(C)(3)	28,125.	0.			RESEARCH GRANT

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table **12.**
- 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) 2021

**Part II** Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments (Schedule I (Form 990), Part II.)

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
VANDERBILT UNIVERSITY 1161 21ST AVE. SOUTH NASHVILLE, TN 37232	35-2528741	501(C)(3)	28,125.	0.			RESEARCH GRANT
UNIVERSITY OF MARYLAND, BALTIMORE PO BOX 41428 BALTIMORE, MD 21203	52-6002033	501(C)(3)	18,634.	0.			RESEARCH GRANT
UNIVERSITY OF WASHINGTON 4333 BROOKLYN AVE NE, BOX 359472 SEATTLE, WA 98195	91-6001537	501(C)(3)	25,000.	0.			RESEARCH GRANT
CHILDREN'S HOSPITAL MEDICAL CENTER 3333 BURNET AVENUE CINCINNATI, OH 45229	31-0833936	501(C)(3)	100,000.	0.			CLINICAL RESEARCH
BROWN UNIVERSITY 69 BROWN STREET, BOX 1911 PROVIDENCE, RI 02912	05-0258809	501(C)(3)	55,000.	0.			CLINICAL RESEARCH
BOSTON CHILDREN'S HOSPITAL P.O. BOX 414413 BOSTON, MA 02241-4413	04-2774441	501(C)(3)	57,409.	0.			CLINICAL RESEARCH

**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 TSC ALLIANCE HAS FUNDED \$31 MILLION IN RESEARCH ON TSC SINCE 1984. DIRECTED BY STEVEN L. ROBERDS, PH.D, CHIEF SCIENTIFIC OFFICER, THE TSC ALLIANCE RESEARCH GRANTS PROGRAM FUNDS RESEARCH FOCUSED ON TSC WITH PRIORITIES SET BY THE RESEARCHERS TOGETHER WITH THE TSC ALLIANCE. COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS ARE ENCOURAGED AND FOSTERED, AND THE TSC ALLIANCE IS WORKING TO INCREASE FUNDING FOR RESEARCH ON TSC. THROUGH THE TSC ALLIANCE RESEARCH GRANTS PROGRAM, APPLICATIONS CAN BE SUBMITTED FOR POSTDOCTORAL FELLOWSHIPS AND TSC RESEARCH GRANTS.

**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 AS WELL AS CONSUMERS REVIEW ALL GRANT APPLICATIONS FOR SCIENTIFIC MERIT, RELEVANCY TO THE FUNDING PRIORITIES OF THE ORGANIZATION AND WITH A FOCUS ON UNDERSTANDING THE MECHANISMS OF TSC AND/OR THE DEVELOPMENT OF TREATMENTS AND THERAPIES FOR THE MANIFESTATIONS OF THE DISEASE.

2. THE SCIENCE AND MEDICAL COMMITTEE OF THE BOARD OF DIRECTORS THEN REVIEWS THE GRANT REVIEW COMMITTEE'S CONCLUSIONS AND MAKES FUNDING RECOMMENDATIONS TO THE BOARD OF DIRECTORS.

3. THE BOARD OF DIRECTORS THEN REVIEWS THE RECOMMENDATIONS OF THE SCIENCE AND MEDICAL COMMITTEE AND MAKES FINAL APPROVAL FOR THE FUNDING OF GRANTS.

**SCHEDULE J  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Compensation Information**

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees  
 ▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 23.  
 ▶ Attach to Form 990.  
 ▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2021**

Open to Public Inspection

Name of the organization: **NATIONAL TUBEROUS SCLEROSIS ASSOCIATION**  
 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 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>		<b>X</b>
<b>4b</b>		<b>X</b>
<b>4c</b>		<b>X</b>
<b>5a</b>	<b>X</b>	
<b>5b</b>		<b>X</b>
<b>6a</b>	<b>X</b>	
<b>6b</b>		<b>X</b>
<b>7</b>		<b>X</b>
<b>8</b>		<b>X</b>
<b>9</b>		

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

Schedule J (Form 990) 2021

**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 and/or 1099-NEC 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) STEVEN L. ROBERDS CHIEF SCIENTIFIC OFFICER	(i)	212,421.	16,175.	258.	7,007.	24,311.	260,172.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(2) KARI L. ROSBECK PRESIDENT & CEO	(i)	196,498.	17,866.	244.	6,806.	30,738.	252,152.	0.
	(ii)	3,638.	331.	5.	0.	0.	3,974.	0.
(3) RICHARD GOLLUB CFO	(i)	146,390.	9,972.	372.	5,207.	32,130.	194,071.	0.
	(ii)	9,344.	636.	24.	0.	0.	10,004.	0.
(4) DEAN RAGER-AGUIAR DIRECTOR, PRECLINICAL RESEARCH	(i)	157,178.	6,379.	138.	5,180.	31,130.	200,005.	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)							



**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, DEAN AGUIAR, JAYE  
ISHAM, LISA MOSS AND APRIL COOPER ALL HAVE INCENTIVE COMPENSATION EQUAL TO  
A PERCENTAGE OF THEIR SALARIES BASED ON KEY PERFORMANCE OBJECTIVES AS  
ESTABLISHED BY THE COMPENSATION COMMITTEE.

PART I, LINE 6:

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

**SCHEDULE M  
(Form 990)**

**Noncash Contributions**

OMB No. 1545-0047

**2021**

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** 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	X		34,028.	FMV
5 Clothing and household goods	X		724.	FMV
6 Cars and other vehicles				
7 Boats and planes				
8 Intellectual property				
9 Securities - Publicly traded	X	7	250,515.	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 ( )				
26 Other ( )				
27 Other ( )				
28 Other ( )				

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part V, Donee Acknowledgement **29** **0**

- 30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least three years from the date of the initial contribution, and which isn't required to be used for exempt purposes for the entire holding period? **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.

	Yes	No
30a		X
31	X	
32a		X

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

Schedule M (Form 990) 2021



**SCHEDULE O  
(Form 990)**

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 Form 990-EZ.

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

OMB No. 1545-0047

**2021**

Open to Public  
Inspection

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

AND POSTDOCTORAL FELLOWSHIPS, \$4.6 MILLION INTO THE NATURAL HISTORY  
DATABASE AND BIOSAMPLE REPOSITORY, \$5.9 MILLION INTO THE PRECLINICAL  
CONSORTIUM, AND \$0.95 MILLION INTO THE CLINICAL RESEARCH CONSORTIUM.

