

efile GRAPHIC print - DO NOT PROCESS

As Filed Data -

DLN: 93493104008530

Form 990

Return of Organization Exempt From Income Tax

OMB No 1545-0047

2019

Open to Public Inspection

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

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

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

Department of the Treasury
Internal Revenue Service

A For the 2019 calendar year, or tax year beginning 01-01-2019 , and ending 12-31-2019

B Check if applicable

☒ Address change

☐ Name change

☐ Initial return

☐ Final return/terminated

☐ Amended return

☐ Application pending

C Name of organization

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
INC

Doing business as
TUBEROUS SCLEROSIS ALLIANCE

Number and street (or P O box if mail is not delivered to street address) Room/suite
8737 COLESVILLE ROAD NO 400

City or town, state or province, country, and ZIP or foreign postal code
SILVER SPRING, MD 20910

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

H(a) Is this a group return for subordinates?

☐ Yes ☒ No

H(b) Are all subordinates included?

☐ Yes ☐ No

If "No," attach a list (see instructions)

H(c) Group exemption number ▶

D Employer identification number

95-3018799

E Telephone number

(301) 562-9890

G Gross receipts \$ 7,030,007

I Tax-exempt status

☒ 501(c)(3) ☐ 501(c) () ◀(insert no) ☐ 4947(a)(1) or ☐ 527

J Website: ▶ WWW TSALLIANCE ORG

K Form of organization

☒ Corporation ☐ Trust ☐ Association ☐ Other ▶

L Year of formation 1975

M State of legal domicile CA

Part I

Summary

Activities & Governance

1 Briefly describe the organization's mission or most significant activities

FINDING A CURE FOR TUBEROUS SCLEROSIS COMPLEX WHILE IMPROVING THE LIVES OF THOSE AFFECTED

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

3 Number of voting members of the governing body (Part VI, line 1a) 25

4 Number of independent voting members of the governing body (Part VI, line 1b) 25

5 Total number of individuals employed in calendar year 2019 (Part V, line 2a) 22

6 Total number of volunteers (estimate if necessary) 2,122

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

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

Revenue

8 Contributions and grants (Part VIII, line 1h)

9 Program service revenue (Part VIII, line 2g)

10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)

11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)

12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)

Prior Year

4,105,376

1,884,102

12,198

-510,235

5,491,441

Current Year

5,527,543

461,658

27,826

699,207

6,716,234

Expenses

13 Grants and similar amounts paid (Part IX, column (A), lines 1–3)

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

15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)

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

b Total fundraising expenses (Part IX, column (D), line 25) ▶1,021,467

17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)

18 Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)

19 Revenue less expenses Subtract line 18 from line 12

Prior Year

464,190

0

2,013,185

0

3,391,158

5,868,533

-377,092

Current Year

617,106

0

2,223,956

0

2,798,273

5,639,335

1,076,899

Net Assets or Fund Balances

20 Total assets (Part X, line 16)

21 Total liabilities (Part X, line 26)

22 Net assets or fund balances Subtract line 21 from line 20

Beginning of Current Year

9,281,566

601,878

8,679,688

End of Year

10,351,316

594,729

9,756,587

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

2020-04-13

Date

KARI L ROSBECK PRESIDENT & CEO

Type or print name and title

Paid Preparer Use Only

Print/Type preparer's name

Preparer's signature

Date

Check ☐ if self-employed

PTIN P00397829

Firm's name ▶ RSM US LLP

Firm's EIN ▶ 42-0714325

Firm's address ▶ 2021 L STREET NW SUITE 400

WASHINGTON, DC 20036

Phone no (202) 293-2200

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

For Paperwork Reduction Act Notice, see the separate instructions.

Cat No 11282Y

Form 990 (2019)

Part III Statement of Program Service AccomplishmentsCheck if Schedule O contains a response or note to any line in this Part III ☒**1** Briefly describe the organization's mission

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

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

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

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

If "Yes," describe these changes on Schedule O

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

4a	(Code)	(Expenses \$	2,469,373	including grants of \$	552,606)	(Revenue \$	461,658)
See Additional Data							

4b	(Code)	(Expenses \$	744,912	including grants of \$		(Revenue \$	)
See Additional Data							

4c	(Code)	(Expenses \$	438,744	including grants of \$		(Revenue \$	)
See Additional Data							

See Additional Data Table

4d	Other program services (Describe in Schedule O)						
	(Expenses \$	442,569	including grants of \$	64,500)	(Revenue \$		

4e	Total program service expenses ▶	4,095,598					
-----------	---	-----------	--	--	--	--	--

Part IV Checklist of Required Schedules

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

Part IV Checklist of Required Schedules (continued)

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

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V ☐

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable	1a	46
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable	1b	0
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	Yes

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

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 22			
b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)		2b	Yes	
3a Did the organization have unrelated business gross income of \$1,000 or more during the year? . . .		3a		No
b If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in Schedule O . . .		3b		
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)? . . .		4a		No
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? . . .		5a		No
b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		5b		No
c If "Yes," to line 5a or 5b, did the organization file Form 8886-T?		5c		
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? . . .		6a		No
b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		6b		
7 Organizations that may receive deductible contributions under section 170(c).				
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?		7a	Yes	
b If "Yes," did the organization notify the donor of the value of the goods or services provided?		7b	Yes	
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		7c		No
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?		7e		No
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? . . .		7f		No
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		7g		
h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		7h		
8 Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?		8		
9 Sponsoring organizations maintaining donor advised funds.				
a Did the sponsoring organization make any taxable distributions under section 4966?		9a		
b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? . . .		9b		
10 Section 501(c)(7) organizations. 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 Section 501(c)(12) organizations. 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 Section 4947(a)(1) non-exempt charitable trusts. 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 Section 501(c)(29) qualified nonprofit health insurance issuers.				
a Is the organization licensed to issue qualified health plans in more than one state? Note. 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		No
b If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O . . .		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 instructions and file Form 4720, Schedule N		15		No
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		No

Part VI

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

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

Section A. Governing Body and Management

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	25	
If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O			
b	Enter the number of voting members included in line 1a, above, who are independent	25	
2	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?		No
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?		No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		No
5	Did the organization become aware during the year of a significant diversion of the organization's assets?		No
6	Did the organization have members or stockholders?	Yes	
7a	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?	Yes	
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a	The governing body?	Yes	
b	Each committee with authority to act on behalf of the governing body?	Yes	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O		No

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

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

Section C. Disclosure

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

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

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

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

19 Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.

20 State the name, address, and telephone number of the person who possesses the organization's books and records

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

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

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

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

● List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.

● List all of the organization's **current** key employees, if any. See instructions for definition of "key employee."

• List the organization's five **current** highest compensated employees (other than an officer, director, trustee or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations

● List all of the organization's **former** officers, key employees, or highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations

• List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations

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

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

[illegible]

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
See Additional Data Table										
1b Sub-Total										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)								911,076	12,962	146,447

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 **▶ 6**

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

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.		
(A) Name and business address	(B) Description of services	(C) Compensation
PSYCHOGENICS INC 20 GRAMERCY PARK SOUTH NEW YORK, NY 10003 PORSOLT SAS	RESEARCH LAB SERVICES	218,333
ZA DE GLATIGNE LE GENESTSAINTISLE 53940 FR	RESEARCH LAB SERVICES	140,155
VAN ANDEL RESEARCH INSTITUTE 333 BOSTWICK AVE NE GRAND RAPIDS, MI 49503	LABORATORY SERVICES	119,005
CAVAROCCHI RUSCIO DENNIS AND ASSOCIATES 600 MARYLAND AVE SW WASHINGTON, DC 20024	GOVERNMENT RELATIONS	103,164
2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization ▶ 4		

Form 990 (2019)										Page 9			
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	1a Federated campaigns		1a	35,476									
	b Membership dues		1b	4,329									
	c Fundraising events		1c	2,417,642									
	d Related organizations		1d	180,000									
	e Government grants (contributions)		1e										
	f All other contributions, gifts, grants, and similar amounts not included above		1f	2,890,096									
	g Noncash contributions included in lines 1a - 1f \$		1g	51,895									
	h Total. Add lines 1a-1f				5,527,543								
Program Service Revenue				Business Code									
	2a CONTRACT REVENUE			900099	247,384	247,384							
	b CONFERENCE REVENUE			900099	214,274				214,274				
	c												
	d												
	e												
	f All other program service revenue												
	g Total. Add lines 2a-2f				461,658								
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)				27,444				27,444				
	4 Income from investment of tax-exempt bond proceeds												
	5 Royalties												
			(i) Real	(ii) Personal									
	6a Gross rents		6a										
	b Less rental expenses		6b										
	c Rental income or (loss)		6c										
	d Net rental income or (loss)												
			(i) Securities	(ii) Other									
	7a Gross amount from sales of assets other than inventory		7a	45,638									
	b Less cost or other basis and sales expenses		7b	45,256									
	c Gain or (loss)		7c	382									
	d Net gain or (loss)				382				382				
	8a Gross income from fundraising events (not including \$ 2,417,642 of contributions reported on line 1c) See Part IV, line 18		8a	245,139									
	b Less direct expenses		8b	268,517									
	c Net income or (loss) from fundraising events				-23,378				-23,378				
	9a Gross income from gaming activities See Part IV, line 19		9a										
	b Less direct expenses		9b										
	c Net income or (loss) from gaming activities												
	10a Gross sales of inventory, less returns and allowances		10a										
b Less cost of goods sold		10b											
c Net income or (loss) from sales of inventory													
Miscellaneous Revenue			Business Code										
11a CHANGE INT-ENDOWMENT			900099	721,871				721,871					
b MISCELLANEOUS			900099	714				714					
c													
d All other revenue													
e Total. Add lines 11a-11d				722,585									
12 Total revenue. See instructions				6,716,234	247,384	0	941,307						

Form 990 (2019)

