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Form

990

Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

OMB No 1545-0047

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)

Open to Public Inspection

The organization may have to use a copy of this return to satisfy state reporting requirements

2009

A For the 2009 calendar year, or tax year beginning 07-01-2009 and ending 06-30-2010

B Check if applicable:
☐ Address change
☐ Name change
☐ Initial return
☐ Terminated
☐ Amended return
☐ Application pending

C Name of organization: NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC.
Doing Business As:
Number and street (or P O box if mail is not delivered to street address): 801 Roeder Road No 750 Room/suite:
City or town, state or country, and ZIP + 4: silver spring, MD 20910

D Employer identification number: 95-3018799

E Telephone number: (301) 562-9890

G Gross receipts \$ 3,356,797

F Name and address of principal officer: KARI L ROSBECK, 801 Roeder Road No 750, silver spring, MD 20910

H(a) Is this a group return for affiliates? ☐ Yes ☒ No

H(b) Are all affiliates included? ☐ Yes ☐ No If "No," attach a list (see instructions)

H(c) Group exemption number

I Tax-exempt status: ☒ 501(c) (3) ☐ (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. The National Tuberous Sclerosis Association DBA Tuberous Sclerosis Alliance is dedicated to finding a cure for tuberous sclerosis while improving the lives of those affected.

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

3 Number of voting members of the governing body (Part VI, line 1a) 3 2

4 Number of independent voting members of the governing body (Part VI, line 1b) 4 2

5 Total number of employees (Part V, line 2a) 5 1

6 Total number of volunteers (estimate if necessary) 6 2,00

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

7b Net unrelated business taxable income from Form 990-T, line 34 7b

Revenue: 8 Contributions and grants (Part VIII, line 1h) 8 3,320,882 3,221,297

9 Program service revenue (Part VIII, line 2g) 9 41,527 56,970

10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) 10 35,978 4,704

11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) 11 4,533 -140,803

12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12) 12 3,402,920 3,142,168

Expenses: 13 Grants and similar amounts paid (Part IX, column (A), lines 1–3) 13 786,027 919,094

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

15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10) 15 997,061 951,012

16a Professional fundraising fees (Part IX, column (A), line 11e) 16a 43,176 96,043

b Total fundraising expenses (Part IX, column (D), line 25) b 512,278

17 Other expenses (Part IX, column (A), lines 11a–11d, 11f–24f) 17 1,576,589 1,167,760

18 Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25) 18 3,402,853 3,133,909

19 Revenue less expenses Subtract line 18 from line 12 19 67 8,259

Net Assets or Fund Balances: 20 Total assets (Part X, line 16) 20 7,408,506 7,511,173

21 Total liabilities (Part X, line 26) 21 132,802 111,014

22 Net assets or fund balances Subtract line 21 from line 20 22 7,275,704 7,400,159

Part II Signature Block

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

Signature of officer: KARI L ROSBECK President and CEO Date: 2010-11-03

Paid Preparer's Use Only: Preparer's signature: Tate and Tryon Date: Washington, DC 20005 Check if self-employed EIN Phone no (202) 293-2200

Part IIIS

Statement of Program Service Accomplishments

1

Briefly describe the organization’s mission

THE TS ALLIANCE IS DEDICATED TO FINDING A CURE FOR TUBEROUS SCLEROSIS COMPLEX WHILE IMPROVING THE LIVES OF THE 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 exempt purpose achievements for each of the organization’s three largest program services by expenses

Section 501(c)(3) and 501(c)(4) organizations and section 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

4a

(Code) (Expenses \$ 1,425,738 including grants of \$ 919,094) (Revenue \$)

