

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

Form 990

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)
Do not enter social security numbers on this form as it may be made public.
Go to www.irs.gov/Form990 for instructions and the latest information.

2023

Open to Public Inspection

A For the 2023 calendar year, or tax year beginning and ending
B Check if applicable:
C Name of organization: NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
Doing business as TSC ALLIANCE
D Employer identification number: 95-3018799
E Telephone number: 301-562-9890
G Gross receipts \$: 10,180,515.
H(a) Is this a group return for subordinates? Yes [X] No
H(b) Are all subordinates included? Yes No
I Tax-exempt status: [X] 501(c)(3)
J Website: WWW.TSCALLIANCE.ORG
K Form of organization: [X] Corporation
L Year of formation: 1975
M State of legal domicile: CA

Part I Summary

Table with 3 columns: Description, Prior Year, Current Year. Rows include: 1-7a Activities & Governance, 8-12 Revenue, 13-19 Expenses, 20-22 Net Assets or Fund Balances.

Part II Signature Block

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

Signature of officer: KARI L. ROSBECK, PRESIDENT & CEO
Date:
Preparer: KRISTIN A. JACQUELIN, CPA
Date: 04/17/24
Firm: CALIBRE CPA GROUP, PLLC
Address: 7501 WISCONSIN AVENUE, SUITE 1200 WEST BETHESDA, MD 20814

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

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

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: TO IMPROVE QUALITY OF LIFE FOR EVERYONE AFFECTED BY TUBEROUS SCLEROSIS COMPLEX BY CATALYZING NEW TREATMENTS, DRIVING RESEARCH TOWARD A CURE AND EXPANDING ACCESS TO LIFELONG SUPPORT.

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

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

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

4a (Code: ) (Expenses \$ 5,022,281. including grants of \$ 845,292. ) (Revenue \$ 2,621,353. ) 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 MORE THAN \$37 MILLION INTO TSC RESEARCH PROJECTS THROUGH GRANTS AND CONTRACTS: \$20.6 MILLION IN

4b (Code: ) (Expenses \$ 895,227. including grants of \$ ) (Revenue \$ ) SUPPORT SERVICES. SEE SCHEDULE O FOR FULL PROGRAM DESCRIPTION.

4c (Code: ) (Expenses \$ 554,030. including grants of \$ ) (Revenue \$ ) PUBLIC HEALTH. SEE SCHEDULE O FOR FULL PROGRAM DESCRIPTION.

4d Other program services (Describe on Schedule O.) (Expenses \$ 287,855. including grants of \$ ) (Revenue \$ )

4e Total program service expenses 6,759,393.

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**Part IV Checklist of Required Schedules**

	Yes	No
<b>1</b> Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i> .....	<b>X</b>	
<b>2</b> Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? See instructions .....	<b>X</b>	
<b>3</b> Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i> .....		<b>X</b>
<b>4 Section 501(c)(3) organizations.</b> Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i> .....	<b>X</b>	
<b>5</b> Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? <i>If "Yes," complete Schedule C, Part III</i> .....		<b>X</b>
<b>6</b> Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i> .....		<b>X</b>
<b>7</b> Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i> .....		<b>X</b>
<b>8</b> Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i> .....		<b>X</b>
<b>9</b> Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i> .....		<b>X</b>
<b>10</b> Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i> .....	<b>X</b>	
<b>11</b> If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X, as applicable.		
<b>a</b> Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i> .....	<b>X</b>	
<b>b</b> Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII</i> .....		<b>X</b>
<b>c</b> Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i> .....		<b>X</b>
<b>d</b> Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i> .....	<b>X</b>	
<b>e</b> Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i> .....	<b>X</b>	
<b>f</b> Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i> .....		<b>X</b>
<b>12a</b> Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i> .....		<b>X</b>
<b>b</b> Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i> .....	<b>X</b>	
<b>13</b> Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i> .....		<b>X</b>
<b>14a</b> Did the organization maintain an office, employees, or agents outside of the United States? .....		<b>X</b>
<b>b</b> Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i> .....	<b>X</b>	
<b>15</b> Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i> .....	<b>X</b>	
<b>16</b> Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i> .....		<b>X</b>
<b>17</b> Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I.</i> See instructions .....		<b>X</b>
<b>18</b> Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i> .....	<b>X</b>	
<b>19</b> Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i> .....		<b>X</b>
<b>20a</b> Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i> .....		<b>X</b>
<b>b</b> If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? .....		
<b>21</b> Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i> .....	<b>X</b>	

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

	Yes	No
<b>22</b> Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i> .....	<b>22</b>	<b>X</b>
<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> .....	<b>23</b>	<b>X</b>
<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> .....	<b>24a</b>	<b>X</b>
<b>b</b> Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? .....	<b>24b</b>	
<b>c</b> Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? .....	<b>24c</b>	
<b>d</b> Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? .....	<b>24d</b>	
<b>25a 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> .....	<b>25a</b>	<b>X</b>
<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> .....	<b>25b</b>	<b>X</b>
<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> .....	<b>26</b>	<b>X</b>
<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> .....	<b>27</b>	<b>X</b>
<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> .....	<b>28a</b>	<b>X</b>
<b>b</b> A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i> .....	<b>28b</b>	<b>X</b>
<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> .....	<b>28c</b>	<b>X</b>
<b>29</b> Did the organization receive more than \$25,000 in noncash contributions? <i>If "Yes," complete Schedule M</i> .....	<b>29</b>	<b>X</b>
<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> .....	<b>30</b>	<b>X</b>
<b>31</b> Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> .....	<b>31</b>	<b>X</b>
<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> .....	<b>32</b>	<b>X</b>
<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> .....	<b>33</b>	<b>X</b>
<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> .....	<b>34</b>	<b>X</b>
<b>35a</b> Did the organization have a controlled entity within the meaning of section 512(b)(13)? .....	<b>35a</b>	<b>X</b>
<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>35b</b>	
<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> .....	<b>36</b>	<b>X</b>
<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> .....	<b>37</b>	<b>X</b>
<b>38</b> Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? .....	<b>38</b>	<b>X</b>

**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>1a</b>	33
<b>b</b> Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable .....	<b>1b</b>	0
<b>c</b> Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? .....	<b>1c</b>	<b>X</b>

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

		Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return		
	2a		26
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	X	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		X
b	If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation on Schedule O</i>		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?		X
b	If "Yes," enter the name of the foreign country See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
<b>7 Organizations that may receive deductible contributions under section 170(c).</b>			
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	X	
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	X	
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
d	If "Yes," indicate the number of Forms 8282 filed during the year		
	7d		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		X
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
8	<b>Sponsoring organizations maintaining donor advised funds.</b> Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?		
9	<b>Sponsoring organizations maintaining donor advised funds.</b>		
a	Did the sponsoring organization make any taxable distributions under section 4966?		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		
10	<b>Section 501(c)(7) organizations.</b> Enter:		
a	Initiation fees and capital contributions included on Part VIII, line 12	10a	
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b	
11	<b>Section 501(c)(12) organizations.</b> Enter:		
a	Gross income from members or shareholders	11a	
b	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b	
12a	<b>Section 4947(a)(1) non-exempt charitable trusts.</b> Is the organization filing Form 990 in lieu of Form 1041?	12a	
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b	
13	<b>Section 501(c)(29) qualified nonprofit health insurance issuers.</b>		
a	Is the organization licensed to issue qualified health plans in more than one state? <b>Note:</b> See the instructions for additional information the organization must report on Schedule O.	13a	
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans	13b	
c	Enter the amount of reserves on hand	13c	
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a	X
b	If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation on Schedule O</i>	14b	
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see the instructions and file Form 4720, Schedule N.	15	X
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.	16	X
17	<b>Section 501(c)(21) organizations.</b> Did the trust, or any disqualified or other person engage in any activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953? If "Yes," complete Form 6069.	17	

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**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	<b>1a</b>	30		
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.				
<b>b</b> Enter the number of voting members included on line 1a, above, who are independent	<b>1b</b>	30		
<b>2</b> Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?	<b>2</b>			<b>X</b>
<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?	<b>3</b>			<b>X</b>
<b>4</b> Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	<b>4</b>			<b>X</b>
<b>5</b> Did the organization become aware during the year of a significant diversion of the organization's assets?	<b>5</b>			<b>X</b>
<b>6</b> Did the organization have members or stockholders?	<b>6</b>		<b>X</b>	
<b>7a</b> Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?	<b>7a</b>		<b>X</b>	
<b>b</b> Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	<b>7b</b>			<b>X</b>
<b>8</b> Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:				
<b>a</b> The governing body?	<b>8a</b>		<b>X</b>	
<b>b</b> Each committee with authority to act on behalf of the governing body?	<b>8b</b>		<b>X</b>	
<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	<b>9</b>			<b>X</b>