GRANT AND FELLOWSHIP APPLICATIONS ARE REVIEWED IN A THREE-STEP PROCESS:

(1) ALL APPLICATIONS ARE REVIEWED BY A COMMITTEE COMPRISED OF  
SCIENTISTS KNOWLEDGEABLE ABOUT THE TOPIC AREA FOR SCIENTIFIC MERIT AND  
OF CAREGIVERS OR ADULTS AFFECTED BY TSC FOR POTENTIAL IMPACT ON THE  
LIVES OF THOSE AFFECTED BY TSC; (2) THE SCIENCE AND MEDICAL COMMITTEE  
OF THE BOARD OF DIRECTORS EVALUATES THE GRANT REVIEW COMMITTEE'S  
RECOMMENDATIONS AND THE RELEVANCE OF THE APPLICATIONS TO THE TSC  
ALLIANCE'S FUNDING PRIORITIES; AND (3) THE BOARD OF DIRECTORS THEN  
REVIEWS THE RECOMMENDATIONS OF THE SCIENCE AND MEDICAL COMMITTEE AND  
MAKES FINAL APPROVAL FOR FUNDING. FOR A COMPLETE LIST OF CURRENTLY  
FUNDED PROJECTS AND AN ARCHIVE OF PAST AWARDEES, PLEASE VISIT  
TSCALLIANCE.ORG/GRANTS.

IMPLEMENTED IN 2006, THE TSC NATURAL HISTORY DATABASE (NHD) CAPTURES  
CLINICAL DATA TO DOCUMENT THE IMPACT OF THE DISEASE ON A PERSON'S  
HEALTH OVER THEIR LIFETIME. THE DATABASE SERVES AS A RESOURCE OF  
INFORMATION THAT HELPS TSC RESEARCHERS BETTER UNDERSTAND THE  
PROGRESSION OF THE DISEASE, DESIGN HYPOTHESIS-DRIVEN QUESTIONS TO  
HASTEN THE DISCOVERY OF NEW TREATMENTS AND IDENTIFY PERSONS WITH TSC  
WHO ARE ELIGIBLE TO PARTICIPATE IN RESEARCH STUDIES. AS OF DECEMBER

2021, 2,357 PEOPLE WITH TSC WERE ENROLLED IN THE PROJECT FROM AMONG 18

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U.S.-BASED SITES AND THROUGH THE TSC ALLIANCE. THE TSC ALLIANCE PROVIDES FUNDING TO PARTICIPATING CLINICS TO PERFORM DATA ENTRY, MONITORS THE INTEGRITY OF THE DATABASE, AND MAKES DATA AVAILABLE TO INVESTIGATORS TO ANSWER SPECIFIC RESEARCH QUESTIONS AND IDENTIFY POTENTIAL PARTICIPANTS FOR CLINICAL TRIALS AND STUDIES. IN 2020, THE TSC ALLIANCE ADDED A COVID-19 SUB-PROJECT TO ADDRESS DETAILED QUESTIONS ABOUT COVID-19 INFECTION IN INDIVIDUALS WITH TSC. FOR THIS PROJECT, THE TSC ALLIANCE OPENED THIS NHD SUB-PROJECT UP TO PARTICIPANTS WITH SPORADIC LYMPHANGIOLEIOMYOMATOSIS (S-LAM) IN PARTNERSHIP WITH THE LAM FOUNDATION. IN 2021, THE TSC ALLIANCE EXPANDED THE SUB-PROJECT'S VARIABLES TO INCLUDE ENTRIES FOR COVID-19 VACCINATIONS AND ANTIBODY TESTS.

BUILDING UPON THE NATURAL HISTORY DATABASE, THE TSC BIOSAMPLE REPOSITORY IS A TSC ALLIANCE-DIRECTED PROJECT INITIATED IN 2014 THAT WILL IMPACT RESEARCH OVER THE NEXT 10 YEARS OR MORE. THE TSC ALLIANCE'S SCIENCE AND MEDICAL COMMITTEE IDENTIFIED THIS AS A GAP THAT CAN ONLY BE FILLED EFFECTIVELY WITH LEADERSHIP OF THE TSC ALLIANCE, GUIDED BY A STEERING COMMITTEE OF CLINICIANS AND RESEARCHERS. HIGH-QUALITY BIOSAMPLES SUCH AS BLOOD, DNA, AND TISSUES LINKED TO DETAILED CLINICAL DATA ARE CRITICAL FOR RESEARCHERS TO UNDERSTAND WHY TSC IS SO DIFFERENT FROM PERSON TO PERSON. SAMPLES IN THE REPOSITORY ARE LINKED TO DETAILED CLINICAL DATA IN OUR EXISTING TSC NATURAL HISTORY DATABASE AND ARE AVAILABLE TO QUALIFIED RESEARCHERS WORLDWIDE. SAMPLES ARE HOUSED AT AND DISTRIBUTED FROM THE VAN ANDEL INSTITUTE IN GRAND RAPIDS, MI, UNDER CONTROL OF THE TSC ALLIANCE. AS OF DECEMBER 31, 2021, THE TSC BIOSAMPLE REPOSITORY HAS ACQUIRED 2,000 BIOSAMPLES: 615 BLOOD SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 367 BUCCAL SAMPLES FROM

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INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 154 TISSUE SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 465 BLOOD SAMPLES FROM THE TSC CLINICAL RESEARCH CONSORTIUM COLLABORATIVE PROJECTS, AND 389 DNA SAMPLES FROM THE TSC AUTISM CENTER OF EXCELLENCE NETWORK AUTISM BIOMARKER STUDY.

THE ORGANIZATION CONTINUES TO GROW THE BIOSAMPLE REPOSITORY BY COLLECTING BLOOD SAMPLES ANNUALLY FROM PARTICIPANTS WHO VOLUNTEER TO DO SO, ENABLING RESEARCHERS TO STUDY CHANGES IN PROTEINS AND OTHER MOLECULES IN THE BLOOD OVER TIME; ADDING ADDITIONAL TSC CLINICS AS PARTICIPATING BIOSAMPLE REPOSITORY COLLECTION SITES; AND COLLECTING BLOOD USING MOBILE PHLEBOTOMY, ENABLING PEOPLE TO DONATE SAMPLES REGARDLESS OF WHERE THEY LIVE IN THE US AND WHETHER THEY ARE SEEN AT A TSC CLINIC. SINCE THE INCEPTION OF OUR MOBILE PHLEBOTOMY INITIATIVE, WE HAVE ACQUIRED 187 BLOOD SAMPLES VIA MOBILE PHLEBOTOMY. UNIQUE ADDITIONS IN 2021 INCLUDED THE ACQUISITION OF 100 TISSUES FROM THE MARYLAND BRAIN AND TISSUE BANK, FIVE CORD BLOOD SAMPLES FROM INFANTS WITHOUT TSC TO USE AS CONTROLS IN FUTURE EXPERIMENTS FOR THE NEWBORN SCREENING INITIATIVE, AND ONE CORD BLOOD SAMPLE FROM AN INDIVIDUAL WITH TSC. TO ENCOURAGE AND ENABLE MORE RESEARCHERS TO UTILIZE BIOSAMPLES, THE TSC ALLIANCE FUNDED THREE SEED GRANTS IN 2021, TOTALING \$54,940.80, TO LABS THAT SUBMITTED MERITORIOUS AND INNOVATIVE IDEAS FOR RESEARCH ON TSC BIOSAMPLES.