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
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21.	474,302	474,302		
2 Grants and other assistance to domestic individuals. See Part IV, line 22.				
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16.	142,804	142,804		
4 Benefits paid to or for members.				
5 Compensation of current officers, directors, trustees, and key employees.	672,082	404,350	107,523	160,209
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B).				
7 Other salaries and wages.	1,242,198	751,154	201,228	289,816
8 Pension plan accruals and contributions (include section 401 (k) and 403(b) employer contributions).	34,402	20,148	5,143	9,111
9 Other employee benefits.	150,458	88,118	22,493	39,847
10 Payroll taxes.	124,816	73,100	18,660	33,056
11 Fees for services (non-employees):				
a Management.				
b Legal.	29,600	14,728	14,872	
c Accounting.	24,200		24,200	
d Lobbying.	110,760	110,760		
e Professional fundraising services. See Part IV, line 17.				
f Investment management fees.				
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O).	278,557	136,817	14,939	126,801
12 Advertising and promotion.				
13 Office expenses.	340,397	145,984	21,498	172,915
14 Information technology.	190,555	113,335	30,054	47,166
15 Royalties.				
16 Occupancy.	92,966	54,001	14,790	24,175
17 Travel.	341,541	283,901	3,302	54,338
18 Payments of travel or entertainment expenses for any federal, state, or local public officials.				
19 Conferences, conventions, and meetings.	278,816	246,936	20,440	11,440
20 Interest.				
21 Payments to affiliates.				
22 Depreciation, depletion, and amortization.	95,440	70,843	6,521	18,076
23 Insurance.	8,022	4,665	1,286	2,071
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O):				
a PRECLINICAL CONSORTIUM	579,493	579,493		
b NHD BIOSAMPLE REPOSIT	355,027	355,027		
c DUES AND SUBSCRIPTIONS	66,537	22,505	13,130	30,902
d MISCELLANEOUS EXPENSES	6,362	2,627	2,191	1,544
e All other expenses.				
25 Total functional expenses. Add lines 1 through 24e.	5,639,335	4,095,598	522,270	1,021,467
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ☒ if following SOP 98-2 (ASC 958-720).	79,827	39,914	0	39,913

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

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	785,107	1	809,370
	2 Savings and temporary cash investments	1,469,865	2	1,227,121
	3 Pledges and grants receivable, net	1,249,706	3	2,033,626
	4 Accounts receivable, net	158,782	4	10,243
	5 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		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	263,093	9	251,370
	10a Land, buildings, and equipment—cost or other basis—Complete Part VI of Schedule D	10a 391,656		
	b Less—accumulated depreciation	10b 311,435	169,346	10c 80,221
	11 Investments—publicly traded securities	65	11	27,556
	12 Investments—other securities—See Part IV, line 11		12	
	13 Investments—program-related—See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets—See Part IV, line 11	5,185,602	15	5,911,809
16 Total assets. Add lines 1 through 15 (must equal line 34)	9,281,566	16	10,351,316	
Liabilities	17 Accounts payable and accrued expenses	452,001	17	532,853
	18 Grants payable		18	
	19 Deferred revenue	114,499	19	54,700
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability—Complete Part IV of Schedule D		21	
	22 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		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 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	35,378	25	7,176
	26 Total liabilities. Add lines 17 through 25	601,878	26	594,729
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here ☒ and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	5,024,877	27	5,661,364
	28 Net assets with donor restrictions	3,654,811	28	4,095,223
	Organizations that do not follow FASB ASC 958, check here ☐ and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		29	
	30 Paid-in or capital surplus, or land, building or equipment fund		30	
	31 Retained earnings, endowment, accumulated income, or other funds		31	
32 Total net assets or fund balances	8,679,688	32	9,756,587	
33 Total liabilities and net assets/fund balances	9,281,566	33	10,351,316	

Part XI Reconciliation of Net AssetsCheck if Schedule O contains a response or note to any line in this Part XI ☐

1	Total revenue (must equal Part VIII, column (A), line 12)	1	6,716,234
2	Total expenses (must equal Part IX, column (A), line 25)	2	5,639,335
3	Revenue less expenses Subtract line 2 from line 1	3	1,076,899
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	8,679,688
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	9,756,587

Part XII Financial Statements and ReportingCheck if Schedule O contains a response or note to any line in this Part XII ☐

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

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

Form 990 (2019)

Form 990, Part III, Line 4a:

RESEARCH PROGRAM STIMULATES AND SUPPORTS BASIC, TRANSLATIONAL, AND CLINICAL RESEARCH ON THE VARIOUS MANIFESTATIONS OF TUBEROUS SCLEROSIS COMPLEX (TSC) TO FURTHER THE DEVELOPMENT OF CLINICAL THERAPIES AND, ULTIMATELY, A CURE FOR TSC DIRECTED BY STEVEN L ROBERDS, PHD, CHIEF SCIENTIFIC OFFICER, THE TS 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 THE TS ALLIANCE HAS FUNDED MORE THAN \$21.2 MILLION IN RESEARCH GRANTS ON TSC SINCE 1984 THROUGH THE TS ALLIANCE RESEARCH GRANTS PROGRAM, APPLICATIONS CAN BE SUBMITTED FOR POSTDOCTORAL FELLOWSHIPS AND RESEARCH GRANTS. GRANTS ARE REVIEWED IN A THREE-STEP PROCESS: (1) ALL GRANT APPLICATIONS ARE REVIEWED BY A COMMITTEE COMPRISED OF SCIENTISTS KNOWLEDGEABLE ABOUT THE TOPIC AREA FOR SCIENTIFIC MERIT AND OF ADULTS/CAREGIVERS AFFECTED BY TSC FOR POTENTIAL IMPACT ON THE LIVES OF THOSE AFFECTED BY TSC, (2) THE SCIENCE AND MEDICAL COMMITTEE OF THE BOARD OF DIRECTORS EVALUATES THE GRANT REVIEW COMMITTEE'S RECOMMENDATIONS AND THE RELEVANCE OF THE APPLICATIONS TO THE TS ALLIANCE'S FUNDING PRIORITIES, AND (3) THE BOARD OF DIRECTORS THEN REVIEWS THE RECOMMENDATIONS OF THE SCIENCE AND MEDICAL COMMITTEE AND MAKES FINAL APPROVAL FOR FUNDING. FOR A COMPLETE LIST OF CURRENTLY-FUNDED PROJECTS AS WELL AS AN ARCHIVE OF PAST AWARDEES (BACK TO FY02, PLEASE VISIT [HTTPS://WWW.TSALLIANCE.ORG/RESEARCHERS/GRANTS-AND-FUNDING/IMPLEMENTED](https://www.tsalliance.org/researchers/grants-and-funding/implemented) IN 2006, THE TSC NATURAL HISTORY DATABASE CAPTURES CLINICAL DATA TO DOCUMENT THE IMPACT OF THE DISEASE ON A PERSON'S HEALTH OVER THEIR LIFETIME. AS OF DECEMBER 31, 2019, 2,227 PEOPLE WITH TSC WERE ENROLLED IN THE PROJECT FROM AMONG 18 U.S.-BASED SITES. THE TS ALLIANCE PROVIDES FUNDING TO PARTICIPATING CLINICS TO PERFORM DATA ENTRY, 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 TS ALLIANCE-DIRECTED PROJECT INITIATED IN 2014 THAT WILL IMPACT RESEARCH OVER THE NEXT TEN YEARS OR MORE. HIGH-QUALITY BIOSAMPLES SUCH AS BLOOD, DNA, AND TISSUES LINKED TO DETAILED CLINICAL DATA ARE REQUIRED FOR RESEARCHERS TO UNDERSTAND WHY TSC IS SO DIFFERENT FROM PERSON TO PERSON. THE TS ALLIANCE'S SCIENCE AND MEDICAL COMMITTEE IDENTIFIED THIS AS A GAP THAT CAN ONLY BE FILLED EFFECTIVELY WITH LEADERSHIP OF THE TS ALLIANCE, GUIDED BY A STEERING COMMITTEE OF CLINICIANS AND RESEARCHERS. THE TSC BIOSAMPLE REPOSITORY ENDED 2019 WITH 967 BIOSAMPLES: 649 BLOOD, BUCCAL CELL, OR TISSUE SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE TSC NATURAL HISTORY DATABASE, AND AN ADDITIONAL 318 SAMPLES FROM THE RARE DISEASE CLINICAL RESEARCH NETWORK'S DEVELOPMENTAL SYNAPTOPATHIES CONSORTIUM AND THE PREVENTING EPILEPSY USING VIGABATRIN IN INFANTS WITH TUBEROUS SCLEROSIS COMPLEX (PREVENT) CLINICAL TRIAL. SAMPLES IN THE REPOSITORY ARE LINKED TO DETAILED CLINICAL DATA IN OUR EXISTING TSC NATURAL HISTORY DATABASE AND ARE AVAILABLE TO QUALIFIED RESEARCHERS WORLDWIDE. SAMPLES ARE HOUSED AT AND DISTRIBUTED FROM THE VAN ANDEL INSTITUTE IN GRAND RAPIDS, MICHIGAN, UNDER CONTROL OF THE TS ALLIANCE. IN DECEMBER WE BEGAN COLLECTING BLOOD FROM INDIVIDUALS WITH TSC OF ANY AGE FROM THE CONVENIENCE OF THEIR HOME USING THE MOBILE PHLEBOTOMY COMPANY PHLEBOTEK. THIS ENABLES PEOPLE TO DONATE SAMPLES REGARDLESS OF WHERE THEY LIVE IN THE US AND WHETHER THEY ARE SEEN AT A TSC CLINIC. THANKS TO A GENEROUS DONATION FROM LORNE AND HEIDI WAXLAX, THE WAXLAX BIOSAMPLE COLLECTION INITIATIVE WILL FUND COLLECTION OF 1500 BLOOD SAMPLES COLLECTED IN THIS WAY. TO RAPIDLY GROW AND DRIVE THIS PROJECT, THE TS ALLIANCE HIRED GABRIELLE V. RUSHING, PHD IN DECEMBER 2019 AS ASSOCIATE DIRECTOR. RESEARCH: GABRIELLE COMPLETED HER PHD AT VANDERBILT UNIVERSITY, STUDYING TSC SEGA TUMOR DEVELOPMENT AND NEURAL STEM CELLS UNDER THE GUIDANCE OF DR. REBECCA IHRIG. PRIOR TO JOINING THE TS ALLIANCE, GABRIELLE SERVED AS PROJECT MANAGER FOR THE PREDICT (PHARMACOGENOMIC RESOURCE FOR ENHANCED DECISIONS IN CARE AND TREATMENT) PROGRAM AT VANDERBILT UNIVERSITY MEDICAL CENTER. GABRIELLE HAS PREVIOUS EXPERIENCE WORKING WITH NON-PROFITS INCLUDING AN INTERNSHIP AT THE TS ALLIANCE IN 2017, WHERE SHE PARTICIPATED IN THE MARCH ON THE HILL, CONTRIBUTED TO THE PATIENT-FOCUSED DRUG DEVELOPMENT MEETING AND WROTE THE RESEARCH PRESENTATION SUMMARIES FOR THE INTERNATIONAL TSC AND LAM RESEARCH CONFERENCE. THE TS ALLIANCE LAUNCHED THE TSC PRECLINICAL CONSORTIUM IN 2015, WHICH ENABLES PRIORITIZATION OF CANDIDATE TREATMENTS BASED ON COMPARING HEAD-TO-HEAD DATA USING CONSISTENT ANIMAL MODELS AND RIGOROUS TESTING PROCEDURES. THE TS ALLIANCE IS IDEALLY POSITIONED TO DRIVE THIS COLLABORATION - WITH INPUT FROM ACADEMIC, REGULATORY, AND INDUSTRY STAKEHOLDERS - BY MAINTAINING CONSTANT FOCUS ON THE NEEDS OF PEOPLE WITH TSC. THE TS ALLIANCE HAS LICENSES TO USE SPECIFIC TSC MOUSE MODELS FOR EXPERIMENTS CARRIED OUT BY THE PRECLINICAL CONSORTIUM, AND ALL MOUSE LICENSE AGREEMENTS INCLUDE THE RIGHTS FOR THE TS ALLIANCE TO PERFORM EXPERIMENTS UNDER CONTRACT FOR COMMERCIAL ENTITIES. THIS ENSURES DATA GENERATED BY THE PRECLINICAL CONSORTIUM CAN BE USED TO ACCELERATE THE DEVELOPMENT OF NEW TREATMENTS BY COMMERCIAL ENTITIES AS WELL AS ACADEMIC INVESTIGATORS. THE CONSORTIUM BEGAN RUNNING EPILEPSY EXPERIMENTS IN AUGUST 2016 AT PSYCHOGENICS, A CONTRACT RESEARCH ORGANIZATION. TUMOR GRAFT EXPERIMENTS BEGAN IN AUGUST 2017 AT PORSOLT, ANOTHER CONTRACT RESEARCH ORGANIZATION. THE TS ALLIANCE HAS ALSO DRIVEN NOVEL MODEL DEVELOPMENT, INCLUDING A SYNGENEIC TUMOR GRAFT MODEL AT PORSOLT IN 2019. THE TS ALLIANCE PARTNERED WITH VAN ANDEL RESEARCH INSTITUTE, THE CONTRACT RESEARCH ORGANIZATION THAT BOTH HOUSES THE BIOSAMPLE REPOSITORY AND MAINTAINS THE COLONY OF TSC2+/- AJ MICE, TO RUN EXPERIMENTS IN THOSE MICE ON BEHALF OF THE PRECLINICAL CONSORTIUM TO STREAMLINE THE RESEARCH PROCESS. TWO PHARMACEUTICAL COMPANIES JOINED THE PRECLINICAL CONSORTIUM IN 2019, BRINGING THE CUMULATIVE TOTAL TO ELEVEN INDUSTRY PARTNERS, FIVE OF WHOM REMAIN ACTIVE MEMBERS. THE TSC PRECLINICAL RESEARCH CONSORTIUM RAN 16 STUDIES TO TEST 12 COMPOUNDS IN 2019, COMPARED TO 12 STUDIES AND 10 COMPOUNDS IN 2019. NOTABLY, THE CONSORTIUM RAN TWO STUDIES RELEVANT TO TSC-ASSOCIATED NEUROPSYCHIATRIC DISORDERS (TAND) MODEL DEVELOPMENT, A KEY PRIORITY FOR THE TSC COMMUNITY. THE TS ALLIANCE CONTINUED TO BE A KEY PART OF THE TSC CLINICAL RESEARCH CONSORTIUM ALTHOUGH ONLY A SMALL AMOUNT OF TS ALLIANCE FINANCIAL SUPPORT WAS REQUIRED BECAUSE OF THE CONSORTIUM'S SUCCESS IN OBTAINING NIH FUNDING. NOW CONSISTING OF THIRTEEN SITES, THE CONSORTIUM HAS RECEIVED MORE THAN \$35 MILLION IN COMPETITIVE GRANT FUNDING FROM THE NATIONAL INSTITUTES OF HEALTH (NIH) TO SUPPORT CLINICAL STUDIES IN TSC. THE CLINICAL RESEARCH CONSORTIUM IS MAKING HISTORY WITH THE PREVENT TRIAL - PREVENTING EPILEPSY USING VIGABATRIN IN INFANTS WITH TUBEROUS SCLEROSIS COMPLEX. PREVENT IS THE FIRST PREVENTATIVE TRIAL FOR ANY FORM OF EPILEPSY IN THE US AND BUILDS DIRECTLY UPON THE CONSORTIUM'S FIRST CLINICAL STUDY FROM WHICH RESULTS HAVE BEEN PUBLISHED ([WWW.NCBI.NLM.NIH.GOV/PUBMED/31691264](http://www.ncbi.nlm.nih.gov/pubmed/31691264)) SHOWING THAT ABNORMAL ACTIVITY ON EEGS PREDICTS ONSET OF SEIZURES. THIS TRIAL WILL DETERMINE WHETHER TREATMENT WITH VIGABATRIN PRIOR TO THE ONSET OF CLINICAL SEIZURES IN TSC IS BENEFICIAL TO CHILDREN'S DEVELOPMENTAL AND NEUROLOGIC OUTCOMES. THE TS ALLIANCE'S CHIEF SCIENTIFIC OFFICER SERVES ON THE CONSORTIUM'S LEADERSHIP TEAM. THIS DESCRIPTION IS CONTINUED ON LINE 4D.

Form 990, Part III, Line 4b:

SUPPORT SERVICES DEVELOPS PROGRAMS AND SERVICES THAT PROVIDE INDIVIDUALS WITH TSC DIRECT ACCESS TO INFORMATION, RESOURCES, AND SPECIALISTS EXPERIENCED IN THE DIAGNOSIS, TREATMENT AND MANAGEMENT OF TSC. IN 2019 THE TS ALLIANCE FACILITATED 32,932 PEER-TO-PEER SUPPORTS FROM ADULT REGIONAL COORDINATORS (10), CLINIC AMBASSADORS (24), DEPENDENT ADULT TRANSITION RESOURCE COORDINATORS (31), EDUCATION PARENT MENTORS (33), AND COMMUNITY ALLIANCE LEADERS (93) THROUGH THE TSC CONNECT PROGRAM AND JUNIOR LEADERS (4). EDUCATION PARENT MENTORS ATTENDED 128 SCHOOL MEETINGS (IEPS, EVALUATION TEAM MEETINGS, 504 PLAN MEETINGS, RESOLUTION MEETINGS, AND MEDIATIONS) IN PERSON, THROUGH SKYPE/ FACETIME, AND VIA CONFERENCE CALLS TO SUPPORT FAMILIES IN ATTAINING EDUCATIONAL SERVICES FOR THEIR CHILDREN THROUGHOUT THE COUNTRY. MANY OF THE SCHOOL SYSTEMS REQUESTED "TSC 101" IN AN EFFORT TO HELP THEM UNDERSTAND THE COMPLEXITIES OF TSC AND LEARNING ISSUES FOR CHILDREN WITH TSC. THERE WERE THREE NEW PUBLICATIONS DEVELOPED TO SUPPORT FAMILIES IN THE AREA OF EDUCATION: EARLY CHILDHOOD IN EDUCATION, TSC ASSOCIATED NEUROPSYCHOLOGICAL DISORDERS (TAND) AND EDUCATION, AND THE BODY OF SAMPLE LETTERS. EVERYTHING YOU NEED TO BUILD A PAPER TRAIL FOR YOUR CHILD'S SPECIAL EDUCATION CAREER. THROUGH A NETWORK OF 37 VOLUNTEER BRANCHES OF THE ORGANIZATION, CALLED COMMUNITY ALLIANCES, LOCAL EDUCATION AND SUPPORT GROUP MEETINGS WERE HELD THROUGHOUT THE COUNTRY EDUCATING AND SUPPORTING 1,405 FAMILIES/INDIVIDUALS LIVING WITH TSC. THE COMMUNITY PROGRAMS TEAM SUPPORTS THE COMMUNITY ALLIANCES IN TWO REGIONS, WITH A COMMUNITY PROGRAMS MANAGER ASSIGNED TO EACH REGION TO MANAGE THE DAY-TO-DAY ACTIVITIES WITHIN THEIR COMMUNITIES. IN 2019, OF 97 LEADERSHIP POSITIONS (44 COMMUNITY ALLIANCE CHAIRS, CO-CHAIRS AND VICE CHAIRS, 49 WALK CHAIRS AND CO-CHAIRS AND 4 JUNIOR LEADERS), 92 POSITIONS WERE FILLED WITH FIVE OPEN AS OF DECEMBER 31, 2019. IN 2019, THE TS ALLIANCE CO-HOSTED FIVE REGIONAL CONFERENCES WITH THE LAM FOUNDATION IN BOSTON, ST. LOUIS, CHICAGO, ATLANTA AND LOS ANGELES. THESE EVENTS DREW 503 TOTAL ATTENDEES FROM 29 STATES. THE CONFERENCES INCLUDED TWO GENERAL SESSIONS AT THE BEGINNING AND END OF THE DAY AND THREE BREAKOUT TRACKS WITH PRESENTATIONS SPECIFIC TO CHILDREN WITH TSC (PEDIATRIC TRACK), TRANSITIONING FROM CHILDHOOD TO ADULTHOOD (TRANSITION TRACK) AND ADULT SESSIONS FOR TSC AND LAM (ADULT TRACK). THE OPENING SESSION FOCUSED ON RESEARCH UPDATES AND UPCOMING CLINICAL TRIALS.