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

			Yes	No
<b>10a</b> Did the organization have local chapters, branches, or affiliates?	<b>10a</b>		<b>X</b>	
<b>b</b> If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	<b>10b</b>		<b>X</b>	
<b>11a</b> Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	<b>11a</b>		<b>X</b>	
<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	<b>12a</b>		<b>X</b>	
<b>b</b> Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	<b>12b</b>		<b>X</b>	
<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	<b>12c</b>		<b>X</b>	
<b>13</b> Did the organization have a written whistleblower policy?	<b>13</b>		<b>X</b>	
<b>14</b> Did the organization have a written document retention and destruction policy?	<b>14</b>		<b>X</b>	
<b>15</b> Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?				
<b>a</b> The organization's CEO, Executive Director, or top management official	<b>15a</b>		<b>X</b>	
<b>b</b> Other officers or key employees of the organization	<b>15b</b>		<b>X</b>	
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?	<b>16a</b>			<b>X</b>
<b>b</b> If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?	<b>16b</b>			

**Section C. Disclosure**

- 17** List the states with which a copy of this Form 990 is required to be filed AL, AR, CA, FL, GA, HI, IL, IN, KS, KY, MD, MA
- 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  
TSC ALLIANCE - 301-562-9890  
8737 COLLESVILLE ROAD, 400, SILVER SPRING, MD 20910

NATIONAL TUBEROUS SCLEROSIS  
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**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, box 6 of 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 ROBERDS CHIEF SCIENTIFIC OFFICER	45.00				X		237,208.	0.	26,563.	
(2) KARI LUTHER ROSBECK PRESIDENT & CEO	54.00 1.00			X			223,746.	2,260.	29,417.	
(3) DEAN RAGER-AGUIAR VICE PRESIDENT, TRANSLATIONAL RESEAR	45.00				X		177,725.	0.	28,091.	
(4) CYNTHIA ARCURI CHIEF FINANCIAL OFFICER	42.00 1.00			X			176,989.	9,315.	9,482.	
(5) LISA MOSS VICE PRESIDENT, DONOR RELATIONS	45.00				X		124,914.	0.	24,144.	
(6) JAYE ISHAM CHIEF OUTREACH OFFICER	45.00				X		137,218.	0.	5,426.	
(7) ASHLEY POUNDERS DIRECTOR OF MEDICAL AFFAIRS	45.00				X		115,372.	0.	13,076.	
(8) WILLIAM JOSEPH CHAIR	5.00	X		X			0.	0.	0.	
(9) PAUL WAXLAX VICE-CHAIR	5.00 1.00	X		X			0.	0.	0.	
(10) BRITTANY SMITH TREASURER	5.00 1.00	X		X			0.	0.	0.	
(11) LESLEY HOLMES SECRETARY	2.00	X		X			0.	0.	0.	
(12) PETER CRINO IMMEDIATE PAST CHAIR	2.00	X					0.	0.	0.	
(13) DEREK BAUER BOARD MEMBER	2.00	X					0.	0.	0.	
(14) JULIE BLUM BOARD MEMBER	2.00	X					0.	0.	0.	
(15) MATT BOLGER BOARD MEMBER	2.00	X					0.	0.	0.	
(16) CHIP BURKHALTER BOARD MEMBER	2.00	X					0.	0.	0.	
(17) LISA CARLTON BOARD MEMBER	2.00	X					0.	0.	0.	

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC/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) DAVID COIT BOARD MEMBER	2.00	X						0.	0.	0.
(19) MARK CARROLL BOARD MEMBER	2.00	X						0.	0.	0.
(20) JULIAN GANGOLLI BOARD MEMBER	2.00	X						0.	0.	0.
(21) TANJALA GIPSON BOARD MEMBER	2.00	X						0.	0.	0.
(22) JONATHAN GOLDSTEIN BOARD MEMBER	2.00	X						0.	0.	0.
(23) STEVEN GOLDSTEIN BOARD MEMBER	2.00	X						0.	0.	0.
(24) ROB GRANDIA BOARD MEMBER	2.00	X						0.	0.	0.
(25) DANA HOLINKA BOARD MEMBER	2.00	X						0.	0.	0.
(26) SHAFALI JESTE BOARD MEMBER	2.00	X						0.	0.	0.
<b>1b Subtotal</b>								1,193,172.	11,575.	136,199.
<b>c Total from continuation sheets to Part VII, Section A</b>								0.	0.	0.
<b>d Total (add lines 1b and 1c)</b>								1,193,172.	11,575.	136,199.

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization 7

	Yes	No
3 Did the organization list any 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 S, NEW YORK, NY 10003	RESEARCH LAB SERVICES	1,565,754.
VAN ANDEL RESEARCH INSTITUTE, 333 BOSTWICK AVE, NE, GRAND RAPIDS, MI 49503	RESEARCH LAB SERVICES	493,453.
CAVAROCCHI RUSCIO DENNIS & ASSOCIATES, 600 MARYLAND AVE SW, SUITE 220 EAST,	GOVERNMENT RELATIONS	117,714.

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 3

SEE PART VII, SECTION A CONTINUATION SHEETS

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**Part 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 (check all that apply)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(27) JESSICA KREPTING BOARD MEMBER	2.00	X						0.	0.	0.
(28) DARCY KRUEGER BOARD MEMBER	2.00	X						0.	0.	0.
(29) PATROSKI LAWSON BOARD MEMBER	2.00	X						0.	0.	0.
(30) KRISTI LENGYEL BOARD MEMBER	2.00	X						0.	0.	0.
(31) HEATHER LENS BOARD MEMBER	2.00	X						0.	0.	0.
(32) LAURA MARKS BOARD MEMBER	2.00	X						0.	0.	0.
(33) DIANE MCSWAIN BOARD MEMBER	2.00	X						0.	0.	0.
(34) MUSTAFA SAHIN BOARD MEMBER	2.00	X						0.	0.	0.
(35) SEAN SHILLINGER BOARD MEMBER	2.00	X						0.	0.	0.
(36) VANESSA VAZQUEZ BOARD MEMBER	2.00	X						0.	0.	0.
(37) TARA ZIMMERMAN BOARD MEMBER	2.00	X						0.	0.	0.
Total to Part VII, Section A, line 1c .....										

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**Part VIII Statement of Revenue**

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

			(A)	(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>	40,093.				
	<b>b</b> Membership dues .....	<b>1b</b>	1,100.				
	<b>c</b> Fundraising events .....	<b>1c</b>	1,179,453.				
	<b>d</b> Related organizations .....	<b>1d</b>	572,625.				
	<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>	4,954,677.				
	<b>g</b> Noncash contributions included in lines 1a-1f .....	<b>1g</b>	\$				
	<b>h Total.</b> Add lines 1a-1f .....			6,747,948.			
Program Service Revenue	<b>2 a</b> CONTRACT REVENUE	<b>Business Code</b>					
		900099	2,548,976.	2,548,976.			
	<b>b</b> CONFERENCE REVENUE	900099	266,377.	72,377.		194,000.	
	<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 .....			2,815,353.				
Other Revenue	<b>3</b> Investment income (including dividends, interest, and other similar amounts) .....		36,732.			36,732.	
	<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				
			(ii) Other				
	<b>b</b> Less: cost or other basis and sales expenses .....	<b>7b</b>					
	<b>c</b> Gain or (loss) .....	<b>7c</b>					
	<b>d</b> Net gain or (loss) .....						
<b>8 a</b> Gross income from fundraising events (not including \$ 1,179,453. of contributions reported on line 1c). See Part IV, line 18 .....	<b>8a</b>		258,687.				
			164,132.				
<b>b</b> Less: direct expenses .....	<b>8b</b>						
<b>c</b> Net income or (loss) from fundraising events .....			94,555.		94,555.		
<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 IN INTEREST OF AFFILIATE	<b>Business Code</b>					
		900099	320,800.			320,800.	
	<b>b</b> .....						
	<b>c</b> .....						
	<b>d</b> All other revenue .....	900099	995.			995.	
<b>e Total.</b> Add lines 11a-11d .....			321,795.				
<b>12 Total revenue.</b> See instructions .....			10,016,383.	2,621,353.	0.	647,082.	