IN 2021, THE TSC ALLIANCE COMPLETED A WHOLE-GENOME SEQUENCING (WGS) PILOT STUDY USING DNA FROM BLOOD SAMPLES IN OUR BIOSAMPLE REPOSITORY TO DEMONSTRATE THE FEASIBILITY OF THIS APPROACH. THE TSC ALLIANCE SUBMITTED 20 DNA SAMPLES WHICH HAD NOT BEEN PREVIOUSLY ANALYZED TO THE

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TRANSLATIONAL GENOMICS RESEARCH INSTITUTE (TGEN) FOR WGS. RESULTS REVEALED DISEASE-CAUSING VARIANTS IN 19 OF 20 SAMPLES AND DEMONSTRATED FEASIBILITY OF WGS TO DELIVER VALUABLE INFORMATION TO BOTH PATIENTS AND RESEARCHERS. WE INTEND TO SCALE UP WGS IN COMING YEARS AS FUNDS ARE RAISED FOR THIS INITIATIVE.

IN DECEMBER 2021, THE TSC ALLIANCE ADDED THE TSC SELF-REPORT PORTAL TO THE TSC NATURAL HISTORY DATABASE. THIS NEW PORTAL WILL PERMIT THE COLLECTION OF PATIENT-REPORTED OUTCOMES ON HOW TSC AFFECTS INDIVIDUALS AND FAMILIES, WHICH WILL COMPLEMENT MEDICAL DATA IN THE NATURAL HISTORY DATABASE. THE PURPOSE OF THIS INITIATIVE IS TO HELP THE TSC ALLIANCE AND TSC RESEARCHERS BETTER UNDERSTAND THE PERSPECTIVE OF THOSE AFFECTED BY TSC TO DEVELOP TOOLS TO MEASURE IMPROVEMENT IN AREAS MOST IMPORTANT TO THE TSC COMMUNITY. EVENTUALLY, THESE MEASUREMENTS CAN BE USED TO IDENTIFY ENDPOINTS FOR CLINICAL TRIALS AND EVIDENCE-BASED GUIDELINES FOR TREATMENT.

ONE OF THE MOST IMPACTFUL ASPECTS OF TSC ON THE QUALITY OF LIFE FOR PEOPLE LIVING WITH TSC IS TSC-ASSOCIATED NEUROPSYCHIATRIC DISORDERS (TAND). THEREFORE, THE TSC ALLIANCE'S FIRST USE OF THE PORTAL IS THROUGH COLLABORATION WITH THE TANDEM PROJECT (EMPOWERING FAMILIES THROUGH TECHNOLOGY: A MOBILE-HEALTH PROJECT TO REDUCE THE TAND IDENTIFICATION AND TREATMENT GAP) BY ALLOWING THE COMMUNITY TO COMPLETE THE SELF-QUANTIFIED TAND CHECKLIST (TAND-SQ). THE TSC ALLIANCE IS HELPING THE TANDEM PROJECT TEAM VALIDATE THE UTILITY OF THE TAND-SQ FOR FUTURE USE IN A MOBILE APPLICATION.

THE TSC ALLIANCE LAUNCHED THE TSC PRECLINICAL CONSORTIUM IN 2015 TO

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HELP ADVANCE MORE DRUG CANDIDATES INTO CLINICAL TESTING. TO ACHIEVE THIS END, THE PRECLINICAL CONSORTIUM PROVIDES THE INFRASTRUCTURE TO FOSTER COLLABORATION BETWEEN ACADEMIA AND PHARMACEUTICAL INDUSTRY RESEARCHERS AND FOR ACCESS TO RESOURCES DESIGNED TO HELP FACILITATE DRUG DEVELOPMENT IN TSC. COLLABORATING WITH THE TSC COMMUNITY, THE CONSORTIUM HAS IDENTIFIED AND IMPLEMENTED ROBUST AND REPRODUCIBLE CELL AND ANIMAL MODELS FOR TSC MANIFESTATIONS INCLUDING TUMORS, EPILEPSY, AND TAND. THE TSC ALLIANCE HAS LICENSES TO USE SPECIFIC TSC MOUSE MODELS FOR EXPERIMENTS CARRIED OUT BY THE PRECLINICAL CONSORTIUM, AND ALL MOUSE LICENSE AGREEMENTS INCLUDE THE RIGHTS FOR THE TSC ALLIANCE TO PERFORM EXPERIMENTS UNDER CONTRACT FOR COMMERCIAL ENTITIES. THIS ENSURES DATA GENERATED BY THE PRECLINICAL CONSORTIUM CAN BE USED TO ACCELERATE THE DEVELOPMENT OF NEW TREATMENTS BY COMMERCIAL ENTITIES AS WELL AS ACADEMIC INVESTIGATORS. EXPERIMENTS ARE EXECUTED AT PARTNERING RESEARCH INSTITUTIONS TO ENSURE CONSISTENCY IN TESTING, DATA ACQUISITION AND INTERPRETATION. EPILEPSY STUDIES ARE CONDUCTED AT PSYCHOGENICS (US), AND THE TUMOR GRAFT MODEL AND CELL-BASED ASSAYS ARE CONDUCTED AT PORSOLT (FRANCE). THE VAN ANDEL RESEARCH INSTITUTE, A NON-PROFIT RESEARCH ORGANIZATION, MAINTAINS A COLONY OF TSC2+/- AJ MICE AND BREEDING PAIRS OF L7-CRE-TSC2 MICE ON BEHALF OF THE PRECLINICAL CONSORTIUM.

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THE PRECLINICAL CONSORTIUM INVITES COMPOUND NOMINATIONS FROM ACADEMIC AND INDUSTRY RESEARCHERS TO CONTINUE TO REFRESH OUR PIPELINE BASED ON THE LATEST DATA AND NOVEL IDEAS. THE NOMINATIONS ARE PEER-REVIEWED BY CONSORTIUM MEMBERS AND PRIORITIZED BY THE PRECLINICAL CONSORTIUM STEERING COMMITTEE FOR FUNDING BY THE TSC ALLIANCE. IF THE TSC ALLIANCE



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FUNDS THE STUDY, THE DATA ARE SHARED WITH THE CONSORTIUM FOR TRANSPARENCY AND STIMULATION OF ADDITIONAL HYPOTHESES. AN ANNUAL FACE-TO-FACE MEMBERS MEETING IS TYPICALLY HELD EACH YEAR IN APRIL TO KEEP MEMBERS ENGAGED AND ALIGNED ON THE CONSORTIUM'S STRATEGY AND PRIORITIES. PARTNERSHIP WITH PHARMACEUTICAL COMPANIES IS AN IMPORTANT ASPECT OF THE CONSORTIUM, AS THESE ORGANIZATIONS HAVE THE INFRASTRUCTURE TO EFFICIENTLY MOVE PRECLINICAL RESEARCH FINDINGS TO CLINICAL TESTING AND EVENTUALLY COMMERCIAL DISTRIBUTION. AS OF DECEMBER 2021, 10 COMPANIES WERE ACTIVE MEMBERS OF THE CONSORTIUM. THE CONSORTIUM HAS HAD 17 COMPANY MEMBERS SINCE 2016. THERE IS NATURAL TURNOVER OF INDUSTRY MEMBERSHIP, PRINCIPALLY DRIVEN BY RESEARCH DATA GENERATED BY TESTING THEIR DRUGS. DUE TO INTELLECTUAL PROPERTY CONSIDERATIONS, MOST COMPANIES FULLY FUND THEIR STUDIES THROUGH THE TSC ALLIANCE, WHICH ALLOWS THE COMPANY TO KEEP ITS DATA CONFIDENTIAL. THESE CONFIDENTIAL STUDIES ALSO INCUR A 10% OVERHEAD PAID BY THE COMPANY, WHICH IS A SOURCE OF REVENUE FOR THE TSC ALLIANCE. SINCE INCEPTION, THE CONSORTIUM HAS HELPED ADVANCE THE EVALUATION OF DRUGS FOR TSC BY CONDUCTING 90 STUDIES, EVALUATING 57 CANDIDATE DRUGS. IN 2020, THE TSC PRECLINICAL CONSORTIUM EVALUATED 9 CANDIDATE COMPOUNDS AND CONDUCTED 22 EXPERIMENTS.