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 IN 2010, THE TS ALLIANCE SPENT A TOTAL OF \$1,016,232 IN RESEARCH FOR THE TSC NATURAL HISTORY DATABASE AND RESEARCH GRANT AWARDS ONE OF THE INTERESTING THINGS ABOUT TSC IS THAT IT AFFECTS EVERY PERSON DIFFERENTLY THE TS ALLIANCE DEVELOPED THE TSC NATURAL HISTORY DATABASE SIX YEARS AGO TO IDENTIFY IF THERE ARE SPECIFIC CORRELATIONS BETWEEN TSC GENE MUTATIONS AND THE IMPACT OF THE DISEASE ON A PERSON’S HEALTH OVER THEIR LIFETIME AS OF JUNE 30, 2010, 15 US-BASED TSC CLINICS WERE ENTERING DATA WITH 1,014 PEOPLE WITH TUBEROUS SCLEROSIS COMPLEX ENROLLED IN THE PROJECT OF THOSE, 498 ARE MALE, 516 ARE FEMALE SIX HUNDRED SIXTY FOUR (66%) ARE LESS THAN 18 YEARS OLD WITH THE YOUNGEST 3 MONTHS OLD, THE REMAINING 350 (34%) RESEARCH PARTICIPANTS ARE 18 OR OVER WITH THE OLDEST 76 YEARS OLD MEDICAL INFORMATION IS ENTERED IN AT LEAST 13 AREAS AFFECTED BY TSC (E G BRAIN, EYES, HEART, KIDNEYS, SKIN) EPILEPSY IS ENTERED AS A CONDITION AFFECTING 81% OF THE RESEARCH PARTICIPANTS ENROLLED 39% OF THOSE WITH EPILEPSY HAVE A HISTORY OF INFANTILE SPASMS OTHER CONDITIONS INCLUDE ANGIOFIBROMA (48%), RHABDOMYOMA (36%), ANGIOMYOLIPOMA (36%) AND SUBEPENDYMAL GIANT CELL TUMOR (19%) A POSTER OF THE FIRST RESEARCH FINDINGS FROM THE TSC NATURAL HISTORY DATABASE WAS PRESENTED AT THE AMERICAN EPILEPSY SOCIETY IN DECEMBER 2009 THE TS ALLIANCE PROVIDES FUNDING TO PARTICIPATING CLINICS TO PERFORM DATA ENTRY, MONITORS THE INTEGRITY OF THE DATABASE AND UTILIZES THE DATA TO INFORM CLINICAL TRIALS AND STUDIES THE TS ALLIANCE ALSO CONTINUED ITS COMMITMENT TO FUNDING RESEARCH GRANTS IN 2010, ONGOING FUNDING OF \$844,094 SUPPORTED 15 RESEARCH PROJECTS AWARDED IN PREVIOUS FISCAL YEARS IN ADDITION, A GRANT OF \$75,000 WAS AWARDED FROM NET ASSETS THROUGH A TS ALLIANCE ROTHBERG COURAGE AWARD IN SUPPORT OF A NEW TSC NEUROCOGNITIVE CLINICAL TRIAL THAT WILL RECRUIT STUDY PARTICIPANTS IN BOSTON AND CINCINNATI IN SEPTEMBER 2009, THE TS ALLIANCE SPONSORED THE INTERNATIONAL RESEARCH CONFERENCE FROM DNA TO HUMAN THERAPIES THE GOAL OF THE CONFERENCE WAS TO BRING TOGETHER RESEARCHERS AND HEALTH CARE PROFESSIONALS TO DISCUSS OUR CURRENT KNOWLEDGE OF THE UNDERLYING MECHANISMS THAT CAUSE THE VARIOUS MANIFESTATIONS OF TSC AND WHAT RESEARCH IS NEEDED IN THE FUTURE THE CONFERENCE WAS ATTENDED BY 150 PARTICIPANTS FROM 14 COUNTRIES (INCLUDING AUSTRALIA, CANADA, CHINA, ENGLAND, GERMANY, ITALY, JAPAN, MACEDONIA, THE NETHERLANDS, NORTHERN IRELAND, NORWAY, SCOTLAND, SWEDEN, AND THE USA), AND THE PARTICIPANTS INCLUDED PHYSICIANS, GENETIC COUNSELORS, NURSES, BASIC RESEARCHERS, CLINICAL RESEARCHERS, PARENTS OF INDIVIDUALS WITH TSC, AND INDUSTRY REPRESENTATIVES