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**Part IX Statement of Functional Expenses**

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
<b>1</b> Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 ...	696,542.	696,542.		
<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 .....	148,750.	148,750.		
<b>4</b> Benefits paid to or for members .....				
<b>5</b> Compensation of current officers, directors, trustees, and key employees .....	703,405.	439,278.	102,064.	162,063.
<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 .....	1,867,712.	1,166,420.	271,060.	430,232.
<b>8</b> Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	52,530.	33,680.	5,461.	13,389.
<b>9</b> Other employee benefits .....	222,386.	142,119.	24,273.	55,994.
<b>10</b> Payroll taxes .....	178,343.	113,532.	20,556.	44,255.
<b>11</b> Fees for services (nonemployees):				
<b>a</b> Management .....				
<b>b</b> Legal .....	17,690.	11,342.	2,750.	3,598.
<b>c</b> Accounting .....	23,250.	14,907.	3,614.	4,729.
<b>d</b> Lobbying .....	116,364.	74,606.	18,090.	23,668.
<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.)	219,360.	140,642.	34,102.	44,616.
<b>12</b> Advertising and promotion .....	8,473.	5,492.	9.	2,972.
<b>13</b> Office expenses .....	328,107.	172,198.	9,714.	146,195.
<b>14</b> Information technology .....	161,819.	80,801.	15,642.	65,376.
<b>15</b> Royalties .....				
<b>16</b> Occupancy .....	144,753.	91,950.	16,592.	36,211.
<b>17</b> Travel .....	352,743.	294,269.	5,315.	53,159.
<b>18</b> Payments of travel or entertainment expenses for any federal, state, or local public officials ...				
<b>19</b> Conferences, conventions, and meetings .....	447,239.	404,633.	7,811.	34,795.
<b>20</b> Interest .....				
<b>21</b> Payments to affiliates .....				
<b>22</b> Depreciation, depletion, and amortization .....	69,312.	52,790.	5,255.	11,267.
<b>23</b> Insurance .....	13,070.	8,319.	1,511.	3,240.
<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>	2,321,442.	2,321,442.		
<b>b</b> <b>NHD BIOSAMPLE REPOSIT</b>	328,386.	328,386.		
<b>c</b> <b>DUES AND SUBSCRIPTIONS</b>	39,981.	13,730.	12,520.	13,731.
<b>d</b> _____				
<b>e</b> All other expenses _____	5,991.	3,565.	1,625.	801.
<b>25</b> <b>Total functional expenses.</b> Add lines 1 through 24e	8,467,648.	6,759,393.	557,964.	1,150,291.
<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 type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

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**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year	
<b>Assets</b>	<b>1</b> Cash - non-interest-bearing .....	1,711,209.	<b>1</b>	1,487,710.	
	<b>2</b> Savings and temporary cash investments .....	694,859.	<b>2</b>	700,650.	
	<b>3</b> Pledges and grants receivable, net .....	5,280,316.	<b>3</b>	4,306,013.	
	<b>4</b> Accounts receivable, net .....	181,490.	<b>4</b>	350,534.	
	<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 .....	277,696.	<b>9</b>	283,821.	
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....	<b>10a</b> 811,270.			
	<b>b</b> Less: accumulated depreciation .....	<b>10b</b> 417,309.	463,272.	<b>10c</b>	393,961.
	<b>11</b> Investments - publicly traded securities .....		<b>11</b>	1,752,986.	
	<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 .....	6,219,095.	<b>15</b>	6,810,093.	
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33) .....	14,827,937.	<b>16</b>	16,085,768.		
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses .....	891,501.	<b>17</b>	813,246.	
	<b>18</b> Grants payable .....		<b>18</b>		
	<b>19</b> Deferred revenue .....	285,264.	<b>19</b>	189,493.	
	<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 .....	1,196,326.	<b>25</b>	1,085,681.	
	<b>26 Total liabilities.</b> Add lines 17 through 25 .....	2,373,091.	<b>26</b>	2,088,420.	
<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 .....	5,151,339.	<b>27</b>	6,372,958.	
	<b>28</b> Net assets with donor restrictions .....	7,303,507.	<b>28</b>	7,624,390.	
	<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 .....	12,454,846.	<b>32</b>	13,997,348.	
<b>33</b> Total liabilities and net assets/fund balances .....	14,827,937.	<b>33</b>	16,085,768.		

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**Part XI Reconciliation of Net Assets**

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

<b>1</b>	Total revenue (must equal Part VIII, column (A), line 12)	<b>1</b>	10,016,383.
<b>2</b>	Total expenses (must equal Part IX, column (A), line 25)	<b>2</b>	8,467,648.
<b>3</b>	Revenue less expenses. Subtract line 2 from line 1	<b>3</b>	1,548,735.
<b>4</b>	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	<b>4</b>	12,454,846.
<b>5</b>	Net unrealized gains (losses) on investments	<b>5</b>	-6,233.
<b>6</b>	Donated services and use of facilities	<b>6</b>	
<b>7</b>	Investment expenses	<b>7</b>	
<b>8</b>	Prior period adjustments	<b>8</b>	
<b>9</b>	Other changes in net assets or fund balances (explain on Schedule O)	<b>9</b>	0.
<b>10</b>	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	<b>10</b>	13,997,348.

**Part XII Financial Statements and Reporting**

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

		Yes	No
<b>1</b>	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
<b>2a</b>	Were the organization's financial statements compiled or reviewed by an independent accountant? _____ If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		<b>X</b>
<b>b</b>	Were the organization's financial statements audited by an independent accountant? _____ If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input checked="" type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	<b>X</b>	
<b>c</b>	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? _____ If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	<b>X</b>	
<b>3a</b>	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F? _____		<b>X</b>
<b>b</b>	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits _____		

Form **990** (2023)

**SCHEDULE A  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.  
Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

**2023**

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

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

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

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

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

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

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

**Section A. Public Support**

Calendar year (or fiscal year beginning in)	(a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....	5527543.	4345011.	5769053.	7016851.	6496698.	29155156.
<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 .....	5527543.	4345011.	5769053.	7016851.	6496698.	29155156.
<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) .....						4732702.
<b>6 Public support.</b> Subtract line 5 from line 4.						24422454.

**Section B. Total Support**

Calendar year (or fiscal year beginning in)	(a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total
<b>7</b> Amounts from line 4 .....	5527543.	4345011.	5769053.	7016851.	6496698.	29155156.
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....	27,444.	11,188.	3,809.	2,382.	36,732.	81,555.
<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.) .....	714.			15,492.	995.	17,201.
<b>11 Total support.</b> Add lines 7 through 10						29253912.
<b>12</b> Gross receipts from related activities, etc. (see instructions) .....					12	10,557,404.
<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 2023 (line 6, column (f), divided by line 11, column (f)) .....	<b>14</b>	83.48	%
<b>15</b> Public support percentage from 2022 Schedule A, Part II, line 14 .....	<b>15</b>	82.01	%
<b>16a 33 1/3% support test - 2023.</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 - 2022.</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 - 2023.</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 - 2022.</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"/>

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

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) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 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						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
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						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						

14 First 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

15 Public support percentage for 2023 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2022 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2023 (line 10c, column (f), divided by line 13, column (f))	17	%
18 Investment income percentage from 2022 Schedule A, Part III, line 17	18	%

19a 33 1/3% support tests - 2023. 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 - 2022. 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



**NATIONAL TUBEROUS SCLEROSIS  
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**Part IV Supporting Organizations**

(Complete only if you checked a box on line 12 of 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>		

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**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>			

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

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

<b>Section A - Adjusted Net Income</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b>	Net short-term capital gain	<b>1</b>	
<b>2</b>	Recoveries of prior-year distributions	<b>2</b>	
<b>3</b>	Other gross income (see instructions)	<b>3</b>	
<b>4</b>	Add lines 1 through 3.	<b>4</b>	
<b>5</b>	Depreciation and depletion	<b>5</b>	
<b>6</b>	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	<b>6</b>	
<b>7</b>	Other expenses (see instructions)	<b>7</b>	
<b>8</b>	<b>Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4)	<b>8</b>	