IN 2012, THE TSC ALLIANCE HELPED CREATE THE TSC CLINICAL RESEARCH CONSORTIUM IN PARTNERSHIP WITH INVESTIGATORS RUNNING CLINICAL STUDIES TO ENSURE CLINICAL RESEARCH IN TSC IS AS EFFICIENT AND EFFECTIVE AS POSSIBLE. SINCE THEN, TSC CLINICAL RESEARCH CONSORTIUM INVESTIGATORS HAVE BEEN AWARDED MORE THAN \$39 MILLION BY THE NATIONAL INSTITUTES OF HEALTH (NIH) AND FOOD AND DRUG ADMINISTRATION (FDA) THROUGH COMPETITIVE GRANT PROCESSES. TSC ALLIANCE PERSONNEL SERVE ON THE LEADERSHIP TEAM

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FOR THE CONSORTIUM, ACTIVELY TRACK ENROLLMENT, AND RAISE COMMUNITY AWARENESS TO HELP IDENTIFY POTENTIAL PARTICIPANTS FOR CLINICAL STUDIES. TSC ALLIANCE ALSO PROVIDES SUPPLEMENTAL FINANCIAL SUPPORT TO ACCELERATE OR EXPAND NIH-FUNDED STUDIES. THE PREVENT TRIAL - PREVENTING EPILEPSY USING VIGABATRIN IN INFANTS WITH TSC - IS THE FIRST PREVENTATIVE TRIAL IN THE UNITED STATES FOR ANY FORM OF EPILEPSY AND HAS COMPLETED ENROLLMENT OF 86 PARTICIPANTS. WE EXPECT THE FIRST RESULTS IN THE FIRST QUARTER OF 2022 AND FINAL RESULTS IN EARLY 2023. THIS TRIAL BUILDS DIRECTLY UPON THE CLINICAL RESEARCH CONSORTIUM'S FIRST CLINICAL STUDY, WHICH IDENTIFIED SPECIFIC EEG CHANGES IN INFANTS WITH TSC PRIOR TO THE ONSET OF SEIZURES. IN THE PREVENT TRIAL, INFANTS WITH TSC RECEIVE REGULAR EEG MONITORING, AND THOSE WHO DEVELOP EEG ABNORMALITIES ARE PLACED ON EITHER VIGABATRIN OR PLACEBO. ANY INFANT WHO SUBSEQUENTLY DEVELOPS CLINICAL SEIZURES IS IMMEDIATELY PLACED ON STANDARD TREATMENT. THIS TRIAL WILL DETERMINE WHETHER TREATMENT WITH VIGABATRIN PRIOR TO THE ONSET OF CLINICAL SEIZURES IN TSC IS BENEFICIAL TO CHILDREN'S DEVELOPMENTAL AND NEUROLOGIC OUTCOMES. MORE DETAILS ABOUT THIS STUDY ARE ONLINE AT [WWW.CLINICALTRIALS.GOV/CT2/SHOW/NCT02849457](http://WWW.CLINICALTRIALS.GOV/CT2/SHOW/NCT02849457).

IMMEDIATELY AFTER THE PREVENT TRIAL ENROLLMENT COMPLETED, A SIMILAR CLINICAL TRIAL BEGAN ENROLLING NEWBORNS WITH TSC BEFORE THE ONSET OF SEIZURES TO TEST THE EFFECTS OF SIROLIMUS ON PREVENTING OR DELAYING SEIZURE ONSET. THE STOPPING TSC ONSET AND PROGRESSION 2 (STOP-2) TRIAL ENROLLED FIVE INFANTS AT CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER AS AN INITIAL SAFETY STUDY. THE SECOND STAGE OF THE TRIAL IS NOW CALLED "SIROLIMUS TSC EPILEPSY PREVENTION STUDY (TSC-STEPS)" AND THE TSC ALLIANCE HAS CONTRIBUTED \$200,000 TO ENABLE THE TRIAL TO BE EXPANDED TO ADDITIONAL SITES ACROSS THE COUNTRY. THE TSC ALLIANCE IS ALSO PROVIDING

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SUPPLEMENTAL FUNDING AND COLLECTING BLOOD SAMPLES FOR THE DEVELOPMENTAL SYNAPTOPATHIES CONSORTIUM (DSC), AN NIH-FUNDED PROJECT THAT INCLUDES STUDIES OF TSC AND THE RELATED RARE DISORDERS PHELAN-MCDERMID SYNDROME AND PTEN HAMARTOMA SYNDROME. THESE THREE RARE DISEASES SEEM TO AFFECT CERTAIN SHARED PATHWAYS INFLUENCING THE DEVELOPMENT OF BRAIN CONNECTIONS, OR SYNAPSES. RESEARCHERS IN THIS STUDY ARE TRYING TO FIND EARLIER SIGNS OF AUTISM SPECTRUM DISORDER (ASD) AND INTELLECTUAL DISABILITY (ID) TO GAIN A BETTER UNDERSTANDING OF ASD/ID IN INDIVIDUALS WITH TSC AND ENABLE EFFECTIVE TREATMENTS AND INTERVENTIONS FOR ASD/ID TO BE FOUND. THE DSC WAS RENEWED IN 2019 FOR A SECOND 5-YEAR FUNDING PERIOD. THE TSC ALLIANCE FUNDS A PORTION OF CLINICAL RESEARCH COORDINATORS' SALARIES AT 5 SITES. IN 2021, THE TSC ALLIANCE AWARDED A TWO-YEAR CLINICAL RESEARCH TSC-DSC FELLOWSHIP TO FELIX CHAN, PHD, AT BROWN UNIVERSITY.