Form 990, Part III, Line 4c:

PUBLIC HEALTH EDUCATION HEIGHTENS AWARENESS OF TSC THROUGHOUT THE GENERAL PUBLIC TO BROADEN THE SCOPE OF SUPPORT AND UNDERSTANDING BEYOND TSC INDIVIDUALS AND THEIR FAMILIES DURING 2019, THE TS ALLIANCE PRODUCED TWO ISSUES OF ITS NATIONAL MAGAZINE, PERSPECTIVE, WHICH IS MAILED TO APPROXIMATELY 14,000 CONSTITUENTS AS WELL AS POSTED ON THE WEBSITE THE TS ALLIANCE'S WEBSITE INCREASES AWARENESS AND PROVIDES EXTENSIVE EDUCATION THROUGH AN AVERAGE OF MORE THAN 36,450 UNIQUE VISITORS EACH MONTH THE TS ALLIANCE ALSO RELIES HEAVILY ON SOCIAL MEDIA TO EDUCATE CONSTITUENTS AND PROMOTE NEW RESOURCES AND EVENTS ITS FACEBOOK GROUP BOASTS MORE THAN 9,800 MEMBERS, WHILE ITS TWITTER AND INSTAGRAM ACCOUNTS HAVE 2,240-PLUS AND 1,800-PLUS FOLLOWERS RESPECTIVELY IN 2019, THE TS ALLIANCE INTRODUCED A NEW PODCAST SERIES CALLED TSC NOW, RESULTING IN 8 EPISODES WITH MORE THAN 1,400 TOTAL DOWNLOADS A NEW ELECTRONIC BI-MONTHLY NEWSLETTER, TSC MATTERS, WAS ALSO INTRODUCED, FIVE ISSUES IN 2019 REACHED 5,800 EACH TO INCREASE PUBLIC AWARENESS, THE TS ALLIANCE ONCE AGAIN PARTICIPATED IN TSC GLOBAL AWARENESS DAY ON MAY 15 AS WELL AS TSC AWARENESS MONTH THROUGHOUT MAY, A TSC GLOBAL AWARENESS DAY NEWS RELEASE GARNERED 15.8 MILLION IMPRESSIONS THE TS ALLIANCE AGAIN HEAVILY PROMOTED INFANTILE SPASMS AWARENESS WEEK, DECEMBER 1 TO 7 THIS AWARENESS CAMPAIGN INCLUDED TARGETED SOCIAL MEDIA OUTREACH AND A SATELLITE MEDIA TOUR, WHICH GAINED 235,812 BROADCAST IMPRESSIONS WITH ADDITIONAL NEWS RELEASES, THE TS ALLIANCE REACHED ANOTHER 313 MILLION

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

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

(Code	) (Expenses \$	165,225	including grants of \$	) (Revenue \$
-------	----------------	---------	------------------------	---------------

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 TS ALLIANCE ADVOCATED FOR STATE FUNDING FOR TSC CENTERS IN MISSOURI AND MARYLAND, RESULTING IN \$750,000 IN STATE APPROPRIATIONS THE ANNUAL TS ALLIANCE MARCH ON CAPITOL HILL TO ADVOCATE FOR FEDERAL FUNDING FOR THE TUBEROUS SCLEROSIS COMPLEX RESEARCH PROGRAM (TSCRP) AT THE DEPARTMENT OF DEFENSE'S (DOD) CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP) TOOK PLACE IN EARLY MARCH 2019 MORE THAN 100 MEMBERS OF THE TSC COMMUNITY PARTICIPATED AND ASKED THEIR SENATORS AND REPRESENTATIVES TO SIGN ONTO DEAR COLLEAGUE LETTERS IN SUPPORT OF THE TSCRP MANY OTHER ADVOCATES WHO WERE NOT ABLE TO TRAVEL TO WASHINGTON, DC MET WITH THEIR SENATORS AND REPRESENTATIVES IN THEIR HOME STATES TO MAKE THE CASE FOR CONTINUED FUNDING IN THE HOUSE, 232 DEMOCRATIC AND REPUBLICAN REPRESENTATIVES SIGNED A BIPARTISAN DEAR COLLEAGUE LETTER OF SUPPORT FROM REPRESENTATIVES DAVE LOEBSACK (D-IA) AND MARKWAYNE MULLIN (R-OK) THE SENATE LETTER WAS SPONSORED BY SENATORS CHRIS MURPHY (D-CT) AND JOHNNY ISAKSON (R-GA) AND ENDED WITH 35 SIGNATURES IN FY2020, THE TSC RESEARCH PROGRAM AT THE CDMRP RECEIVED A \$6 MILLION APPROPRIATION, BRINGING THE CUMULATIVE FUNDING TO \$89 MILLION SINCE 2002 AS A RESULT OF OUR SUCCESSFUL GRASSROOTS EFFORTS RESEARCH PERFORMED THROUGH THIS PROGRAM HAS RECENTLY LED TO ADDITIONAL CLINICAL TRIALS INCLUDING DETERMINING IF IMATINIB, A DRUG FDA-APPROVED FOR CANCER, CAN SAFELY IMPROVE LEVELS OF VEGF-D, A BIOMARKER OF LYMPHANGIOLEIOMYOMATOSIS (LAM), A LIFE-THREATENING LUNG MANIFESTATION OF TSC, FUNDED IN FY2013, TESTING A COMBINATION OF TWO DRUGS TO TREAT LAM FUNDED IN FY2012, A MULTI-SITE CLINICAL TRIAL TESTING THE EFFICACY OF AN EXPERIMENTAL TOPICAL RAPAMYCIN CREAM TO TREAT THE DISFIGURING FACIAL TUMORS, CALLED FACIAL ANGIOFIBROMAS, CAUSED BY TSC FUNDED IN FY2010, A CLINICAL RESEARCH NETWORK WAS CREATED TO TEST POTENTIAL NEW THERAPIES, TO VALIDATE BIOMARKERS, AND TO LEARN THE NATURAL HISTORY OF LEADING TO A CLINICAL TRIAL FUNDED IN FY2012 DATA OBTAINED FROM AN FY2010 TSCRP CLINICAL RESEARCH AWARD TO DEFINE EARLY AUTISM PREDICTORS IN TSC AND AN FY2014 TSCRP AWARD FOR A PILOT CLINICAL TRIAL IS BEING TESTED IN A LARGE, NIH-FUNDED CLINICAL TRIAL LOOKING AT THE EFFECTIVENESS OF A BEHAVIORAL INTERVENTION STRATEGY, JASPER, TO IMPROVE OUTCOMES IN CHILDREN WITH AUTISM THE TSCRP HAS ALSO FUNDED RESEARCH TO DEVELOP ANIMAL MODELS OF TSC THAT HAVE SEIZURES, ENABLING A BETTER UNDERSTANDING OF THE ETIOLOGY OF TSC BASED ON DATA FROM TSCRP-FUNDED ANIMAL MODELS OF TSC THAT HAVE SEIZURES AND SHARE PATHOLOGY RELATED TO THAT OF TRAUMATIC BRAIN INJURY, AN INDUSTRY-SPONSORED CLINICAL TRIAL DEMONSTRATED THE EFFECTIVENESS THE MTOR INHIBITOR, EVEROLIMUS, AT TREATING EPILEPSY IN MANY INDIVIDUALS WITH TSC NONE OF THIS PROGRESS WOULD HAVE BEEN POSSIBLE WITHOUT THE CRITICAL SUPPORT PROVIDED THROUGH THE TSCRP

(Code	) (Expenses \$	184,365	including grants of \$	64,000	) (Revenue \$
-------	----------------	---------	------------------------	--------	---------------