<b>Section B - Minimum Asset Amount</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b>	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
<b>a</b>	Average monthly value of securities	<b>1a</b>	
<b>b</b>	Average monthly cash balances	<b>1b</b>	
<b>c</b>	Fair market value of other non-exempt-use assets	<b>1c</b>	
<b>d</b>	<b>Total</b> (add lines 1a, 1b, and 1c)	<b>1d</b>	
<b>e</b>	<b>Discount</b> claimed for blockage or other factors ( <i>explain in detail in Part VI</i> ):		
<b>2</b>	Acquisition indebtedness applicable to non-exempt-use assets	<b>2</b>	
<b>3</b>	Subtract line 2 from line 1d.	<b>3</b>	
<b>4</b>	Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).	<b>4</b>	
<b>5</b>	Net value of non-exempt-use assets (subtract line 4 from line 3)	<b>5</b>	
<b>6</b>	Multiply line 5 by 0.035.	<b>6</b>	
<b>7</b>	Recoveries of prior-year distributions	<b>7</b>	
<b>8</b>	<b>Minimum Asset Amount</b> (add line 7 to line 6)	<b>8</b>	

<b>Section C - Distributable Amount</b>		(A) Prior Year	(B) Current Year
<b>1</b>	Adjusted net income for prior year (from Section A, line 8, column A)		Current Year
<b>2</b>	Enter 0.85 of line 1.		
<b>3</b>	Minimum asset amount for prior year (from Section B, line 8, column A)		
<b>4</b>	Enter greater of line 2 or line 3.		
<b>5</b>	Income tax imposed in prior year		
<b>6</b>	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).		
<b>7</b>	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).		

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Schedule A (Form 990) 2023

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**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 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 2023 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-2023	(iii) Distributable Amount for 2023
<b>1</b> Distributable amount for 2023 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2023 (reasonable cause required - <i>explain in Part VI</i> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2023			
<b>a</b> From 2018			
<b>b</b> From 2019			
<b>c</b> From 2020			
<b>d</b> From 2021			
<b>e</b> From 2022			
<b>f Total</b> of lines 3a through 3e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2023 distributable amount			
<b>i</b> Carryover from 2018 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
<b>4</b> Distributions for 2023 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2023 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from line 4.			
<b>5</b> Remaining underdistributions for years prior to 2023, 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 2023. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
<b>7 Excess distributions carryover to 2024.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a</b> Excess from 2019			
<b>b</b> Excess from 2020			
<b>c</b> Excess from 2021			
<b>d</b> Excess from 2022			
<b>e</b> Excess from 2023			

Schedule A (Form 990) 2023

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

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.)

Horizontal lines for supplemental information input.

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

Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

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

OMB No. 1545-0047

**2023**

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

For Paperwork Reduction Act Notice, see the instructions for Form 990, 990-EZ, or 990-PF.

Schedule B (Form 990) (2023)

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

**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
1		\$ 1,397,860.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2		\$ 964,244.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3		\$ 266,250.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
4		\$ 185,802.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
5		\$ 182,611.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
6		\$ 180,213.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization <b>NATIONAL TUBEROUS SCLEROSIS ASSOCIATION</b>	Employer identification number 95-3018799
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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	_____ _____ _____	\$ 572,625.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
8	_____ _____ _____	\$ 145,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (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 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>
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**Part III** Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this info. once.) \$ \_\_\_\_\_  
Use duplicate copies of Part III if additional space is needed.

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

(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

**2023**

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

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

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

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

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

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

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

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

Schedule C (Form 990) 2023

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

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

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

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)	(a) Filing organization's totals	(b) Affiliated group totals												
<b>1a</b> Total lobbying expenditures to influence public opinion (grassroots lobbying) .....	1,345.													
<b>b</b> Total lobbying expenditures to influence a legislative body (direct lobbying) .....	187,396.													
<b>c</b> Total lobbying expenditures (add lines 1a and 1b) .....	188,741.													
<b>d</b> Other exempt purpose expenditures .....	7,128,616.													
<b>e</b> Total exempt purpose expenditures (add lines 1c and 1d) .....	7,317,357.													
<b>f</b> Lobbying nontaxable amount. Enter the amount from the following table in both columns.	515,868.													
<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 30%;">If the amount on line 1e, column (a) or (b) is:</th> <th style="width: 70%;">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) .....	128,967.													
<b>h</b> Subtract line 1g from line 1a. If zero or less, enter -0- .....	0.													
<b>i</b> Subtract line 1f from line 1c. If zero or less, enter -0- .....	0.													
<b>j</b> If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year? .....		<input type="checkbox"/> Yes <input type="checkbox"/> No												

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

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) Total
<b>2a</b> Lobbying nontaxable amount	423,685.	497,465.	550,968.	515,868.	1,987,986.
<b>b</b> Lobbying ceiling amount (150% of line 2a, column(e))					2,981,979.
<b>c</b> Total lobbying expenditures	123,014.	154,139.	162,771.	188,741.	628,665.
<b>d</b> Grassroots nontaxable amount	105,921.	124,366.	137,742.	128,967.	496,996.
<b>e</b> Grassroots ceiling amount (150% of line 2d, column (e))					745,494.
<b>f</b> Grassroots lobbying expenditures	895.	1,127.	1,395.	1,345.	4,762.

NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION

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

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

2023

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

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

Table with 2 columns: Held at the End of the Tax Year. Rows include: 1 Purpose(s) of conservation easements held by the organization (check all that apply), 2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year, 3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year, 4 Number of states where property subject to conservation easement is located, 5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?, 6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year, 7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year, 8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?, 9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

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

Table with 2 columns: Revenue, Assets. Rows include: 1a If the organization elected, as permitted under 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. 1b 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

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule D (Form 990) 2023

**NATIONAL TUBEROUS SCLEROSIS ASSOCIATION**

**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 <input type="checkbox"/> Public exhibition                   | d <input type="checkbox"/> Loan or exchange program |
| b <input type="checkbox"/> Scholarly research                  | e <input type="checkbox"/> Other _____              |
| c <input type="checkbox"/> Preservation for future generations |   |
- 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 in Part XIII

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	5,500,387.	6,711,748.	5,893,521.	5,915,805.	5,193,934.
b Contributions	141,816.	68,423.	132,476.	54,645.	78,962.
c Net investment earnings, gains, and losses	812,509.	-860,036.	1,053,588.	416,431.	959,121.
d Grants or scholarships					
e Other expenditures for facilities and programs	572,625.	238,000.	333,813.	463,721.	288,356.
f Administrative expenses	60,900.	181,748.	34,024.	29,639.	27,856.
g End of year balance	5,821,187.	5,500,387.	6,711,748.	5,893,521.	5,915,805.

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment 83.6060 %
- b Permanent endowment 15.7890 %
- c Term endowment .6050 %
- 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? | X   |    |
- 4 Describe in Part XIII the intended uses of the organization's endowment funds.

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

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements		449,272.	153,160.	296,112.
d Equipment		281,726.	183,877.	97,849.
e Other		80,272.	80,272.	0.
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B))				393,961.

**NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION**

**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, line 12, col. (B))		

**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, line 13, col. (B))		

**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) <b>NET ASSETS OF AFFILIATE</b>	5,821,187.
(2) <b>OPERATING LEASE RIGHT-OF-USE ASSET</b>	654,282.
(3) <b>DUE FROM AFFILIATE</b>	334,624.
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, line 15, col. (B))	6,810,093.

**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) <b>OPERATING LEASE LIABILITY</b>	1,084,988.
(3) <b>DUE FROM RELATED PARTY</b>	693.
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, line 25, col. (B))	1,085,681.

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 ...



NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION

Schedule D (Form 990) 2023

95-3018799 Page 4

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

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

1	Total revenue, gains, and other support per audited financial statements		1	10,024,868.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	-6,233.	
b	Donated services and use of facilities	2b	14,718.	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d	2e		8,485.
3	Subtract line 2e from line 1	3		10,016,383.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c		0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5		10,016,383.

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

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

1	Total expenses and losses per audited financial statements		1	8,482,366.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	14,718.	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d	2e		14,718.
3	Subtract line 2e from line 1	3		8,467,648.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c		0.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)	5		8,467,648.