IN ADDITION TO SPECIFIC COLLABORATIVE PROJECTS DETAILED ABOVE, THE TSC ALLIANCE STIMULATES COLLABORATION AND INNOVATION THROUGH CONVENING EXPERTS AND STAKEHOLDERS WITHIN AND OUTSIDE THE TSC FIELD. IN 2020, THE TSC ALLIANCE INTRODUCED THE CONCEPT OF AN AD HOC INNOVATION WORKSHOP FOCUSED ON A SPECIFIC RESEARCH GAP OR OPPORTUNITY. THE FIRST INNOVATION WORKSHOP TOPIC WAS NEWBORN SCREENING, HELD USING ZOOM AND POWERNODDLE IN LATE 2020 AND CULMINATING IN A ZOOM MEETING ON JANUARY 29, 2021. PARTICIPANTS INCLUDED 20 RESEARCHERS WITH TSC EXPERTISE; 19 RESEARCHERS WITH NEWBORN SCREENING EXPERIENCE FROM CDC, NIH, AND ACADEMIC LABORATORIES; AND FIVE REPRESENTATIVES OF NON-TSC ADVOCACY ORGANIZATIONS WITH NEWBORN SCREENING EXPERIENCE. FOLLOWING PEER-REVIEW BY EXPERTS IN TSC AND SCREENING RESEARCH, THE TSC ALLIANCE FULLY FUNDED TWO PROPOSALS TOTALING \$164,856 FOR HYPOTHESIS-DRIVEN RESEARCH IN ASSAY

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DEVELOPMENT FOR EARLY DETECTION OF TSC.

THE 2021 VIRTUAL INTERNATIONAL TSC & LAM RESEARCH CONFERENCE: DRIVING DISCOVERIES BEYOND BOUNDARIES HELD OCTOBER 28-30, 2021, WELCOMED 179 PEOPLE FROM 18 COUNTRIES. CO-SPONSORED BY THE TSC ALLIANCE AND THE LAM FOUNDATION, THE CONFERENCE FEATURED THREE PLENARY SESSIONS WITH 17 ORAL PRESENTATIONS AND TWO POSTER SESSIONS WITH 14 POSTERS. ADDITIONALLY, TWO HALF-DAY SESSIONS OF "TOPIC-BASED DISCUSSION" BROUGHT TOGETHER CLINICAL AND BASIC SCIENCE RESEARCHERS TO DISCUSS CROSS-CUTTING TOPICS, INCLUDING BIG DATA AND CLINICAL TRANSLATION.

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

ACTIVE FUTURE LEADERS (8 VOLUNTEERS) AND PAST FUTURE LEADERS (6 VOLUNTEERS) WHO HAVE AGREED TO REMAIN AS LEADERS FOR OTHER YOUNG ADULTS WITH TSC.

EDUCATION PARENT MENTORS ATTENDED 55 SCHOOL MEETINGS (IEPS, EVALUATION TEAM MEETINGS, 504 PLAN MEETINGS, RESOLUTION MEETINGS, AND MEDIATIONS) IN PERSON, THROUGH SKYPE/ZOOM, AND VIA CONFERENCE CALLS TO SUPPORT FAMILIES IN ATTAINING EDUCATIONAL SERVICES FOR THEIR CHILDREN THROUGHOUT THE COUNTRY. SEVERAL SCHOOL SYSTEMS ALSO REQUESTED "TSC 101" IN AN EFFORT TO HELP THEM UNDERSTAND THE COMPLEXITIES OF TSC AND LEARNING ISSUES FOR CHILDREN WITH TSC.

THE COMMUNITY PROGRAMS TEAM SUPPORTS A NETWORK OF 33 VOLUNTEER BRANCHES OF THE ORGANIZATION, CALLED COMMUNITY ALLIANCES, THAT PROVIDE SUPPORT AND COMMUNITY EDUCATION IN ALL 50 STATES.

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TO ENSURE THE TSC COMMUNITY CONTINUE TO RECEIVE UPDATED INFORMATION ABOUT TSC, TSC-ASSOCIATED NEUROPSYCHIATRIC DISORDERS (TAND), TRANSITION AND RESEARCH, THE TSC ALLIANCE DEVELOPED AN E-WEBINAR SERIES. IN 2021, WE HOSTED 27 E-WEBINARS WITH 1,219 CUMULATIVE LIVE ATTENDEES, 5,567 CUMULATIVE RECORDING VIEWS AND 3,123 CUMULATIVE LANDING PAGES VISITS. ADDITIONALLY, WE HELD THE FOLLOWING WEBINARS: APRIL COVID VACCINE TOWN HALL - 66 LIVE ATTENDEES, 304 VIDEO VIEWS; ABC TO SAP WEBINAR - 50 LIVE ATTENDEES, 458 VIDEO VIEWS; AUGUST COVID UPDATE TOWN HALL - 307 LIVE ATTENDEES, 463 VIDEO VIEWS. ADDING IN LIVE ATTENDEES WITH ADDITIONAL WEBINARS TOTAL LIVE AUDIENCE FOR WEBINARS IS 1,642, TOTAL CUMULATIVE RECORDING VIEWS IS 6,636 AND 3,123 CUMULATIVE LANDING PAGE VISITS.

IN 2021, THE TSC ALLIANCE LAUNCHED THE TSC NAVIGATOR, AN EASY-TO-USE, INTERACTIVE ONLINE TOOL TO HELP GUIDE INDIVIDUALS AND FAMILIES THROUGH THE COMPLEXITIES OF TSC ACROSS THE LIFESPAN, PROACTIVELY MANAGE THEIR CARE, AND LIVE THEIR FULLEST LIVES. USERS CAN ACCESS INFORMATION BASED ON THE AGE OF ONE'S DIAGNOSIS, SUCH AS PRENATAL, CHILDHOOD, OR ADULT, TO HELP DETERMINE WHICH STEPS WILL HELP EMPOWER THEM THROUGHOUT THEIR INDIVIDUAL JOURNEYS. REGARDLESS OF AGE, TSC NAVIGATOR ALSO HELPS INDIVIDUALS WITH TSC AND THEIR CAREGIVERS FACE COMPLEX SITUATIONS, OVERCOME ACCESS ISSUES, AND ADDRESS INSURANCE BARRIERS. THE TSC NAVIGATOR LAUNCHED OCTOBER 14, 2019 AND RECEIVED MORE THAN 2,700 VISITS BETWEEN LAUNCH AND YEAR END.

587 INDIVIDUALS AND FAMILIES WERE ASSISTED DIRECTLY BY THE DIRECTOR OF MEDICAL AFFAIRS AND TEAM ACTING AS SUPPORT NAVIGATORS. OF THE ASSISTANCE PROVIDED, 78 WERE MEDICATION-RELATED, 60 WERE TAND-RELATED,

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88 WERE NEW DIAGNOSIS, AND 252 WERE FOR ASSISTANCE WITH ACCESS TO CARE WITH 46 COVID-19 RELATED. THE REMAINDER SERVED A VARIETY OF OTHER NEEDS.

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

AWARENESS AND PROVIDES EXTENSIVE EDUCATION THROUGH AN AVERAGE OF MORE THAN 24,000 UNIQUE VISITORS EACH MONTH.

THE TSC ALLIANCE ALSO RELIES HEAVILY ON SOCIAL MEDIA TO EDUCATE CONSTITUENTS AND PROMOTE NEW RESOURCES AND EVENTS. ITS PRIVATE FACEBOOK TSC DISCUSSION GROUP BOASTS MORE THAN 10,000 MEMBERS, WHILE ITS TWITTER ACCOUNT HAS 2,579 FOLLOWERS AND INSTAGRAM HAS 2,762 FOLLOWERS.