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

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

(Code	(Expenses \$	92,979	including grants of \$	700	(Revenue \$	)
PROFESSIONAL EDUCATION EXPANDS PROGRAMS TO TARGET RESEARCHERS AND HEALTHCARE PROVIDERS CARING FOR INDIVIDUALS WITH TSC, MEDICAL STUDENTS, GENETIC COUNSELORS AND EDUCATORS TO MINIMIZE THE CONSEQUENCES OF IGNORANCE AND MISINFORMATION THE TS ALLIANCE PARTICIPATED IN AND PRESENTED AT 40 PROFESSIONAL MEETINGS INCLUDING DEFENSE HEALTH RESEARCH CONSORTIUM, BIOMEDICAL TRANSPARENCY'S BIOMEDICAL TRANSPARENCY SUMMIT, NIH/NINDS EPILEPSY THERAPY SCREENING PROGRAM (ETSP), NIH RARE DISEASE DAY, RARE DISEASE LEGISLATIVE ADVOCATES, HEALTH RESEARCH ALLIANCE (HRA) SPRING MEETING, WORLD CONGRESS SUMMIT ON PATIENT ADVOCACY, AMERICAN THORACIC SOCIETY (ATS) HILL DAY, PEDIATRIC NEUROLOGY UPDATE, INTERAGENCY COLLABORATIVE TO ADVANCE RESEARCH IN EPILEPSY (ICARE), IMPACT OF RARE DISEASES BRIDGING THE COMMONALITIES, RARE DISEASES CLINICAL RESEARCH NETWORK (RDCRN) COALITION OF PATIENT ADVOCACY GROUPS (CPAG), WORLD ORPHAN DRUG CONGRESS, ALABAMA WOMEN OF IMPACT AWARDS, GLOBAL GENES' DATA DIY, NIH TRANSCOORDINATING COMMITTEE, ATS INTERNATIONAL CONFERENCE, NINDS NONPROFIT FORUM, INTERNATIONAL SOCIETY FOR AUTISM RESEARCH (INSAR) INTERNATIONAL CONFERENCE, DRUG INFORMATION ASSOCIATION (DIA), INTERNATIONAL TSC RESEARCH CONFERENCE WITH TUBEROUS SCLEROSIS COMPLEX INTERNATIONAL (TSCI) WORKING GROUP MEETING, WORLD PHARMA WEEK, BRAIN RECOVERY PROJECT, INTERNATIONAL SOCIETY FOR AUTONOMIC NEUROSCIENCE (ISAN), ATS LEADERSHIP SUMMIT, HRA FALL MEETING, GLOBAL GENES RARE PATIENT ADVOCACY SUMMIT, DIA PROGRAM PLANNING MEETING, SOCIETY FOR NEUROSCIENCE, CHILD NEUROLOGY FOUNDATION SYMPOSIUM ON HARMFUL AND DISRUPTIVE BEHAVIORS, NATIONAL ORGANIZATION FOR RARE DISEASES (NORD) BREAKTHROUGH SUMMIT, EPILEPSY LEARNING HEALTHCARE SYSTEM FALL LEARNING SESSION, LENNOX-GASTAUT SYNDROME (LGS) PATIENT-FOCUSED DRUG DEVELOPMENT MEETING, AMERICAN SOCIETY FOR NEPHROLOGY, PATIENT ORGANIZATION PERSPECTIVES ON THE PATIENT DATA EXCHANGE WORKSHOP, NEURODEVELOPMENTAL DISORDERS SYMPOSIUM, RDCRN CPAG PUBLIC WORKSHOP ON PATIENT-FOCUSED DRUG DEVELOPMENT (FDA), AMERICAN EPILEPSY SOCIETY IN ADDITION, AT THE AMERICAN EPILEPSY SOCIETY MEETING THE TS ALLIANCE CO-HOSTED A RECEPTION WITH THE UNIVERSITY OF MARYLAND MORE THAN 100 GUESTS WERE IN ATTENDANCE, INCLUDING THE GOVERNOR OF MARYLAND, LARRY HOGAN, WHO ADDRESSED ATTENDEES OTHER SPEAKERS INCLUDED TS ALLIANCE LEADERSHIP, COMMUNITY MEMBERS, AND UNIVERSITY OF MARYLAND OFFICIALS AT THE CONFERENCE, THE TS ALLIANCE ALSO PARTICIPATED IN A SPECIAL INTEREST GROUP MEETING ON TSC IN ADDITION, THE VICE PRESIDENT, SUPPORT SERVICES CONTINUES TO COLLABORATE WITH NATIONAL EDUCATIONAL NETWORKS, INCLUDING THE ARC USA, PARENT TRAINING INFORMATION CENTERS ACROSS THE COUNTRY AND THE ASSOCIATION FOR MIDDLE LEVEL EDUCATION						
(Code	(Expenses \$		including grants of \$		(Revenue \$	)
LINE 4A, RESEARCH PROGRAM CONTINUED THE 2019 INTERNATIONAL TSC RESEARCH CONFERENCE CHANGING THE COURSE OF TSC HELD JUNE 20-22, 2019, WELCOMED 251 PEOPLE FROM 28 COUNTRIES TO THE CHELSEA HOTEL IN TORONTO, CANADA SPONSORED BY THE TS ALLIANCE, TUBEROUS SCLEROSIS CANADA SCLEROSE TUBEREUSE (TSCST) AND THE TS ALLIANCE OF MEXICO, THE CONFERENCE FEATURED 34 ORAL PRESENTATIONS AND 62 POSTERS ADDITIONALLY, THREE BREAKOUT GROUPS OF CLINICAL AND BASIC SCIENCE RESEARCHERS DISCUSSED TIMELY TOPICS OF INDUCED PLURIPOTENT STEM CELL APPLICATIONS FOR TSC, GENETIC HETEROGENEITY AND MODIFIERS, AND CLINICAL TRIAL DESIGN FOR NEUROLOGICAL ASPECTS OF TSC ON JUNE 22, AN EDUCATIONAL MEETING FOR TSC COMMUNITY MEMBERS, IN PARALLEL WITH THE SCIENTIFIC SESSIONS, ATTRACTED MORE THAN 70 PEOPLE TO LEARN FROM INTERNATIONAL EXPERTS TSC INTERNATIONAL HELD AN IMPROVING CARE WORKSHOP WITH PARTICIPANTS FROM 25 COUNTRIES THE CONFERENCE'S CLOSING SESSION WAS A JOINT SESSION INCLUDING INDIVIDUALS AND FAMILIES AFFECTED BY TSC TOGETHER WITH RESEARCHERS IN A DISCUSSION OF PRIORITIES FOR IMPORTANT AND TIMELY CLINICAL STUDIES IN TSC THIRTY-SEVEN ATTENDEES REGISTERED FOR THE EDUCATIONAL MEETING ONLY, AND 51 OF THE 214 WHO REGISTERED FOR THE FULL CONFERENCE WERE EARLY CAREER RESEARCHERS A SYMPOSIUM SPECIFICALLY FOR - AND ORGANIZED BY - EARLY CAREER RESEARCHERS WAS HELD JUNE 20 BEFORE THE FULL CONFERENCE BEGAN TO PROVIDE AN OPPORTUNITY FOR THEM TO GET FEEDBACK FROM EACH OTHER AND FROM SENIOR SCIENTISTS ON SELECTED ORAL PRESENTATIONS AND CAREER-DEVELOPMENT TOPICS						

Form 990, Part VII - Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors										
(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
CHRIS RUSSELL CHAIR (FROM 7/2019)	5 00 0 00	X		X				0	0	0
BETH DEAN CHAIR (TIL 7/2019)	5 00 0 00	X		X				0	0	0
CASSANDRA CARROLL VICE CHAIR	5 00 0 00	X		X				0	0	0
TIM DILLS IMMEDIATE PAST CHAIR	5 00 0 00	X		X				0	0	0
TARA ZIMMERMAN SECRETARY	5 00 0 00	X		X				0	0	0
DARREN MILES TREASURER	5 00 0 00	X		X				0	0	0
JOHN J BISSLER MD BOARD MEMBER	2 00 0 00	X						0	0	0
MATT BOLGER BOARD MEMBER	2 00 0 00	X						0	0	0
SARA CHIEFFO BOARD MEMBER	2 00 0 00	X						0	0	0
DAVID COIT BOARD MEMBER	2 00 0 00	X						0	0	0

Form 990, Part VII - Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors										
(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
MARGARET COX BOARD MEMBER	2 00 0 00	X						0	0	0
PETER CRINO MD PHD BOARD MEMBER	2 00 0 00	X						0	0	0
BONNIE HOGUE DUFFY BOARD MEMBER	2 00 0 00	X						0	0	0
STEVEN GOLDSTEIN BOARD MEMBER	2 00 0 00	X						0	0	0
ROB GRANDIA BOARD MEMBER	2 00 0 00	X						0	0	0
TOM GWINN BOARD MEMBER	2 00 0 00	X						0	0	0
DANA HOLINKA BOARD MEMBER	2 00 0 00	X						0	0	0
DARCY A KRUEGER BOARD MEMBER	2 00 0 00	X						0	0	0
HEATHER LENS BOARD MEMBER	2 00 0 00	X						0	0	0
JIM MAGINN BOARD MEMBER	2 00 0 00	X						0	0	0

Form 990, Part VII - Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors										
(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
BRENDAN D MANNING PHD BOARD MEMBER	2 00 0 00	X						0	0	0
DIANE MCSWAIN BOARD MEMBER (FROM 12/2019)	2 00 0 00	X						0	0	0
ADOLFO ORIVE BOARD MEMBER (TIL 5/2019)	2 00 0 00	X						0	0	0
MUSTAFA SAHIN BOARD MEMBER	2 00 0 00	X						0	0	0
SEAN SHILLINGER BOARD MEMBER	2 00 0 00	X						0	0	0
JUDY SHOULAK BOARD MEMBER (FROM 8/2019)	2 00 0 00	X						0	0	0
MATTHEW SIMONIAN BOARD MEMBER	2 00 0 00	X						0	0	0
KARI L ROSBECK PRESIDENT & CEO	54 00 1 00			X				195,071	3,612	33,181
RICHARD GOLLUB CFO	47 00 3 00			X				146,474	9,350	29,692
STEVEN L ROBERDS CHIEF SCIENTIFIC OFFICER	45 00 0 00				X			209,520	0	28,079

Form 990, Part VII - Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099- MISC)	(E) Reportable compensation from related organizations (W- 2/1099- MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
DEAN RAGER-AGUIAR DIRECTOR, PRECLINICAL RESEARCH	45 00 0 00					X		142,036	0	27,130
JAYE D ISHAM VP, COMMUNICATIONS STRATEGY	45 00 0 00					X		113,018	0	4,626
LISA M MOSS SR DIRECTOR OF DONOR RELATIONS	45 00 0 00					X		104,957	0	23,739

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.
▶ Attach to Form 990 or Form 990-EZ.
▶ Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No 1545-0047

2019

Open to Public Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
INC

Employer identification number
95-3018799

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

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

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

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

Part II

Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)
(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III.
If the organization failed to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grant.")	3,514,873	4,517,826	3,949,953	4,105,376	5,527,543	21,615,571
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	3,514,873	4,517,826	3,949,953	4,105,376	5,527,543	21,615,571
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						3,708,214
6 Public support. Subtract line 5 from line 4						17,907,357