**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 ENDOWMENTS INCLUDE ONE TRADITIONAL DONOR-RESTRICTED ENOWMENT FUND AND ONE BOARD-DESIGNATED ENDOWMENT FUND. THE BOARD-DESIGNATED ENDOWMENT FUND SOLELY CONSISTS OF THE ENDOWMENT FUND'S UNRESTRICTED NET ASSET BALANCE.

**PART XII, LINE 2D - OTHER ADJUSTMENTS:**

ROUNDING

**PART XII, LINE 4B - OTHER ADJUSTMENTS:**

FUNDRAISING EXPENSES INCLUDED ON PART VIII



SCHEDULE F (Form 990)

Statement of Activities Outside the United States

OMB No. 1545-0047

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

2023

Open to Public Inspection

Department of the Treasury Internal Revenue Service

Attach to Form 990.

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

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

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

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

Table with 6 columns: (a) Region, (b) Number of offices, (c) Number of employees, (d) Activities conducted, (e) If activity is a program service, (f) Total expenditures. Includes subtotal and totals rows.

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

Schedule F (Form 990) 2023

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

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

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA,	RESEARCH ON TUBEROUS SCLEROSIS COMPLEX	18,750.	WIRE TRANSFER	0.		
		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA,	RESEARCH ON TUBEROUS SCLEROSIS COMPLEX	75,000.	WIRE TRANSFER	0.		
		MIDDLE EAST AND NORTH AFRICA - ALGERIA, SAUDI ARABIA, DJIBOUTI, EGYPT,	RESEARCH	8,500.	WIRE TRANSFER	0.		
		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA,	YOUNG INVESTIGATOR FELLOWSHIP AWARD	27,500.	WIRE TRANSFER	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 ..... 4

NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION

**Part III** Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)

NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION

**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 the 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 the 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 the 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 the 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 the 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 the Instructions for Form 5713; don't file with Form 990)* .....  Yes  No

NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION

**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.

**SCHEDULE G  
(Form 990)**

Department of the Treasury  
Internal Revenue Service

**Supplemental Information Regarding Fundraising or Gaming Activities**

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

Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

**2023**

Open to Public  
Inspection

Name of the organization **NATIONAL TUBEROUS SCLEROSIS ASSOCIATION**

Employer identification number  
**95-3018799**

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

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

- |  |   |
|--|---|
| <b>a</b> <input type="checkbox"/> Mail solicitations               | <b>e</b> <input type="checkbox"/> Solicitation of non-government grants |
| <b>b</b> <input type="checkbox"/> Internet and email solicitations | <b>f</b> <input type="checkbox"/> Solicitation of government grants     |
| <b>c</b> <input type="checkbox"/> Phone solicitations              | <b>g</b> <input type="checkbox"/> Special fundraising events            |
| <b>d</b> <input type="checkbox"/> In-person solicitations          |   |

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

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

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
<b>Total</b> .....						

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

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



**NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION**

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

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events (add col. (a) through col. (c))
		WALK-RUN-RIDE EVENTS	COMEDY FOR A CURE	8	
	Revenue	(event type)	(event type)	(total number)	
1	Gross receipts .....	789,897.	464,844.	183,399.	1,438,140.
2	Less: Contributions .....	789,897.	389,556.		1,179,453.
3	Gross income (line 1 minus line 2) .....		75,288.	183,399.	258,687.
<b>Direct Expenses</b>					
4	Cash prizes .....				
5	Noncash prizes .....	44,986.	1,128.	2,478.	48,592.
6	Rent/facility costs .....	6,147.	28,633.	8,699.	43,479.
7	Food and beverages .....	8,314.	44,988.		53,302.
8	Entertainment .....	12,797.	2,969.		15,766.
9	Other direct expenses .....			2,993.	2,993.
10	Direct expense summary. Add lines 4 through 9 in column (d) .....				164,132.
11	Net income summary. Subtract line 10 from line 3, column (d) .....				94,555.

**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))
1	Gross revenue .....				
<b>Direct Expenses</b>					
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: \_\_\_\_\_

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

- 11 Does the organization conduct gaming activities with nonmembers?
12 Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity formed to administer charitable gaming?
13 Indicate the percentage of gaming activity conducted in:
14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Table with 2 columns: Label (13a, 13b) and Percentage (%).

Name \_\_\_\_\_

Address \_\_\_\_\_

- 15a Does the organization have a contract with a third party from whom the organization receives gaming revenue?
b If "Yes," enter the amount of gaming revenue received by the organization
c If "Yes," enter name and address of the third party:

Name \_\_\_\_\_

Address \_\_\_\_\_

16 Gaming manager information:

Name \_\_\_\_\_

Gaming manager compensation \$ \_\_\_\_\_

Description of services provided \_\_\_\_\_

- Director/officer Employee Independent contractor

17 Mandatory distributions:

- a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?
b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year

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

Multiple horizontal lines for providing supplemental information.

NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION

Schedule G (Form 990)

95-3018799 Page 4

**Part IV** Supplemental Information *(continued)*

[Lined area for supplemental information entry]

**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

**2023**

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
BAYLOR COLLEGE OF MEDICINE PO BOX 301207 DALLAS, TX 70690	74-1613878	501(C)(3)	18,750.	0.			RESEARCH GRANT
BRIGHAM & WOMEN'S HOSPITAL P.O.B 3149 BOSTON, MA 02241	04-2312909	501(C)(3)	56,250.	0.			RESEARCH GRANT
UNIVERSITY OF VIRGINIA 1001 N. EMMET ST CHARLOTTESVILLE, VA 22903	54-6001796	501(C)(3)	18,750.	0.			RESEARCH GRANT
NATIONAL ORGANIZATION FOR RARE DISORDERS - DEPT 5430, PO BOX 4110 - WOBURN, MA 01888	13-3223946	501(C)(3)	125,000.	0.			TSC TRAVEL AND LODGING ASSISTANCE PROGRAM
UNIVERSITY OF CALIFORNIA 10889 WILSHIRE BLVD, SUITE 700 LOS ANGELES, CA 90095	95-6006143	501(C)(3)	20,000.	0.			RESEARCH GRANT
COLUMBIA UNIVERSITY IN THE CITY OF NEW YORK - 615 W. 131ST STREET, 6TH FLOOR, MAIL CODE 8725 - NEW YORK, NY 10027	13-5598093	501(C)(3)	75,000.	0.			RESEARCH GRANT

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

**3** Enter total number of other organizations listed in the line 1 table 0.

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

Schedule I (Form 990) 2023

**NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION**

Schedule I (Form 990)

95-3018799

Page 1

**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
UNIVERSITY OF CALIFORNIA IRVINE 228 ALDRICH HALL IRVINE, CA 92697	95-2226406	501(C)(3)	18,750.	0.			RESEARCH GRANT
UNIVERSITY OF MARYLAND, BALTIMORE PO BOX 41428 BALTIMORE, MD 21203	52-6002033	501(C)(3)	56,250.	0.			RESEARCH GRANT
UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER - 5323 HARRY HINES BLVD - DALLAS, TX 75390	75-6002868	501(C)(3)	56,250.	0.			RESEARCH GRANT
UNIVERSITY OF TEXAS DALLAS 800 WEST CAMPBELL ROAD, SP2 27 RICHARDSON, TX 75080	75-1305566	501(C)(3)	18,750.	0.			RESEARCH GRANT
UNIVERSITY OF ALABAMA, BIRMINGHAM 1720 2ND AVE SOUTH, AB990 BIRMINGHAM, AL 32294	63-6005396	501(C)(3)	91,649.	0.			RESEARCH GRANT
UNIVERSITY OF NEW ENGLAND 11 HILLS BEACH RD, ROOM 207 BIDDEFORD, ME 04005	01-0211810	501(C)(3)	20,000.	0.			RESEARCH GRANT
BOSTON CHILDREN'S HOSPITAL PO BOX 414413 BOSTON, MA 02241	04-2774441	501(C)(3)	57,409.	0.			RESEARCH GRANT

Schedule I (Form 990)

NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION

**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 \$37 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 MERITS, 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