TO INCREASE PUBLIC AWARENESS, THE TSC ALLIANCE PARTICIPATED IN THE SEVENTH ANNUAL TSC GLOBAL AWARENESS DAY ON MAY 15 AS WELL AS TSC AWARENESS MONTH THROUGHOUT MAY. THE TSC ALLIANCE ALSO HEAVILY PROMOTED THE INAUGURAL SEIZURE ACTION PLAN AWARENESS WEEK (FEBRUARY 8-14) AND INFANTILE SPASMS AWARENESS WEEK (DECEMBER 1 TO 7). THESE AWARENESS CAMPAIGNS ALONG WITH THE ORGANIZATIONS VARIOUS NEWS RELEASES CULMINATED IN MORE THAN 1 BILLION CUMULATIVE IMPRESSIONS.

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

GOVERNMENT RELATIONS EFFORTS FOCUS ON INCREASING FEDERAL AND STATE APPROPRIATIONS FOR TSC RESEARCH, RAISING AWARENESS, AND COLLABORATING WITH GOVERNMENT PARTNERS TO DRIVE TSC RESEARCH FORWARD AND IMPROVE CLINICAL CARE AND TREATMENT OPTIONS FOR INDIVIDUALS WITH TSC.

ON THE STATE LEVEL, THE TSC ALLIANCE ADVOCATED FOR STATE FUNDING FOR

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TSC CENTERS IN MISSOURI AND MARYLAND, RESULTING IN AT LEAST \$750,000 IN STATE APPROPRIATIONS. THE ANNUAL TSC 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 2021. MORE THAN 135 PEOPLE PARTICIPATED IN THE VIRTUAL MARCH ON CAPITOL HILL THE WEEK OF MARCH 1-5, 2021. ADVOCATES MADE VIRTUAL APPOINTMENTS WITH 75 SENATE AND 280 HOUSE OFFICES TO ADVOCATE FOR A CONTINUATION OF \$8 MILLION IN FUNDING FOR THE TSCR. THE HOUSE TSCR DEAR COLLEAGUE LETTER SPONSORED BY REPRESENTATIVES MULLIN (R-OK) AND RASKIN (D-MD) CLOSED WITH 202 SIGNERS. THE SENATE LETTER SPONSORED BY SENATORS CRAMER (R-ND) AND HEINRICH (D-NM) CLOSED WITH 34 SIGNERS.

TOTAL FUNDING FOR THE TSCR HAS BEEN \$105 MILLION SINCE 2002. PRESIDENT BIDEN JUST SIGNED THE FY22 DEFENSE BILL INTO LAW ON MARCH 15, 2022, WHICH INCLUDED \$8 MILLION FOR THE TSCR.

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

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FY2010 TSCRP CLINICAL RESEARCH AWARD TO DEFINE EARLY AUTISM PREDICTORS IN TSC AND AN FY2014 TSCRP AWARD FOR A PILOT CLINICAL TRIAL IS BEING TESTED IN A LARGE, NIH-FUNDED CLINICAL TRIAL LOOKING AT THE EFFECTIVENESS OF A BEHAVIORAL INTERVENTION STRATEGY, JASPER, TO IMPROVE OUTCOMES IN CHILDREN WITH AUTISM. THE TSCRP HAS ALSO FUNDED RESEARCH TO DEVELOP ANIMAL MODELS OF TSC THAT HAVE SEIZURES, ENABLING A BETTER UNDERSTANDING OF THE ETIOLOGY OF TSC. BASED ON DATA FROM TSCRP-FUNDED ANIMAL MODELS OF TSC THAT HAVE SEIZURES AND SHARE PATHOLOGY RELATED TO THAT OF TRAUMATIC BRAIN INJURY, AN INDUSTRY-SPONSORED CLINICAL TRIAL DEMONSTRATED THE EFFECTIVENESS THE MTOR INHIBITOR, EVEROLIMUS, AT TREATING EPILEPSY IN MANY INDIVIDUALS WITH TSC. NONE OF THIS PROGRESS WOULD HAVE BEEN POSSIBLE WITHOUT THE CRITICAL SUPPORT PROVIDED THROUGH THE TSCRP.

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

PROFESSIONAL EDUCATION EXPANDS PROGRAMS TO TARGET RESEARCHERS AND



Name of the organization

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number

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HEALTHCARE PROVIDERS CARING FOR INDIVIDUALS WITH TSC, MEDICAL STUDENTS,  
GENETIC COUNSELORS AND EDUCATORS TO MINIMIZE THE CONSEQUENCES OF  
IGNORANCE AND MISINFORMATION.

IN AUGUST, TWO NEW PUBLICATIONS WERE ACCEPTED BY PEDIATRIC NEUROLOGY,  
"UPDATED INTERNATIONAL TSC DIAGNOSTIC CRITERIA AND SURVEILLANCE AND  
MANAGEMENT RECOMMENDATIONS" AND "BEYOND THE GUIDELINES: HOW WE CAN  
IMPROVE HEALTHCARE FOR PEOPLE WITH TSC AROUND THE WORLD." THE NEW  
PAPERS PROVIDE THE FIRST SIGNIFICANT UPDATES TO THE INTERNATIONAL  
GUIDELINES SINCE 2013 BECAUSE OF NEW MEDICATIONS AND ADVANCES IN  
TREATMENTS. TO ADDRESS THE CHANGES, A WORKING GROUP LED BY DARCY A.  
KRUEGER, MD, PHD, OF CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER, AND  
HOPE NORTHRUP, MD, MCGOVERN MEDICAL SCHOOL, UNIVERSITY OF TEXAS HEALTH  
SCIENCE CENTER AT HOUSTON, INCLUDED 80 PARTICIPANTS FROM 16 COUNTRIES.

THE TSC ALLIANCE PARTICIPATED IN OR PRESENTED AT 37 PROFESSIONAL  
MEETINGS IN 2021 INCLUDING CURING THE EPILEPSIES 2020: SETTING RESEARCH  
PRIORITIES, NIMH 2021 VIRTUAL WORKSHOP: GENE-BASED THERAPEUTICS FOR  
RARE NEURODEVELOPMENTAL PSYCHIATRIC DISORDERS, TSC ALLIANCE: NEWBORN  
SCREENING WORKSHOP, ATS BOARD OF DIRECTORS MEETING, RARE DISEASE DAY AT  
NIH, ISAN MEMBERSHIP MEETING, INAUGURAL O'DONNELL BRAIN INSTITUTE  
SYMPOSIUM ON AUTISM SPECTRUM DISORDERS, OVERCOMING BARRIERS TO  
DIVERSIFYING CLINICAL TRIALS (RDCRN), ELHS SPRING LEARNING SESSION,  
HEALTH RESEARCH ALLIANCE CULTURAL COMPETENCY WORKSHOP WITH BME,  
RESEARCH!AMERICA ANNUAL MEETING OF THE MEMBERS, MEDICAID AND CHIP  
PAYMENT AND ACCESS COMMISSION (MACPAC) WEBINAR, ICARE MEETING,  
TRANS-NIH MEETING, ATS PAR MEET-THE-EXPERTS PATIENT/FAMILY FORUM, ATS  
SCIENTIFIC SYMPOSIUM, USF DIVERSITY, EQUITY, AND INCLUSION IN THE