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
7 Amounts from line 4	3,514,873	4,517,826	3,949,953	4,105,376	5,527,543	21,615,571
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	16,038	15,431	10,393	13,784	27,444	83,090
9 Net income from unrelated business activities, whether or not the business is regularly carried on		44,490				44,490
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)	1,401	1,683	642	1,243	714	5,683
11 Total support. Add lines 7 through 10						21,748,834
12 Gross receipts from related activities, etc. (see instructions)					12	6,820,021

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

► ☐

Section C. Computation of Public Support Percentage

14 Public support percentage for 2019 (line 6, column (f) divided by line 11, column (f))	14	82.340 %
15 Public support percentage for 2018 Schedule A, Part II, line 14	15	82.870 %

16a 33 1/3% support test—2019. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization

► ☒

b 33 1/3% support test—2018. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization

► ☐

17a 10%-facts-and-circumstances test—2019. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization

► ☐

b 10%-facts-and-circumstances test—2018. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization

► ☐

18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions

► ☐

Schedule A (Form 990 or 990-EZ) 2019

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) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(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) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(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 in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						

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

Section C. Computation of Public Support Percentage

15 Public support percentage for 2019 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2018 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2019 (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from 2018 Schedule A, Part III, line 17	18	

19a 33 1/3% support tests—2019. 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—2018. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization ► ☐

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

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

	Yes	No
1 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>	1	
2 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>	2	
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer (b) and (c) below.</i>	3a	
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>	3b	
c 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>	3c	
4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes" and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>	4a	
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>	4b	
c 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>	4c	
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed, (ii) the reasons for each such action, (iii) the authority under the organization's organizing document authorizing such action, and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>	5a	
b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?	5b	
c Substitutions only. Was the substitution the result of an event beyond the organization's control?	5c	
6 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>	6	
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>	7	
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>	8	
9a 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>	9a	
b Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i>	9b	
c Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i>	9c	
10a 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>	10a	
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>	10b	

Part IV

Supporting Organizations (continued)

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

Section B. Type I Supporting Organizations

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

Section C. Type II Supporting Organizations

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

Section D. All Type III Supporting Organizations

	Yes	No
1 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?		
2 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>		
3 By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally-Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions)		
a ☐ The organization satisfied the Activities Test. Complete line 2 below.		
b ☐ The organization is the parent of each of its supported organizations. Complete line 3 below.		
c ☐ The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).		
2 Activities Test. Answer (a) and (b) below.		
a 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 Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
3 Parent of Supported Organizations. Answer (a) and (b) below.		
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>Provide details in Part VI.</i>		
b 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>		

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations			
1 ☐ Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI) See instructions. All other Type III non-functionally integrated supporting organizations must complete Sections A through E			
Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	1	
2	Recoveries of prior-year distributions	2	
3	Other gross income (see instructions)	3	
4	Add lines 1 through 3	4	
5	Depreciation and depletion	5	
6	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6	
7	Other expenses (see instructions)	7	
8	Adjusted Net Income (subtract lines 5, 6 and 7 from line 4)	8	
Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year)	1	
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	Total (add lines 1a, 1b, and 1c)	1d	
e	Discount claimed for blockage or other factors (explain in detail in Part VI)		
2	Acquisition indebtedness applicable to non-exempt use assets	2	
3	Subtract line 2 from line 1d	3	
4	Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, see instructions)	4	
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6	Multiply line 5 by .035	6	
7	Recoveries of prior-year distributions	7	
8	Minimum Asset Amount (add line 7 to line 6)	8	
Section C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1	
2	Enter 85% of line 1	2	
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3	
4	Enter greater of line 2 or line 3	4	
5	Income tax imposed in prior year	5	
6	Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions)	6	
7	☐ Check here if the current year is the organization's first as a non-functionally-integrated Type III supporting organization (see instructions)		

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

Section D - Distributions	Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	
4 Amounts paid to acquire exempt-use assets	
5 Qualified set-aside amounts (prior IRS approval required)	
6 Other distributions (describe in Part VI) See instructions	
7 Total annual distributions. Add lines 1 through 6	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI) See instructions	
9 Distributable amount for 2019 from Section C, line 6	
10 Line 8 amount divided by Line 9 amount	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2019	(iii) Distributable Amount for 2019
1 Distributable amount for 2019 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2019 (reasonable cause required-- explain in Part VI) See instructions			
3 Excess distributions carryover, if any, to 2019			
a From 2014.			
b From 2015.			
c From 2016.			
d From 2017.			
e From 2018.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2019 distributable amount			
i Carryover from 2014 not applied (see instructions)			
j Remainder Subtract lines 3g, 3h, and 3i from 3f			
4 Distributions for 2019 from Section D, line 7 \$			
a Applied to underdistributions of prior years			
b Applied to 2019 distributable amount			
c Remainder Subtract lines 4a and 4b from 4			
5 Remaining underdistributions for years prior to 2019, if any Subtract lines 3g and 4a from line 2 If the amount is greater than zero, explain in Part VI See instructions			
6 Remaining underdistributions for 2019 Subtract lines 3h and 4b from line 1 If the amount is greater than zero, explain in Part VI See instructions			
7 Excess distributions carryover to 2020. Add lines 3j and 4c			
8 Breakdown of line 7			
a Excess from 2015.			
b Excess from 2016.			
c Excess from 2017.			
d Excess from 2018.			
e Excess from 2019.			

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

Facts And Circumstances Test

990 Schedule A, Supplemental Information

Return Reference	Explanation
SCHEDULE A, PART II, LINE 10, EXPLANATION OF OTHER INCOME	INCOME FROM ACTIVITIES NOT REGULARLY CARRIED ON - 2015 AMOUNT \$ 1,401 2016 AMOUNT \$ 1,683 2017 AMOUNT \$ 642 2018 AMOUNT \$ 1,243 2019 AMOUNT \$ 714

SCHEDULE C
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities

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

▶Complete if the organization is described below. ▶Attach to Form 990 or Form 990-EZ.
▶Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No 1545-0047

2019

Open to Public Inspection

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals
1a Total lobbying expenditures to influence public opinion (grass roots lobbying)		2,491	
b Total lobbying expenditures to influence a legislative body (direct lobbying)		162,735	
c Total lobbying expenditures (add lines 1a and 1b)		165,226	
d Other exempt purpose expenditures		5,742,626	
e Total exempt purpose expenditures (add lines 1c and 1d)		5,907,852	
f Lobbying nontaxable amount Enter the amount from the following table in both columns		445,393	
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	
g Grassroots nontaxable amount (enter 25% of line 1f)		111,348	
h Subtract line 1g from line 1a If zero or less, enter -0-		0	
i Subtract line 1f from line 1c If zero or less, enter -0-		0	
j 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?		☐ Yes ☐ 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) 2016	(b) 2017	(c) 2018	(d) 2019	(e) Total
2a Lobbying nontaxable amount	394,622	416,065	450,555	445,393	1,706,635
b Lobbying ceiling amount (150% of line 2a, column(e))					2,559,953
c Total lobbying expenditures	145,927	146,199	149,340	165,226	606,692
d Grassroots nontaxable amount	98,656	104,016	112,639	111,348	426,659
e Grassroots ceiling amount (150% of line 2d, column (e))					639,989
f Grassroots lobbying expenditures	986	1,797	823	2,491	6,097

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

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

		(a)		(b)
		Yes	No	Amount
1	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			
a	Volunteers?			
b	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?			
c	Media advertisements?			
d	Mailings to members, legislators, or the public?			
e	Publications, or published or broadcast statements?			
f	Grants to other organizations for lobbying purposes?			
g	Direct contact with legislators, their staffs, government officials, or a legislative body?			
h	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?			
i	Other activities?			
j	Total. Add lines 1c through 1i			
2a	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?			
b	If "Yes," enter the amount of any tax incurred under section 4912			
c	If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d	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
1 Were substantially all (90% or more) dues received nondeductible by members?	1	
2 Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2	
3 Did the organization agree to carry over lobbying and political expenditures from the prior year?	3	

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."

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

Part IV Supplemental Information

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

Return Reference	Explanation

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

2019

Open to Public Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
INC

Employer identification number
95-3018799

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

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

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

☐ Yes ☐ No

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

☐ Yes ☐ No

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

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

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

☐ Preservation of an historically important land area

☐ Protection of natural habitat

☐ Preservation of a certified historic structure

☐ Preservation of open space

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

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

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

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

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

☐ Yes ☐ No

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

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

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

☐ Yes ☐ No

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

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

1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items

b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items

(i) Revenue included on Form 990, Part VIII, line 1

► \$

(ii) Assets included in Form 990, Part X

► \$

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items

a Revenue included on Form 990, Part VIII, line 1

► \$

b Assets included in Form 990, Part X

► \$

Part III

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

3

Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply)

a

☐ Public exhibition

b

☐ Scholarly research

c

☐ Preservation for future generations

d

☐ Loan or exchange programs

e

☐ Other

4

Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII

5

During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?

☐ Yes

☐ No

Part IV

Escrow and Custodial Arrangements.

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

1a

Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIII and complete the following table

c

Beginning balance

d

Additions during the year

e

Distributions during the year

f

Ending balance

	Amount
1c	
1d	
1e	
1f	

2a

Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? . . .

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIII Check here if the explanation has been provided in Part XIII

☐

Part V

Endowment Funds.

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	5,193,934	5,655,555	5,293,989	4,763,517	5,061,299
b Contributions	78,962	82,346	92,635	58,749	29,940
c Net investment earnings, gains, and losses	959,121	-439,321	739,072	525,868	93,294
d Grants or scholarships					
e Other expenditures for facilities and programs	288,356	50,000	403,000		202,000
f Administrative expenses	27,856	54,646	67,141	54,145	32,428
g End of year balance	5,915,805	5,193,934	5,655,555	5,293,989	4,950,105

2

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

a

Board designated or quasi-endowment ▶

85 130 %

b

Permanent endowment ▶

14 870 %

c

Temporarily restricted endowment ▶

0 %

The percentages on lines 2a, 2b, and 2c should equal 100%

3a

Are there endowment funds not in the possession of the organization that are held and administered for the organization by

(i) unrelated organizations

(ii) related organizations

3a(i)

Yes

No

3a(ii)

Yes

3b

Yes

b

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

☐

4

Describe in Part XIII the intended uses of the organization's endowment funds

Part VI

Land, Buildings, and Equipment.