**2023**

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 ..... **1b**

**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? ..... **2**

**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? ..... **4a**
- b** Participate in or receive payment from a supplemental nonqualified retirement plan? ..... **4b**
- c** Participate in or receive payment from an equity-based compensation arrangement? ..... **4c**
- 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? ..... **5a**
- b** Any related organization? ..... **5b**
- 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? ..... **6a**
- b** Any related organization? ..... **6b**
- 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 ..... **7**

**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 ..... **8**

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

	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>		

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

Schedule J (Form 990) 2023



NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION

95-3018799

Schedule J (Form 990) 2023

**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 ROBERDS CHIEF SCIENTIFIC OFFICER	(i)	214,711.	22,497.	0.	7,291.	19,272.	263,771.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(2) KARI LUTHER ROSBECK PRESIDENT & CEO	(i)	201,924.	21,822.	0.	7,012.	22,405.	253,163.	0.
	(ii)	2,040.	220.	0.	0.	0.	2,260.	0.
(3) DEAN RAGER-AGUIAR VICE PRESIDENT, TRANSLATIONAL RESEAR	(i)	159,369.	18,356.	0.	5,660.	22,431.	205,816.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(4) CYNTHIA ARCURI CHIEF FINANCIAL OFFICER	(i)	161,389.	15,600.	0.	5,588.	3,894.	186,471.	0.
	(ii)	8,494.	821.	0.	0.	0.	9,315.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							

NATIONAL TUBEROUS SCLEROSIS  
ASSOCIATION

**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, STEVE ROBERDS, CYNTHIA ARCURI, DEAN AGUIAR, JAYE  
ISHAM, LISA MOSS, AND ASHLEY POUNDERS ALL HAVE INCENTIVE COMPENSATION EQUAL  
TO A PERCENTAGE OF THEIR SALARIES BASED ON KEY PERFORMANCE OBJECTIVES AS  
ESTABLISHED BY THEIR COMPENSATION COMMITTEE.

PART I, LINE 6:

KARI LUTHER ROSBECK, STEVE ROBERDS, CYNTHIA ARCURI, DEAN AGUIAR, JAYE  
ISHAM, LISA MOSS, AND ASHLEY POUNDERS ALL HAVE INCENTIVE COMPENSATION EQUAL  
TO A PERCENTAGE OF THEIR SALARIES BASED ON KEY PERFORMANCE OBJECTIVES AS  
ESTABLISHED BY THEIR COMPENSATION COMMITTEE.

**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

**2023**

Open to Public  
Inspection

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**FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:**  
**TREATMENTS, DRIVING RESEARCH TOWARD A CURE AND EXPANDING ACCESS TO  
LIFELONG SUPPORT.**

**FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:**  
**RESEARCH GRANTS AND POSTDOCTORAL FELLOWSHIPS, \$5.3 MILLION INTO THE  
NATURAL HISTORY DATABASE AND BIOSAMPLE REPOSITORY, \$9.6 MILLION INTO  
THE PRECLINICAL CONSORTIUM, AND \$1.6 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.**

**IN 2023, THE TSC ALLIANCE HOSTED OUR BIENNIAL INTERNATIONAL TSC  
RESEARCH CONFERENCE: FUELING THE FUTURE. FIFTEEN PERCENT OF ATTENDEES  
SELF-IDENTIFIED AS MEMBERS OF GROUPS HISTORICALLY UNDERREPRESENTED IN**

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

Schedule O (Form 990) 2023

LHA 332211 11-14-23

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BIOMEDICAL RESEARCH. THE CONFERENCE FEATURED AN EARLY CAREER RESEARCH SYMPOSIUM, A KEYNOTE SPEECH FROM DR. MARTINA BEBIN, 30 ORAL PRESENTATIONS, 59 POSTERS, A TSC INTERNATIONAL WORKSHOP, AND A COMBINED CLOSING SESSION WITH TSC & LAM REGIONAL CONFERENCE PARTICIPANTS. THE CONFERENCE ALSO FEATURED FOUR BREAKOUT WORKING GROUP SESSIONS (TRANSITION FROM PEDIATRIC TO ADULT, NEURODEVELOPMENT AND EARLY INTERVENTION, CELLULAR ENERGETICS AND METABOLISM, AND BIG DATA AND SINGLE CELL APPROACHES/ANALYSIS) TO ALLOW TIME FOR ATTENDEES TO MEET WITH OTHERS IN THEIR FIELD AND WORK TOWARD SOLUTIONS FOR CURRENT ISSUES IN THEIR AREA.

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 HIS/HER 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 2023, 2,678 PEOPLE WITH TSC WERE ENROLLED IN THE PROJECT FROM AMONG 22 TSC CLINIC 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

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

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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, 2023, THE TSC BIOSAMPLE REPOSITORY HAS ACQUIRED 2,654 BIOSAMPLES: 1012 BLOOD SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 452 BUCCAL SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 197 TISSUE SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 591 BLOOD SAMPLES FROM THE TSC CLINICAL RESEARCH CONSORTIUM COLLABORATIVE PROJECTS, 389 DNA SAMPLES FROM THE TSC AUTISM CENTER OF EXCELLENCE NETWORK AUTISM BIOMARKER STUDY, AND 10 CONTROL SAMPLES.

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 473 BLOOD SAMPLES VIA MOBILE PHLEBOTOMY. TO ENCOURAGE AND ENABLE MORE RESEARCHERS TO UTILIZE BIOSAMPLES, THE TSC ALLIANCE AWARDED

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THREE SEED GRANTS IN 2023, TOTALING \$60,000, TO LABS THAT SUBMITTED  
MERITORIOUS AND INNOVATIVE IDEAS FOR RESEARCH ON TSC BIOSAMPLES.

THE TSC ALLIANCE'S WHOLE-GENOME SEQUENCING (WGS) INITIATIVE USING DNA  
FROM BLOOD SAMPLES IN OUR BIOSAMPLE REPOSITORY SEQUENCED AN ADDITIONAL  
72 SAMPLES IN 2023, TOTALING 115 SAMPLES SINCE INCEPTION. THIS  
INITIATIVE SUPPORTS CLINICAL VALIDATION OF VARIANTS FOUND VIA WGS IN  
EITHER THE TSC1 OR TSC2 GENE, AND GENETIC RESULTS ARE OFFERED BACK TO  
PARTICIPANTS ALONG WITH A GENETIC COUNSELING SESSION FREE OF CHARGE TO  
THE FAMILY TO HELP THEM BETTER UNDERSTAND THEIR UNIQUE TSC DIAGNOSIS  
AND PROVIDE VALUABLE INFORMATION FOR FUTURE DECISION MAKING SUCH AS  
FAMILY PLANNING.

IN DECEMBER 2021, THE TSC ALLIANCE ADDED THE TSC SELF-REPORT PORTAL TO  
THE TSC NATURAL HISTORY DATABASE. THIS PORTAL PERMITS 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

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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). AT THE END OF 2023, 105 INDIVIDUALS WERE ENROLLED THROUGH THE SELF-REPORT PORTAL.

THE TSC ALLIANCE LAUNCHED THE TSC PRECLINICAL CONSORTIUM IN 2015 TO HELP ADVANCE MORE DRUG CANDIDATES INTO CLINICAL TESTING. TO ACHIEVE THIS END, THE PRECLINICAL CONSORTIUM PROVIDES THE INFRASTRUCTURE TO FOSTER COLLABORATION BETWEEN ACADEMIA AND PHARMACEUTICAL INDUSTRY RESEARCHERS AND FOR ACCESS TO RESOURCES DESIGNED TO HELP FACILITATE DRUG DEVELOPMENT IN TSC. COLLABORATING WITH THE TSC COMMUNITY, THE CONSORTIUM HAS IDENTIFIED AND IMPLEMENTED ROBUST AND REPRODUCIBLE CELL AND ANIMAL MODELS FOR TSC MANIFESTATIONS INCLUDING TUMORS, EPILEPSY, AND TAND. IN 2022, THE TSC ALLIANCE ENTERED INTO A PARTNERSHIP WITH THE LAM FOUNDATION TO ADD LAM MOUSE MODELS TO THE PRECLINICAL CONSORTIUM. 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 F L7-CRE-TSC2 MICE ON BEHALF OF THE PRECLINICAL CONSORTIUM.