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WORKPLACE SERIES, ISAN MEMBERSHIP MEETING-SUMMER, GLOBAL GENES RARE  
 DRUG DEVELOPMENT SYMPOSIUM: PRECLINICAL MODELING-WHAT ADVOCATES NEED TO  
 KNOW ABOUT ANIMAL & CELL MODELS, INTERNATIONAL TSC RESEARCH  
 CONFERENCE-UK, RARE DISEASE PATIENT-FOCUSED DRUG DEVELOPMENT (PFDD)  
 GUIDANCE COMPENDIUM, GLOBAL GENES ACCESS WORKING GROUP LUNCH BRIEFING:  
 MEDICAID COVERAGE FOR GENOMIC SEQUENCING, NINDS NONPROFIT FORUM  
 ADVISORY BOARD MEETING-INDUSTRY PARTNER, GLOBAL GENES: ACCESS WORKING  
 GROUP, LGS FOUNDATION MEETING OF THE MINDS, EVERYLIFE VIRTUAL NEWBORN  
 SCREENING BOOTCAMP, CNF SYMPOSIUM (WITHIN CNS), RDCRN FALL MEETING,  
 NIAMS, BIO, VIRTUAL INTERNATIONAL TSC & LAM RESEARCH CONFERENCE, ATS  
 PAR ANNUAL PLANNING MEETING, TSCI VIRTUAL WORKSHOP, TSCRIP PROGRAMMATIC  
 REVIEW & VISION SETTING, AMERICAN EPILEPSY SOCIETY ANNUAL MEETING, AND  
 INFANTILE SPASMS ACTION NETWORK MEMBERS MEETING.  
 EXPENSES \$ 353,569. INCLUDING GRANTS OF \$ 0. REVENUE \$ 34,070.

FORM 990, PART VI:

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 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,

Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
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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 TSC ALLIANCE IS A MEMBERSHIP-BASED ORGANIZATION, WHICH MEANS MEMBERS HELP ELECT THE BOARD OF DIRECTORS. THE TSC ALLIANCE MEMBERSHIP PROGRAM ALLOWS INDIVIDUALS TO STATE THEIR INTENT TO BE A MEMBER FOR THE PURPOSE OF GOVERNANCE. THERE WERE NO LEVELS TO MEMBERSHIP IN 2021. 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

Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
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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 2021:

BOARD MEMBER MUSTAFA SAHIN, PH.D., M.D., IS EMPLOYED AT BOSTON CHILDREN'S HOSPITAL, WHICH RECEIVED \$113,659 IN GRANTS AND \$9,015 IN FEES FOR SERVICES FOR PARTICIPATION IN THE TSC NATURAL HISTORY DATABASE.

BOARD MEMBER DARCY KRUEGER, MD, MPA, IS EMPLOYED AT THE CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER, WHICH RECEIVED A \$100,000 GRANT PAYMENT FOR HIS WORK ON STOP-2 AND \$8,190 IN FEES FOR SERVICES FOR PARTICIPATION IN THE TSC NATURAL HISTORY DATABASE.

BOARD MEMBER JESSICA KREFTING, RN, IS EMPLOYED AT UNIVERSITY OF ALABAMA AT BIRMINGHAM, WHICH RECEIVED \$7,715 IN FEES FOR SERVICES FOR PARTICIPATION IN THE TSC NATURAL HISTORY DATABASE.

BOARD MEMBER AND CHAIR PETER CRINO, MD, PHD, IS CHAIR OF THE DEPARTMENT OF NEUROLOGY AT THE UNIVERSITY OF MD, WHICH RECIEVED A \$18,634 GRANT PAYMENT.

FORM 990, PART VI, SECTION B, LINE 15:

Name of the organization

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THE COMPENSATION COMMITTEE REVIEWS AND APPROVES THE SALARIES OF THE PRESIDENT/CEO, CHIEF SCIENTIFIC OFFICER, CFO, AND ANY EMPLOYEE APPEARING ON THE FORM 990, IN ACCORDANCE WITH THE TSC ALLIANCE BYLAWS. SUCH REVIEW AND APPROVAL OCCURS INITIALLY UPON HIRING, UPON ANNUAL REVIEWS, AND WHENEVER MODIFIED.

THE ORGANIZATION'S EXECUTIVE REMUNERATION HAS BEEN STRUCTURED TO ENSURE THAT IT: IS REASONABLE; PROVIDES A COMPETITIVE COMPENSATION PROGRAM TO RETAIN, ATTRACT AND REWARD KEY EMPLOYEES AND ACHIEVES CLEAR ALIGNMENT BETWEEN TOTAL REMUNERATION AND DELIVERED BUSINESS AND PERSONAL PERFORMANCE OVER THE SHORT AND LONG-TERMS.

THE COMPENSATION IS REVIEWED BY THE COMPENSATION COMMITTEE TO ENSURE:

- COMPARABILITY,
- PROPER REVIEW, AND
- SUBSTANTIATION IN SETTING THE COMPENSATION.

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

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

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

**2021**

Open to Public Inspection

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

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

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

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

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

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

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

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

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

**Part V Transactions With Related Organizations.** Complete if the organization answered "Yes" on Form 990, Part IV, line 34, 35b, or 36.

**Note:** Complete line 1 if any entity is listed in Parts II, III, or IV of this schedule.

**1** During the tax year, did the organization engage in any of the following transactions with one or more related organizations listed in Parts II-IV?

	Yes	No
<b>a</b> Receipt of (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
(1) TSC ALLIANCE ENDOWMENT FUND, INC.	C	226,000.	CASH
(2)			
(3)			
(4)			
(5)			
(6)			







TAXABLE YEAR

**2021**

# California Exempt Organization Annual Information Return

Calendar Year 2021 or fiscal year beginning (mm/dd/yyyy) \_\_\_\_\_, and ending (mm/dd/yyyy) \_\_\_\_\_

Corporation/Organization name <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION</b>		California corporation number <b>0734858</b>
Additional information. See instructions.		FEIN <b>95-3018799</b>
Street address (suite or room) <b>8737 COLESVILLE ROAD, NO. 400</b>		PMB no.
City <b>SILVER SPRING</b>	State <b>MD</b>	ZIP code <b>20910</b>
Foreign country name	Foreign province/state/county	Foreign postal code