4b

(Code) (Expenses \$ 384,849 including grants of \$) (Revenue \$)

FAMILY SERVICES DEVELOPS PROGRAMS AND SERVICES THAT PROVIDE INDIVIDUALS WITH TSC DIRECT ACCESS TO THE INFORMATION, RESOURCES, AND SPECIALISTS EXPERIENCED IN THE DIAGNOSIS, TREATMENT AND MANAGEMENT OF TSC THROUGH THE NETWORK OF 33 VOLUNTEER BRANCHES OF THE ORGANIZATION, CALLED COMMUNITY ALLIANCES, LOCAL EDUCATIONAL AND SUPPORT GROUP MEETINGS ARE HELD THROUGHOUT THE COUNTRY IN FEBRUARY 2010, THE TS ALLIANCE SPONSORED AND UNDERWROTE ITS ANNUAL LEADERSHIP TRAINING FOR OUR COMMUNITY ALLIANCE CHAIRS IN DC THESE GRASSROOTS VOLUNTEER LEADERS ARE TRULY THE HEART AND SOUL OF OUR ORGANIZATION AND THEIR EFFORTS NOT ONLY ACCOUNT FOR 50% OF THE REVENUE GENERATED BY THE ORGANIZATION, BUT ALSO MUCH OF THE EDUCATIONAL OUTREACH CONDUCTED ACROSS THE NATION THE TS ALLIANCE BELIEVES STRONGLY IN INVESTING IN THE ADVOCACY PROGRAM AND LEADERSHIP TRAINING TO PROVIDE SKILLS FOR OUR COMMUNITY LEADERS TO EFFECTIVELY BUILD NETWORKS ACROSS THE COUNTRY, TO MAKE TSC MORE VISIBLE IN THEIR COMMUNITIES, TO STRENGTHEN THEIR SPECIAL EVENTS AND TO EMPOWER THE VOLUNTEERS IN APRIL 2010, THE TS ALLIANCE INSTITUTED THE FIRST OF 18 TOWN HALL MEETINGS HELD AT COMMUNITY ALLIANCE LOCATIONS FROM APRIL TO DECEMBER 2010 THESE MEETINGS FACILITATE STRONGER CONNECTIONS WITH PEERS, RESEARCHERS, AND CLINICIANS IN THE COMMUNITY AND EDUCATE THE TSC COMMUNITY ABOUT CLINICAL TRIALS THE TS ALLIANCE ALSO CONTINUED A SERIES OF TELECONFERENCES AIMED AT REACHING CONSTITUENTS ACROSS THE COUNTRY WITH CLINICAL CARE SPECIALISTS AND SCIENTISTS FROM THE CONVENIENCE OF THEIR HOME EIGHT TELECONFERENCES TOOK PLACE ON SUBJECTS INCLUDING UNDERSTANDING NEUROCOGNITION AND BRAIN MANIFESTATIONS IN TSC, GENETICS AND TSC, KIDNEY INVOLVEMENT IN TSC, AUTISM SPECTRUM DISORDER AND TSC, TS ALLIANCE RESEARCH UPDATE, AND TSC CLINICAL TRIALS UPDATES IN ADDITION, THE DEPARTMENT OF EDUCATION AND ADVOCACY SUPPORTS FAMILIES AND INDIVIDUALS FROM ALL OVER THE UNITED STATES BY ATTENDING INDIVIDUAL EDUCATION PROGRAM (IEP) MEETINGS IN PERSON, THROUGH SKYPE, AND CONFERENCE CALLS DURING THE IEP SEASON APRIL THROUGH JUNE 2010 THERE WERE 16 TRAININGS HELD IN COLLABORATION WITH COMMUNITY ALLIANCES THROUGH CONFERENCE CALL TRAINING IN SPECIAL EDUCATION THE TS ALLIANCE COSPONSORED AN EDUCATIONAL RIGHTS TRAINING WITH THE OHIO STATE DEPARTMENT OF EDUCATION'S STATE