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FORM 990, PART III, LINE 4A, DESCRIPTION OF PROGRAM SERVICE:

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 FUNDS THE STUDY, THE DATA ARE SHARED WITH THE CONSORTIUM FOR TRANSPARENCY AND STIMULATION OF ADDITIONAL HYPOTHESES. A MEMBERS MEETING IS HELD ANNUALLY 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. IN 2023, TWO NEW INDUSTRY MEMBERS JOINED THE CONSORTIUM WITH A TOTAL OF 9 ACTIVE INDUSTRY MEMBERS AT THE END OF THE YEAR. THE CONSORTIUM HAS HAD 22 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. THE CONSORTIUM TESTED 17 UNIQUE COMPOUNDS IN 2023, RAISING THE TOTAL TESTED TO 82 SINCE 2016. MANY COMPOUNDS WILL ENTER PRECLINICAL TESTING, THOUGH ONLY SOME WILL ADVANCE TO CLINICAL TESTING DUE TO LACK OF EFFICACY AND SAFETY.



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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 \$40 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 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 WAS THE FIRST PREVENTATIVE TRIAL IN THE UNITED STATES FOR ANY FORM OF EPILEPSY. INITIAL RESULTS FROM THE STUDY WERE REPORTED THIS YEAR. IN THE PREVENT TRIAL, INFANTS WITH TSC RECEIVED REGULAR EEG MONITORING AND THOSE WHO DEVELOPED EEG ABNORMALITIES WERE PLACED ON EITHER VIGABATRIN (SUPPLIED BY LUNDBECK) OR A PLACEBO. ANY INFANT WHO SUBSEQUENTLY DEVELOPED CLINICAL SEIZURES WAS IMMEDIATELY PLACED ON STANDARD TREATMENT. RESULTS OF THE STUDY SHOWED THAT PREVENTATIVE TREATMENT WITH VIGABATRIN BEGINNING WHEN EEG BIOMARKER CHANGES WERE OBSERVED DELAYED THE ONSET AND LOWERED THE OVERALL OCCURRENCE OF INFANTILE SPASMS IN INFANTS WITH TSC. HOWEVER, THERE WAS NO SIGNIFICANT DIFFERENCE BETWEEN THE TREATMENT GROUP AND THE PLACEBO GROUP IN TERMS OF DRUG-RESISTANT EPILEPSY, FOCAL SEIZURES, OR COGNITIVE AND BEHAVIORAL OUTCOMES AT TWO YEARS OF AGE. IN THIS TRIAL, THE BIGGEST PREDICTOR OF POORER DEVELOPMENTAL OUTCOMES WAS THE AGE AT WHICH THE EEG BIOMARKER CHANGES OCCURRED: THOSE INFANTS WHOSE EEG CHANGES OCCURRED PRIOR TO SEVEN MONTHS OF AGE HAD, ON AVERAGE, LOWER COGNITIVE AND BEHAVIORAL SCORES THAN THOSE WHOSE EEG CHANGES OCCURRED

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LATER, REGARDLESS OF TREATMENT VIA VIGABATRIN VERSUS PLACEBO. THIS SUGGESTS THAT RAPID DIAGNOSIS OF TSC IN INFANTS, PRIOR TO HAVING ANY SEIZURES, FOLLOWED BY A CLOSE MONITORING AND RAPID INITIATION OF TREATMENT WHEN SEIZURES BEGIN IS CRITICAL FOR ENSURING THE BEST OUTCOMES POSSIBLE. 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 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

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TWO-YEAR CLINICAL RESEARCH TSC-DSC FELLOWSHIP TO FELIX CHAN, PHD, AT BROWN UNIVERSITY WHO MOVED IN 2022 TO ASTON UNIVERSITY IN BIRMINGHAM, ENGLAND.

FORM 990, PART III, LINE 4B, DESCRIPTION OF PROGRAM SERVICE:  
SUPPORT SERVICES IS DEDICATED TO SUPPORTING INDIVIDUALS AND FAMILIES AFFECTED BY TSC THROUGH OUTREACH PROGRAMS, SUPPORT SERVICES, IMPROVED MEDICAL ACCESS, AND EDUCATIONAL RESOURCES.

IN 2023, THE TSC ALLIANCE IMPLEMENTED A NEW COMMUNITY SUPPORT MODEL THAT PUTS THE TSC COMMUNITY CENTER FOCUSING ON LOCAL RESOURCES, SUPPORT SERVICES, AND ACCESS TO MEDICAL CARE IN CONJUNCTION WITH ENERGIZING THE CURRENT AND FUTURE VOLUNTEER LEADERS TO PROPEL THE TSC ALLIANCE TO THE NEXT LEVEL. THIS MODEL UNITED 36 COMMUNITY ALLIANCES AND ORGANIZED THEM INTO 15 COMMUNITY REGIONS, LED BY MORE THAN 150 DEDICATED LEADERS THROUGHOUT THE UNITED STATES.

THE COMMUNITY PROGRAMS TEAM INVESTED MORE THAN 900 TRAINING HOURS TO OUR LEADERS, TO ENSURE THEY WERE WELL EQUIPPED TO SUPPORT AND EMPOWER THE TSC COMMUNITY. AS A RESULT, WE PROVIDED 4,278 PEER-TO-PEER SUPPORT ENGAGEMENTS AND FACILITATED 50 SCHOOL MEETINGS, WHICH INVOLVED TSC 101 TRAINING AND IEP CONSULTATIONS. IN ADDITION, TWO "ASK AN ADVOCATE" WEBINARS ATTRACTED 94 REGISTRANTS.

THE COMMUNITY PROGRAMS TEAM COLLABORATED WITH KEY STAFF TO HOST SEVEN RESEARCH AND CORPORATE PARTNER WEBINARS. THESE WEBINARS ATTRACTED 312 LIVE ATTENDEES AND GARNERED 832 RECORDED VIEWS, WITH 801 LANDING PAGE

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VIEWS AS OF DECEMBER 31, 2023.

THE TSC ALLIANCE ALSO PARTNERED WITH THE LAM FOUNDATION TO CO-HOST FOUR EDUCATIONAL CONFERENCE SERIES HELD IN SEATTLE, WA; DENVER, CO; BIRMINGHAM, AL; WASHINGTON, DC. THESE CONFERENCES ATTRACTED 350-PLUS PARTICIPANTS.

THE TSC ALLIANCE'S TSC NAVIGATOR IS 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. IN 2023, THE TOOL HAD 2,379 USERS. EIGHT INDIVIDUALS OR FAMILIES WERE ALSO SUPPORTED FOR MEDICATION ACCESS ISSUES VIA OUR TSC NAVIGATOR PROGRAM DURING 2023, DOWN FROM 55 IN 2022, CONSISTENT WITH THE GOAL OF PROACTIVELY HELPING PEOPLE AVOID MEDICATION ACCESS ISSUES.

FORM 990, PART III, LINE 4C, DESCRIPTION OF PROGRAM SERVICE:

PUBLIC HEALTH EDUCATION INCREASES AWARENESS OF TSC THROUGHOUT THE GENERAL PUBLIC TO BROADEN THE SCOPE OF SUPPORT AND UNDERSTANDING BEYOND TSC INDIVIDUALS AND THEIR FAMILIES; THESE EFFORTS ALSO WORK TO HELP REACH THE UNDIAGNOSED AND NEWLY DIAGNOSED.

DURING 2023, THE TSC ALLIANCE PRODUCED TWO ISSUES OF ITS NATIONAL MAGAZINE, PERSPECTIVE, WHICH IS MAILED TO APPROXIMATELY 18,500 CONSTITUENTS AS WELL AS POSTED ON THE WEBSITE. THE TSC ALLIANCE'S

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PODCAST SERIES, CALLED TSC NOW, PRODUCED EIGHT EPISODES WITH 2,180  
TOTAL LISTENS. FIVE ISSUES OF THE ELECTRONIC TSC MATTERS NEWSLETTER  
WERE DISTRIBUTED TO 17,514 RECIPIENTS. THE TSC ALLIANCE'S WEBSITE  
INCREASES AWARENESS AND PROVIDES EXTENSIVE EDUCATION THROUGH A MONTHLY  
AVERAGE OF 26,916 PAGE VIEWS.

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 10,800 MEMBERS FROM AROUND THE  
WORLD, WHILE ITS TWITTER ACCOUNT HAS 2,684 FOLLOWERS AND INSTAGRAM HAS  
3,432 FOLLOWERS.