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements		156,545	151,059	5,486
d Equipment		155,880	81,145	74,735
e Other		79,231	79,231	0
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c)) . . . ▶				80,221

Schedule D (Form 990) 2019

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)		
Total. (Column (b) must equal Form 990, Part X, col (B) line 12) ▶		

Part VIII

Investments—Program Related.

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

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

Part IX

Other Assets.

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

(a) Description	(b) Book value
(1) INTEREST IN NET ASSETS OF AFFI	5,915,805
(2) DUE FROM AFFILIATE	-3,996
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col (B) line 15) ▶	5,911,809

Part X

Other Liabilities.

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

(a) Description of liability	(b) Book value
1. Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col (B) line 25) ▶	7,176

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

Schedule D (Form 990) 2019

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	6,864,498
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains (losses) on investments	2a	
b	Donated services and use of facilities	2b	148,264
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII)	2d	
e	Add lines 2a through 2d	2e	148,264
3	Subtract line 2e from line 1	3	6,716,234
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	6,716,234

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

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

1	Total expenses and losses per audited financial statements	1	5,787,599
2	Amounts included on line 1 but not on Form 990, Part IX, line 25		
a	Donated services and use of facilities	2a	148,264
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII)	2d	
e	Add lines 2a through 2d	2e	148,264
3	Subtract line 2e from line 1	3	5,639,335
4	Amounts included on Form 990, Part IX, line 25, but not on line 1 :		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	4b	
c	Add lines 4a and 4b	4c	0
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18)	5	5,639,335

Part XIII Supplemental Information

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

Return Reference	Explanation
See Additional Data Table	

Part XIII Supplemental Information *(continued)*

Return Reference	Explanation

Additional Data

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

Supplemental Information

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

SCHEDULE F
(Form 990)

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

► Complete if the organization answered "Yes" to Form 990, Part IV, line 14b, 15, or 16.
► Attach to Form 990.
► Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No 1545-0047

2019

Open to Public Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
INC

Employer identification number
95-3018799

Part I

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

- 1 For grantmakers. Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance?

☒ Yes ☐ No
- 2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States
- 3 Activities per Region (The following Part I, line 3 table can be duplicated if additional space is needed)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
See Add'l Data					
3a Sub-total	0	0			282,959
b Total from continuation sheets to Part I	0	0			0
c Totals (add lines 3a and 3b)	0	0			282,959

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.

[illegible]

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

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

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.

[illegible]

Part IV Foreign Forms

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

Part V Supplemental Information

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

990 Schedule F, Supplemental Information

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

990 Schedule F, Supplemental Information

Return Reference	Explanation
PART III ACCOUNTING METHOD	

Additional Data

Software ID:

Software Version:

EIN: 95-3018799

Name: NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
INC

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

(a) Region	(b) Number of offices in the region	(c) Number of employees or agents in region	(d) Activities conducted in region (by type) (i.e., fundraising, program services, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for region
EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM	0	0	GRANTMAKING		82,804
NORTH AMERICA	0	0	GRANTMAKING		35,000

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

(a) Region	(b) Number of offices in the region	(c) Number of employees or agents in region	(d) Activities conducted in region (by type) (i.e., fundraising, program services, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for region
MIDDLE EAST AND NORTH AFRICA - ALGERIA, BAHRAIN, DJIBOUTI, EGYPT,	0	0	GRANTMAKING		25,000
EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM	0	0	PROGRAM SERVICE ACTIVITIES	PRECLINICAL RESEARCH STUDIES	140,155

Form 990 Schedule F Part II - Grants or Entities Outside The United States								
(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 non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		EUROPE/ICELAND/GREENLAND	RESEARCH ON TUBEROUS SCLEROSIS COMPLEX	58,804	WIRE			
		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM	PROGRAMMATIC SUPPORT	24,000	WIRE			

Form 990 Schedule F Part II - Grants or Entities Outside The United States								
(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 non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		NORTH AMERICA	RESEARCH ON TUBEROUS SCLEROSIS COMPLEX	20,000	CHECK			
		NORTH AMERICA	PROGRAMMATIC SUPPORT	15,000	WIRE			

Form 990 Schedule F Part II - Grants or Entities Outside The United States								
(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 non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		MIDDLE EAST AND NORTH AFRICA	PROGRAMMATIC SUPPORT IN ISRAEL	25,000	WIRE			

Supplemental Information Regarding Fundraising or Gaming Activities

2019

Open to Public Inspection

Complete if the organization answered "Yes" on Form 990, Part IV, lines 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 for instructions and the latest information.

Employer identification number

95-3018799

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

- 2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? ☐ Yes ☐ No
- b** If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization

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

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

Revenue		(a) Event #1 45TH ANNIVERSARY GALA (event type)	(b) Event #2 WALKS (event type)	(c) Other events 11 (total number)	(d) Total events (add col (a) through col (c))
Revenue	1 Gross receipts	1,069,016	902,981	690,784	2,662,781
	2 Less Contributions	953,817	827,981	635,844	2,417,642
	3 Gross income (line 1 minus line 2)	115,199	75,000	54,940	245,139
Direct Expenses	4 Cash prizes				
	5 Noncash prizes	2,031	39,411	2,997	44,439
	6 Rent/facility costs	72,152	17,615	35,889	125,656
	7 Food and beverages	43,042	4,978	32,992	81,012
	8 Entertainment	10,692	4,672	2,046	17,410
	9 Other direct expenses				
	10 Direct expense summary Add lines 4 through 9 in column (d) ▶				268,517
	11 Net income summary Subtract line 10 from line 3, column (d) ▶				-23,378

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

Revenue		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col (a) through col (c))
Revenue	1 Gross revenue				
	2 Cash prizes				
	3 Noncash prizes				
	4 Rent/facility costs				
	5 Other direct expenses				
Direct Expenses	6 Volunteer labor	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ 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 _____

11 Does the organization conduct gaming activities with nonmembers?	☐ Yes ☐ No						
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?	☐ Yes ☐ No						
13 Indicate the percentage of gaming activity conducted in							
a The organization's facility	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 10%;">13a</td> <td style="width: 70%;"></td> <td style="width: 20%; text-align: right;">%</td> </tr> <tr> <td>13b</td> <td></td> <td style="text-align: right;">%</td> </tr> </table>	13a		%	13b		%
13a		%					
13b		%					
b An outside facility							

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records

Name ►

Address ►

15a Does the organization have a contract with a third party from whom the organization receives gaming revenue? ☐ **Yes** ☐ **No**

b If "Yes," enter the amount of gaming revenue received by the organization ► \$ and the amount of gaming revenue retained by the third party ► \$

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? ☐ **Yes** ☐ **No**

b Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ► \$

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

Return Reference

Explanation

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

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 for the latest information.

OMB No 1545-0047

2019

Open to Public
Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
INC

Employer identification number
95-3018799

Part I

General Information on Grants and Assistance

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

Part II

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

(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
(1) See Additional Data							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table 9

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

Part III Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22

Part III can be duplicated if additional space is needed

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

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

Return Reference	Explanation
PART I, LINE 2	THE TS ALLIANCE HAS FUNDED MORE THAN \$21.2 MILLION IN RESEARCH ON TSC SINCE 1984. DIRECTED BY STEVEN L. ROBERDS, PH.D., CHIEF SCIENTIFIC OFFICER, THE TS ALLIANCE RESEARCH GRANTS PROGRAM FUNDS RESEARCH FOCUSED ON TSC WITH PRIORITIES SET BY THE RESEARCHERS TOGETHER WITH THE TS ALLIANCE. COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS ARE ENCOURAGED AND FOSTERED, AND THE TS ALLIANCE IS WORKING TO INCREASE FUNDING FOR RESEARCH ON TSC THROUGH THE TS ALLIANCE RESEARCH GRANTS PROGRAM. APPLICATIONS CAN BE SUBMITTED FOR POSTDOCTORAL FELLOWSHIPS AND TSC RESEARCH GRANTS. GRANTS ARE REVIEWED IN A THREE-STEP PROCESS: 1. A GRANT REVIEW COMMITTEE COMPOSED OF INDIVIDUALS KNOWLEDGEABLE ABOUT THE CLINICAL AND BASIC COMPONENTS OF TSC AS WELL AS CONSUMERS REVIEW ALL GRANT APPLICATIONS FOR SCIENTIFIC MERIT, RELEVANCY TO THE FUNDING PRIORITIES OF THE ORGANIZATION AND WITH A FOCUS ON UNDERSTANDING THE MECHANISMS OF TSC AND/OR THE DEVELOPMENT OF TREATMENTS AND THERAPIES FOR THE MANIFESTATIONS OF THE DISEASE. 2. THE SCIENCE AND MEDICAL COMMITTEE OF THE BOARD OF DIRECTORS THEN REVIEWS THE GRANT REVIEW COMMITTEE'S CONCLUSIONS AND MAKES FUNDING RECOMMENDATIONS TO THE BOARD OF DIRECTORS. 3. THE BOARD OF DIRECTORS THEN REVIEWS THE RECOMMENDATIONS OF THE SCIENCE AND MEDICAL COMMITTEE AND MAKES FINAL APPROVAL FOR THE FUNDING OF GRANTS.