SUPPORT TEAM REGION 7, WITH MORE 190 PARTICIPANTS ATTENDING EDUCATIONAL ADVOCACY IS AN IMPORTANT SERVICE TO TSC INDIVIDUALS AND FAMILIES AS THEY NAVIGATE THE SCHOOL SYSTEM AND AS THOSE AFFECTED TRANSITION FROM SCHOOL INTO THE COMMUNITY AS ADULTS IN ADDITION TO THE TRAININGS, TWO EDUCATIONAL PUBLICATIONS WERE WRITTEN TEACHER'S GUIDE EDUCATING CHILDREN WITH TSC, BEHAVIORS AND TSC, AND WHAT IS SECTION 504? THE TS ALLIANCE DIRECTOR OF ADVOCACY AND EDUCATION ALSO MAINTAINED AN ONGOING BLOG TO ENCOURAGE FREQUENT AND INTERACTIVE CONVERSATIONS WITH CONSTITUENTS AS THEY ENCOUNTERED CHALLENGES ON A DAILY BASIS AND FACILITATED THE ADULT TASK FORCE A SURVEY WAS SENT OUT TO ADULTS IN 2008 TO IDENTIFY AREAS OF NEEDS FOR ADULTS WITH TSC THE ADULT TASK FORCE IMPLEMENTED TOPIC CALLS IN THESE IDENTIFIED NEED AREAS TO SUPPORT OUR ADULT POPULATION THERE WERE 5 FIVE ADULT TOPIC CONFERENCE CALLS HELD IN 2010 TO ADDRESS THE NEEDS OF ADULTS DEALING WITH TSC THE TOPICS WERE "ANXIETY IN THE WORK PLACE AND SCHOOL, PART 1 AND PART 2," "WORKING WITH YOUR DOCTOR," AND TWO OPEN FORUMS IN RESPONSE TO REQUESTS FOR SUPPORT OF SIBLINGS OF CHILDREN WITH TSC, THE TS ALLIANCE CONTINUED ONLINE INTERACTIVE CHAT GROUPS HELD THREE TIMES A MONTH BASED ON SEVERAL AGE GROUPS THERE WERE MORE THAN 30 SIBLING CHATS HELD IN 2010 THE TS ALLIANCE HOSTS FOUR ONLINE DISCUSSION GROUPS TO OFFER EDUCATION AND SUPPORT, BASED ON PEER TYPES ADULTS WITH TSC, PARENTS/CAREGIVERS, TEENS, AND TSC PROFESSIONALS FINALLY, THE MANAGEMENT AND BOARD OF DIRECTORS OF THE TS ALLIANCE LAUNCHED AN ONLINE CONSTITUENCY STUDY TO GAUGE THE ORGANIZATION'S PERFORMANCE AND DETERMINE CONSTITUENTS' UNMET NEEDS THE SPECIFIC OBJECTIVES OF THE 2010 TS ALLIANCE CONSTITUENCY STUDY WERE AS FOLLOWS - TO GAUGE THE PERFORMANCE OF THE TS ALLIANCE IN MEETING CONSTITUENTS' NEEDS AND LIVING UP TO ITS MISSION, - TO DETERMINE AWARENESS, USAGE AND OPINION OF VARIOUS TS ALLIANCE RESOURCES, PROGRAMS AND EVENTS, - TO GAIN A BETTER UNDERSTANDING OF THE CHALLENGES FACED BY INDIVIDUALS AND FAMILIES LIVING WITH TSC AND IDENTIFY UNMET NEEDS, AND - TO PRIORITIZE THE ORGANIZATION'S STRATEGIC GOALS THE SURVEY WAS CONDUCTED BETWEEN FEBRUARY 11, 2010 AND APRIL 6, 2010 WITH 759 TOTAL RESPONDENTS THE RESULTS WILL ASSIST THE TS ALLIANCE IN EVALUATING FUTURE GOALS AND STRATEGIES OF THE ORGANIZATION AND THE NEEDS OF FUTURE PROGRAMS AND SERVICES