<p><b>A</b> First return ..... Yes <input checked="" type="checkbox"/> No</p> <p><b>B</b> Amended return ..... Yes <input checked="" type="checkbox"/> No</p> <p><b>C</b> IRC Section 4947(a)(1) trust ..... Yes <input checked="" type="checkbox"/> No</p> <p><b>D</b> Final information return?  <input type="checkbox"/> Dissolved    <input type="checkbox"/> Surrendered (Withdrawn)    <input type="checkbox"/> Merged/Reorganized                  Enter date: (mm/dd/yyyy) _____</p> <p><b>E</b> Check accounting method: (1) Cash (2) <input checked="" type="checkbox"/> Accrual (3) Other</p> <p><b>F</b> Federal return filed? (1) 990T (2) 990PF (3) Sch H (990) (4) <input checked="" type="checkbox"/> Other 990 series</p> <p><b>G</b> Is this a group filing? See instructions ..... Yes <input checked="" type="checkbox"/> No</p> <p><b>H</b> Is this organization in a group exemption ..... Yes <input checked="" type="checkbox"/> No                  If "Yes," what is the parent's name? _____</p>	<p><b>I</b> Did the organization have any changes to its guidelines not reported to the FTB? See instructions ..... Yes <input checked="" type="checkbox"/> No</p> <p><b>J</b> If exempt under R&amp;TC Section 23701d, has the organization engaged in political activities? See instructions. .... Yes <input checked="" type="checkbox"/> No</p> <p><b>K</b> Is the organization exempt under R&amp;TC Section 23701g? ..... Yes <input checked="" type="checkbox"/> No                  If "Yes," enter the gross receipts from nonmember sources \$ _____</p> <p><b>L</b> Is the organization a limited liability company? ..... Yes <input checked="" type="checkbox"/> No</p> <p><b>M</b> Did the organization file Form 100 or Form 109 to report taxable income? ..... Yes <input checked="" type="checkbox"/> No</p> <p><b>N</b> Is the organization under audit by the IRS or has the IRS audited in a prior year? ..... Yes <input checked="" type="checkbox"/> No</p> <p><b>O</b> Is federal Form 1023/1024 pending? ..... Yes <input checked="" type="checkbox"/> No                  Date filed with IRS _____</p>
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**Part I Complete Part I unless not required to file this form. See General Information B and C.**

<b>Receipts and Revenues</b>	1 Gross sales or receipts from other sources. From Side 2, Part II, line 8	1	3,292,650	00
	2 Gross dues and assessments from members and affiliates	2	4,132	00
	3 Gross contributions, gifts, grants, and similar amounts received	3	5,764,921	00
	4 Total gross receipts for filing requirement test. Add line 1 through line 3. <b>This line must be completed.</b> If the result is less than \$50,000, see General Information B	4	9,061,703	00
	5 Cost of goods sold	5		00
	6 Cost or other basis, and sales expenses of assets sold	6		00
	7 Total costs. Add line 5 and line 6	7		00
	8 Total gross income. Subtract line 7 from line 4	8	9,061,703	00
<b>Expenses</b>	9 Total expenses and disbursements. From Side 2, Part II, line 18	9	6,915,278	00
	10 Excess of receipts over expenses and disbursements. Subtract line 9 from line 8	10	2,146,425	00
<b>Filing Fee</b>	11 Total payments	11		00
	12 Use tax. See General Information K	12		00
	13 Payments balance. If line 11 is more than line 12, subtract line 12 from line 11	13		00
	14 Use tax balance. If line 12 is more than line 11, subtract line 11 from line 12	14		00
	15 Penalties and interest. See General Information J	15		00
16 <b>Balance due.</b> Add line 12 and line 15. Then subtract line 11 from the result	16		00	

**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.

<b>Sign Here</b>	Signature of officer <i>[Signature]</i>	Title <b>PRESIDENT &amp; CE</b>	Date <b>4/12/22</b>	Telephone <b>301-562-9890</b>
<b>Paid Preparer's Use Only</b>	Preparer's signature <i>[Signature]</i>	Date <b>04/08/22</b>	Check if self-employed <input type="checkbox"/>	PTIN <b>P00397829</b>
	Firm's name (or yours, if self-employed) and address <b>RSM US LLP 2021 L STREET NW, SUITE 400 WASHINGTON, DC 20036</b>			Firm's FEIN <b>42-0714325</b>
				Telephone <b>202-293-2200</b>

May the FTB discuss this return with the preparer shown above? See instructions .....  Yes    No

**Part II** Organizations with gross receipts of more than \$50,000 and private foundations regardless of amount of gross receipts - complete Part II or furnish substitute information.

128951 01-19-22

**SEE PART II SUBSTITUTE ATTACHMENT**

<b>Receipts from Other Sources</b>	1	Gross sales or receipts from all business activities. See instructions	•	1		00	
	2	Interest	•	2		00	
	3	Dividends	•	3		00	
	4	Gross rents	•	4		00	
	5	Gross royalties	•	5		00	
	6	Gross amount received from sale of assets (See instructions)	•	6		00	
	7	Other income	•	7		00	
	8	<b>Total</b> gross sales or receipts from other sources. Add line 1 through line 7. Enter here and on Side 1, Part I, line 1		8		00	
	9	Contributions, gifts, grants, and similar amounts paid	•	9		00	
	10	Disbursements to or for members	•	10		00	
	11	Compensation of officers, directors, and trustees	•	11		0 00	
	12	Other salaries and wages	•	12		00	
	<b>Expenses and Disbursements</b>	13	Interest	•	13		00
		14	Taxes	•	14		00
		15	Rents	•	15		00
		16	Depreciation and depletion (See instructions)	•	16		00
		17	Other expenses and disbursements	•	17		00
	18	<b>Total</b> expenses and disbursements. Add line 9 through line 17. Enter here and on Side 1, Part I, line 9		18		00	

<b>Schedule L Balance Sheet</b>	Beginning of taxable year			End of taxable year
	(a)	(b)	(c)	(d)
<b>Assets</b>				
1 Cash				•
2 Net accounts receivable				•
3 Net notes receivable				•
4 Inventories				•
5 Federal and state government obligations				•
6 Investments in other bonds				•
7 Investments in stock				•
8 Mortgage loans				•
9 Other investments				•
10 a Depreciable assets				
b Less accumulated depreciation	( )		( )	
11 Land				•
12 Other assets				•
13 <b>Total assets</b>				
<b>Liabilities and net worth</b>				
14 Accounts payable				•
15 Contributions, gifts, or grants payable				•
16 Bonds and notes payable				•
17 Mortgages payable				•
18 Other liabilities				
19 Capital stock or principal fund				•
20 Paid-in or capital surplus. Attach reconciliation				•
21 Retained earnings or income fund				•
22 <b>Total liabilities and net worth</b>				

<b>Schedule M-1 Reconciliation of income per books with income per return</b>			
Do not complete this schedule if the amount on Schedule L, line 13, column (d), is less than \$50,000.			
1 Net income per books	•	7 Income recorded on books this year not included in this return. Attach schedule	•
2 Federal income tax	•	8 Deductions in this return not charged against book income this year. Attach schedule	•
3 Excess of capital losses over capital gains	•	9 Total. Add line 7 and line 8	
4 Income not recorded on books this year. Attach schedule	•	10 Net income per return. Subtract line 9 from line 6	
5 Expenses recorded on books this year not deducted in this return. Attach schedule	•		
6 Total. Add line 1 through line 5			