TO INCREASE PUBLIC AWARENESS, THE TSC ALLIANCE PARTICIPATED IN THE 11TH  
ANNUAL TSC GLOBAL AWARENESS DAY ON MAY 15 AS WELL AS TSC AWARENESS  
MONTH THROUGHOUT MAY. THE TSC ALLIANCE ALSO HEAVILY PROMOTED INFANTILE  
SPASMS AWARENESS WEEK (DECEMBER 1 TO 7). THESE AWARENESS CAMPAIGNS  
ALONG WITH THE ORGANIZATION'S VARIOUS NEWS RELEASES AND SOCIAL MEDIA  
OUTREACH EFFORTS CULMINATED IN MORE THAN 812 MILLION CUMULATIVE  
IMPRESSIONS AND ENGAGEMENTS.

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 ALABAMA, MISSOURI, AND MARYLAND, RESULTING IN AT LEAST \$1.25 MILLION IN STATE APPROPRIATIONS. THE ANNUAL TSC ALLIANCE MARCH ON CAPITOL HILL TO ADVOCATE FOR FEDERAL FUNDING FOR THE TUBEROUS SCLEROSIS COMPLEX RESEARCH PROGRAM (TSCRCP) AT THE DEPARTMENT OF DEFENSE'S (DOD) CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP) TOOK PLACE IN EARLY MARCH 2023. ADVOCATES MET WITH MORE THAN 322 CONGRESSIONAL OFFICES VIRTUALLY AND IN PERSON TO ASK FOR \$10 MILLION IN FUNDING FOR THE TSCRCP. THE HOUSE TSCRCP DEAR COLLEAGUE LETTER SPONSORED BY REPRESENTATIVES FITZPATRICK (R-PA) AND RASKIN (D-MD) CLOSED WITH 191 SIGNERS. THE SENATE LETTER SPONSORED BY SENATORS CRAMER (R-ND) AND HEINRICH (D-NM) CLOSED WITH 41 SIGNERS.

TOTAL FUNDING FOR THE TSCRCP HAS BEEN \$113 MILLION SINCE 2002, INCLUDING A \$10 MILLION APPROPRIATION FOR FY234. 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; TWO TSCRCP AWARDS IN FY2012 AND FY2015 THAT ENABLED GENERATION OF A POTENTIAL APPROACH FOR GENE THERAPY OF TSC, WHICH HAS SHOWN PROMISING RESULTS IN A MOUSE MODEL OF TSC TUMORS IN THE BRAIN; 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 THAT LED THE THIRD FDA-APPROVED DRUG TO TREAT TSC IN APRIL 2022; AND A CLINICAL RESEARCH NETWORK THAT WAS CREATED TO TEST POTENTIAL NEW THERAPIES, TO VALIDATE BIOMARKERS, AND TO LEARN THE NATURAL HISTORY OF LEADING TO A CLINICAL TRIAL FUNDED IN FY2012. DATA OBTAINED FROM AN FY2010 TSCRCP CLINICAL

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RESEARCH AWARD TO DEFINE EARLY AUTISM PREDICTORS IN TSC AND AN FY2014

TSCRIP 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 TSCRIP 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 TSCRIP-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 TSCRIP.

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 13 TSC CLINICS IN GLOBAL ALLIANCE COUNTRIES.

PROFESSIONAL EDUCATION EXPANDS PROGRAMS TO TARGET RESEARCHERS AND  
HEALTHCARE PROVIDERS CARING FOR INDIVIDUALS WITH TSC, MEDICAL STUDENTS,

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GENETIC COUNSELORS AND EDUCATORS TO MINIMIZE THE CONSEQUENCES OF IGNORANCE AND MISINFORMATION. THE TSC ALLIANCE EXHIBITED AT THE AMERICAN EPILEPSY SOCIETY ANNUAL MEETING. STAFF MEMBERS AND A VOLUNTEER SHARED EDUCATIONAL MATERIALS WITH ATTENDEES WHO VISITED THE BOOTH. STAFF ALSO PARTICIPATED IN THE TSC SPECIAL INTEREST GROUP SESSION, AND THE TSC ALLIANCE HOSTED MORE THAN 100 PEOPLE AT A RECEPTION WITH PRESENTATIONS BY PARENTS OF A CHILD WITH TSC AND BY DR. ANGELIQUE BORDEY, WHO DESCRIBED HOW TSC ALLIANCE HAS IMPACTED HER RESEARCH.

THE TSC ALLIANCE PARTICIPATED IN OR PRESENTED AT 26 PROFESSIONAL MEETINGS IN 2023 INCLUDING PRETOLA COURSE, RESEARCH AMERICA ANNUAL ADVOCACY AWARDS, WOMEN AT BRIDGE LEADERSHIP SPEAKING SERIES, INSITRO TOWN HALL, RARE DISEASE INNOVATION AND PARTNERING SUMMIT, ANYA'S ACCELERATOR WORKSHOP, NORD, TSC ALLIANCE MEXICO BRIEFING, EAN CONGRESSIONAL BRIEFING, ATS ANNUAL MEETING, INTERAGENCY COLLABORATIVE TO ADVANCE RESEARCH IN EPILEPSY (ICARE), RARE DISEASES INTERNATIONAL WORLD HEALTH ASSEMBLY, UCP ANNUAL CONFERENCE, MARINUS TOWN HALL, TANDEM MINI SYMPOSIUM, ETSC WORKSHOP, NINDS NONPROFIT FORUM, CRISIS INTERVENTION TRAINING INTERNATIONAL, TSCI WORKSHOP, TSC REPRODUCTIVE & PERINATAL TASK FORCE MEETING, LGS MEETING, GLOBAL GENES RARE SUMMIT, PCORI ANNUAL MEETING, APERTURA TOWN HALL, RDCRN FALL MEETING, AES, AND EAN BRIEFING.

EXPENSES \$ 287,855. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

FORM 990, PART VI, SECTION A, LINE 6:

MEMBERSHIP IN THE CORPORATION IS AVAILABLE TO ANY PERSON WHO SUBSCRIBES TO THE PURPOSES AND OBJECTIVES OF THE CORPORATION, WITHOUT REGARD TO RACE, RELIGION, GENDER, SEXUAL ORIENTATION, AGE, COLOR, NATIONAL ORIGIN, OR



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MENTAL OR PHYSICAL HANDICAP OR DISABILITY. THERE IS 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 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

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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 2023:  
BOARD MEMBER MUSTAFA SAHIN, PH.D., M.D., IS EMPLOYED AT BOSTON CHILDREN'S HOSPITAL, WHICH RECEIVED \$57,409 IN GRANTS AND \$6,300 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 \$3,420 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 \$91,649 IN GRANTS AND \$9,010 IN FEES FOR SERVICES FOR PARTICIPATION IN THE TSC NATURAL HISTORY DATABASE.

BOARD MEMBER AND IMMEDIATE PAST CHAIR PETER CRINO, MD, PHD, IS CHAIR OF THE DEPARTMENT OF NEUROLOGY AT THE UNIVERSITY OF MD, WHICH RECIEVED \$56,250 OF GRANT PAYMENTS."

FORM 990, PART VI, SECTION B, LINE 15:  
"THE COMPENSATION COMMITTEE REVIEWS AND APPROVES THE SALARIES OF THE PRESIDENT/CEO, CHIEF SCIENTIFIC OFFICER, CFO, AND ANY EMPLOYEE APPEARING

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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.

FORM 990, PART XII, LINE 2C:

THIS PROCESS HAS NOT CHANGED FROM THE PRIOR YEAR.

**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

**2023**

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

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**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

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**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	572,625.	ACTUAL CASH RECEIVED
(2)			
(3)			
(4)			
(5)			
(6)			

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ASSOCIATION

Schedule R (Form 990) 2023

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**Part VI Unrelated Organizations Taxable as a Partnership.** Complete if the organization answered "Yes" on Form 990, Part IV, line 37.

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

(a) Name, address, and EIN of entity	(b) Primary activity	(c) Legal domicile (state or foreign country)	(d) Predominant income (related, unrelated, excluded from tax under sections 512-514)	(e) Are all partners sec. 501(c)(3) orgs.?		(f) Share of total income	(g) Share of end-of-year assets	(h) Dispropor- tionate 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		Yes	No	