4c

(Code) (Expenses \$ 189,302 including grants of \$) (Revenue \$)

PUBLIC HEALTH EDUCATION HEIGHTENS AWARENESS OF TSC THROUGHOUT THE GENERAL PUBLIC TO BROADEN THE SCOPE OF SUPPORT AND UNDERSTANDING BEYOND TSC INDIVIDUALS AND THEIR FAMILIES IN 2010, THE TS ALLIANCE USED ONLINE BANNER OUTREACH ON EPILEPSY COM AND USNEWS COM TO INCREASE AWARENESS OF THE DISORDER AND TO DRIVE VISITORS TO OUR WEBSITE FOR MORE INFORMATION TSC, AS WELL AS THE WORK OF THE TS ALLIANCE, WAS ALSO HIGHLIGHTED IN DOZENS OF LOCAL STORIES GENERATED BY OUR GRASSROOTS VOLUNTEERS, RANGING FROM REPORTS ON EVENTS SUCH AS STEP FORWARD TO CURE TSC TO HUMAN INTEREST AND HEALTH REPORTS ABOUT FAMILIES AND INDIVIDUALS DEALING WITH THE DAILY STRUGGLES OF TSC THREE ISSUES OF OUR NATIONAL MAGAZINE, PERSPECTIVE, WERE PUBLISHED IN FY10 AND SENT TO 11,800 CONSTITUENTS PERSPECTIVE INCLUDES ARTICLES ON RESEARCH UPDATES, CONSTITUENT STORIES, EDUCATIONAL INITIATIVES, AND COMMUNITY GRASSROOTS ACTIVITIES THE TS ALLIANCE INCREASES AWARENESS AND PROVIDES EXTENSIVE EDUCATION THOUGH ITS WEBSITE VIA 950,000 TO 1.1 MILLION HITS MONTHLY FROM AN AVERAGE OF 18,500 UNIQUE VISITORS THE TS ALLIANCE ALSO HAS A PROLIFIC SOCIAL MEDIA OUTREACH PROGRAM UTILIZING FACEBOOK, MYSPACE, YOUTUBE, AND TWITTER, AND ITS ONLINE DISCUSSION GROUPS PROVIDE CRITICAL INFORMATION TO THE NEWLY DIAGNOSED AND OTHERS

4d

Other program services (Describe in Schedule O) See also Additional Data for Description

(Expenses \$ 164,736 including grants of \$) (Revenue \$ 56,970)

4e

Total program service expenses➤\$ 2,164,625

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? 	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? If "Yes," complete Schedule C, Part II 	4	Yes					
5	Section 501(c)(4), 501(c)(5), and 501(c)(6) organizations. Is the organization subject to the section 6033(e) notice and reporting requirement and proxy tax? If "Yes," complete Schedule C, Part III	5						
6	Did the organization maintain any donor advised funds or any similar funds or accounts where 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, 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 term, permanent, or quasi-endowments? If "Yes," complete Schedule D, Part V 	10	Yes					
11	Is the organization's answer to any of the following questions "Yes"? If so, complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable. 	11	Yes					
	• Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI.							
	• 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.							
	• 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.							
	• 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.							
	• Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X.							
	• 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? If "Yes," complete Schedule D, Part X.							
12	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI, XII, and XIII 	12		No				
12A	Was the organization included in consolidated, independent audited financial statements for the tax year? <table><tr><td>Yes</td><td>No</td></tr><tr><td></td><td>12A Yes</td></tr></table>	Yes	No		12A Yes			
Yes	No							
	12A Yes							
	If "Yes," completing Schedule D, Parts XI, XII, and XIII is optional							
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, and program service activities outside the United States? If "Yes," complete Schedule F, Part I 	14b	Yes					
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the U S ? If "Yes," complete Schedule F, Part II 	15	Yes					
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the U S ? If "Yes," complete Schedule F, Part III 	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 	17	Yes					
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				
20	Did the organization operate one or more hospitals? If "Yes," complete Schedule H	20		No				