Additional Data

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

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

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
BRIGHAM & WOMAN'S HOSPITAL 75 SAINT FRANCIS STREET BOSTON, MA 02115	04-2312909	501(C)(3)	70,625				RESEARCH GRANTS
UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER 5323 HARRY HINES BLVD DALLAS, TX 75287	75-6002868	501(C)(3)	75,000				RESEARCH GRANTS

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
YALE UNIVERSITY POBOX 1873 NEW HAVEN, CT 06508	06-0646973	501(C)(3)	74,235				RESEARCH GRANTS
AMERICAN THORACIC SOCIETY 25 BROADWAY 18TH FLOOR NEW YORK, NY 10004	06-1548706	501(C)(3)	5,500				RESEARCH GRANTS

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
CHILDREN'S HOSPITAL MEDICAL CENTER SPONSORED PRGS ACTG ML 4900 3333 BURNET AVE CINCINNATI, OH 45229	31-0833936	501(C)(3)	50,000				RESEARCH GRANTS
NATIONAL ORGANIZATION FOR RARE DISORDERS 55 KENOSIA AVENUE DANBURY, CT 06810	13-3223946	501(C)(3)	50,000				TSC TRAVEL AND LODGING ASSISTANCE PROGRAM

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
NORTHWESTERN UNIVERSITY 7TH FLOOR RUBLOFF BUILDING CHICAGO, IL 60611	36-2167818	501(C)(3)	18,750				RESEARCH GRANTS
CHILDREN'S HOSPITAL CORPORATION 300 LONGWOOD AVENUE BOSTON, MA 02115	04-2774441	501(C)(3)	37,500				RESEARCH GRANTS

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.							
(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
BOSTON CHILDREN'S HOSPITAL 300 LONGWOOD AVENUE BOSTON, MA 02115	04-2774441	501(C)(3)	92,692				CLINICAL RESEARCH GRANT

Schedule J (Form 990)	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 for instructions and the latest information.	OMB No 1545-0047
		2019
		Open to Public Inspection

Department of the Treasury Internal Revenue Service	Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC	Employer identification number 95-3018799
--	--	--

Part I	Questions Regarding Compensation	Yes	No
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. ☐ First-class or charter travel ☐ Travel for companions ☐ Tax indemnification and gross-up payments ☐ Discretionary spending account ☐ Housing allowance or residence for personal use ☐ Payments for business use of personal residence ☐ Health or social club dues or initiation fees ☐ Personal services (e.g., 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, officers, including the CEO/Executive Director, regarding the items checked on Line 1a?	2	
3	Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III. ☒ Compensation committee ☐ Independent compensation consultant ☒ Form 990 of other organizations ☐ Written employment contract ☒ Compensation survey or study ☒ Approval by the board or compensation committee		
4	During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization: a Receive a severance payment or change-of-control payment? b Participate in, or receive payment from, a supplemental nonqualified retirement plan? c Participate in, or receive payment from, an equity-based compensation arrangement? If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.	4a 4b 4c	No No No
	Only 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.		
5	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of: a The organization? b Any related organization? If "Yes," on line 5a or 5b, describe in Part III.	5a 5b	Yes No
6	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of: a The organization? b Any related organization? If "Yes," on line 6a or 6b, describe in Part III.	6a 6b	Yes No
7	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described in lines 5 and 6? If "Yes," describe in Part III.	7	No
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	No
9	If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?	9	

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

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

[illegible]

Part III **Supplemental Information**

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

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

SCHEDULE M
(Form 990)

Department of the Treasury
Internal Revenue Service

Noncash Contributions

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

OMB No 1545-0047

2019

Open to Public Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
INC

Employer identification number
95-3018799

Part I

Types of Property

	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1 Art—Works of art				
2 Art—Historical treasures				
3 Art—Fractional interests				
4 Books and publications				
5 Clothing and household goods				
6 Cars and other vehicles				
7 Boats and planes				
8 Intellectual property				
9 Securities—Publicly traded	X	3	45,256	FMV
10 Securities—Closely held stock				
11 Securities—Partnership, LLC, or trust interests				
12 Securities—Miscellaneous				
13 Qualified conservation contribution—Historic structures				
14 Qualified conservation contribution—Other				
15 Real estate—Residential				
16 Real estate—Commercial				
17 Real estate—Other				
18 Collectibles				
19 Food inventory	X	18	6,639	FMV
20 Drugs and medical supplies				
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ► ()				
26 Other ► ()				
27 Other ► ()				
28 Other ► ()				

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

29

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

30a

No

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

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

31

No

32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?

32a

No

b If "Yes," describe in Part II

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

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

Return Reference	Explanation
------------------	-------------

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury

Name of the organization

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
INC**Supplemental Information to Form 990 or 990-EZ**Complete to provide information for responses to specific questions on
Form 990 or 990-EZ or to provide any additional information.

▶ Attach to Form 990 or 990-EZ.

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

OMB No 1545-0047

2019**Open to Public
Inspection****Employer identification number**

95-3018799

990 Schedule O, Supplemental Information

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

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION A, LINE 7A	THE TS ALLIANCE IS A MEMBERSHIP-BASED ORGANIZATION, WHICH MEANS MEMBERS HELP ELECT THE BOARD OF DIRECTORS. THE TS ALLIANCE MEMBERSHIP PROGRAM ALLOWED INDIVIDUALS TO STATE THEIR INTENT TO BE A MEMBER FOR THE PURPOSE OF GOVERNANCE. THERE WERE NO LEVELS TO MEMBERSHIP IN 2019. ANYONE CAN BE A MEMBER AT NO COST.

990 Schedule O, Supplemental Information

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

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 12C	ANNUALLY EACH MEMBER OF THE BOARD OF DIRECTORS WILL RECEIVE NOTICE OF THE ORGANIZATION'S CONFLICT OF INTEREST STATEMENT EACH MEMBER WILL BE PROVIDED WITH A STATEMENT TO MAKE DISCLOSURE OF ANY POTENTIAL CONFLICT OF INTEREST IF DURING THE COURSE OF THE YEAR A POTENTIAL CONFLICT OF INTEREST ARISES THAT HAS NOT PREVIOUSLY BEEN DISCLOSED, THE BOARD MEMBER WILL MAKE WRITTEN NOTICE OF A POTENTIAL CONFLICT OF INTEREST AND RECUSE HIMSELF OR HERSELF FROM ANY DISCUSSIONS AND VOTES IN CONNECTION WITH THE ISSUE IDENTIFIED ANY TIME A MEMBER IS RECUSED FROM DISCUSSION ON AN ISSUE, THE MINUTES OF COMMITTEE MEETING AND BOARD MEETING WILL DULY RECORD SUCH ACTIONS THE FOLLOWING POTENTIAL CONFLICTS OF INTEREST WERE DISCLOSED FOR 2019 BOARD MEMBER MUSTAFA SAHIN, PH D , M D , IS EMPLOYED AT HARVARD MEDICAL COLLEGE AND BOSTON CHILDREN'S HOSPITAL, WHICH RECEIVED A \$92,692 GRANT AND ADDITIONALLY \$20,200 FOR HIS WORK ON THE TSC NATURAL HISTORY DATABASE AND BIOSAMPLE REPOSITORY BOARD MEMBER DARCY KRUEGER, MD, MPA, IS EMPLOYED AT THE CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER, WHICH RECEIVED A \$50,000 GRANT AND ADDITIONALLY \$14,630 FOR HIS WORK ON THE TSC NATURAL HISTORY DATABASE AND BIOSAMPLE REPOSITORY BOARD MEMBER JUDY SHOULAK, IS CEO OF RELATIVELY SPEAKING, WHICH RECEIVED A \$4,000 CONSULTING FEE PRIOR TO HER JOINING THE BOARD IN AUGUST 2019, FOR TRAINING TS ALLIANCE STAFF ON GOALS, EXECUTING, OVERCOMING OBSTACLES AND ANALYZING RESULTS

990 Schedule O, Supplemental Information

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

990 Schedule O, Supplemental Information

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

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART IX	DURING FY 2019, THE TUBEROUS SCLEROSIS ALLIANCE (TS ALLIANCE) AND TS ALLIANCE ENDOWMENT FUND BOARD OF DIRECTORS AUTHORIZED AN UNBUDGETED RESEARCH CAMPAIGN STUDY TO UNDERSTAND THE FEASIBILITY OF CONDUCTING A RESEARCH CAPITAL CAMPAIGN WITH THE GOAL TO CHANGE THE COURSE OF TUBEROUS SCLEROSIS COMPLEX (TSC) FOR THOSE LIVING WITH TSC TODAY AND FOR GENERATIONS TO COME. THIS STUDY WAS AN IMPORTANT STEP TO ENSURE WE UNDERSTOOD THE VIABILITY AND COMMITMENT OF THE TSC COMMUNITY AND DONORS TOWARD THIS BOLD RESEARCH VISION. THIS WAS A ONE-TIME EXPENSE IN 2019 THAT ELEVATED OUR FUNDRAISING EXPENSES AND WE ARE MONITORING FUNDRAISING AND ADMINISTRATIVE EXPENSES IN FY 2020. SIMULTANEOUSLY, FOR THE FIRST TIME IN THREE YEARS, WE SAW A DECLINE IN PRECLINICAL CONSORTIUM TESTING BY INDUSTRY PARTNERS. THE PRECLINICAL STUDIES ARE INCLUDED IN OUR PROGRAM EXPENSES. STEPS HAVE BEEN TAKEN TO DECREASE DOLLARS BUDGETED FOR INDUSTRY STUDIES IN FUTURE YEARS SO TS ALLIANCE PROGRAM EXPENSES ARE LESS IMPACTED BY INDUSTRY STUDIES. AS A RESULT OF THESE CIRCUMSTANCES, IN FY 2019, OUR PROGRAM EXPENSES WERE 72.6% AND OUR FUNDRAISING/ADMINISTRATIVE EXPENSES WERE 27.4%.

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 for instructions and the latest information.

OMB No 1545-0047

2019

Open to Public Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
INC

Employer identification number
95-3018799

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

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

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

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

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

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

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

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

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

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

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

(a) Name of related organization	(b) Transaction type (a-s)	(c) Amount involved	(d) Method of determining amount involved
(1) TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FUND	C	180,000	CASH

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

[illegible]

Part VII **Supplemental Information**

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

Return Reference	Explanation