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21	Yes	
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22		No
23	Did the organization answer "Yes" to Part VII, Section A, questions 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	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? <i>If "Yes," answer questions 24b-24d and complete Schedule K. If "No," go to line 25</i>	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) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	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? <i>If "Yes," complete Schedule L, Part I</i>	25b		No
26	Was a loan to or by a current or former officer, director, trustee, key employee, highly compensated employee, or disqualified person outstanding as of the end of the organization's tax year? <i>If "Yes," complete Schedule L, Part II</i>	26		No
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor, or a grant selection committee member, or to a person related to such an individual? <i>If "Yes," complete Schedule L, Part III</i>	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, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28a		No
b	A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>	28b		No
c	An entity of which a current or former officer, director, trustee, or key employee of the organization (or a family member) was an officer, director, trustee, or owner? <i>If "Yes," complete Schedule L, Part IV</i>	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	29		No
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	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? <i>If "Yes," complete Schedule R, Part I</i>	33		No
34	Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Parts II, III, IV, and V, line 1</i>	34	Yes	
35	Is any related organization a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35		No
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	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? <i>If "Yes," complete Schedule R, Part VI</i>	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11 and 19? Note. All Form 990 filers are required to complete Schedule O	38	Yes	

Part V

Statements Regarding Other IRS Filings and Tax Compliance

			Yes	No	
1a	Enter the number reported in Box 3 of Form 1096, <i>Annual Summary and Transmittal of U.S. Information Returns</i> . Enter -0- if not applicable	1a	39		
	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	
2a	Enter the number of employees reported on Form W-3, <i>Transmittal of Wage and Tax Statements</i> filed for the calendar year ending with or within the year covered by this return	2a	13		
	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 this return (see instructions)				2b
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year covered by this return?			3a	No
b If "Yes," has it filed a Form 990-T for this year? If "No," 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 the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts				
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, Disclosure by Tax-Exempt Entity Regarding Prohibited Tax Shelter Transaction?			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?			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, during the year, 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 For all contributions of qualified intellectual property, did the organization file Form 8899 as required?			7g		
h For contributions of cars, boats, airplanes, and other vehicles, did the organization file a Form 1098-C as required?			7h		
8 Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?			8		
9 Sponsoring organizations maintaining donor advised funds.					
a Did the organization make any taxable distributions under section 4966?			9a		
b Did the 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		

Part VII

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.

Section A. Governing Body and Management

			Yes	No
1a	Enter the number of voting members of the governing body	1a	29	
b	Enter the number of voting members that are independent	1b	29	
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?	2	Yes	
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?	3		No
4	Did the organization make any significant changes to its organizational documents since the prior Form 990 was filed?	4	Yes	
5	Did the organization become aware during the year of a material diversion of the organization's assets?	5		No
6	Does the organization have members or stockholders?	6	Yes	
7a	Does the organization have members, stockholders, or other persons who may elect one or more members of the governing body?	7a	Yes	
b	Are any decisions of the governing body subject to approval by members, stockholders, or other persons?	7b		No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following			
a	The governing body?	8a	Yes	
b	Each committee with authority to act on behalf of the governing body?	8b	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	9		No

Section B. Policies

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

			Yes	No
10a	Does the organization have local chapters, branches, or affiliates?	10a	Yes	
b	If "Yes," does the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with those of the organization?	10b	Yes	
11	Has the organization provided a copy of this Form 990 to all members of its governing body before filing the form?	11	Yes	
11A	Describe in Schedule O the process, if any, used by the organization to review the Form 990			
12a	Does the organization have a written conflict of interest policy? If "No," go to line 13	12a	Yes	
b	Are officers, directors or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Yes	
c	Does the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this is done	12c	Yes	
13	Does the organization have a written whistleblower policy?	13	Yes	
14	Does the organization have a written document retention and destruction policy?	14	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	15a	Yes	
b	Other officers or key employees of the organization	15b	Yes	
	If "Yes" to line a or b, 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?	16a		No
b	If "Yes," has the organization adopted a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and taken steps to safeguard the organization's exempt status with respect to such arrangements?	16b		

Section C. Disclosure

17	List the States with which a copy of this Form 990 is required to be filed	MD , CA , DC , ND , AK , AZ , RI , PA , CO , MA , NH , NY , NC , OH , OR , VA , CT , ME , GA , NV , AR , HI , IL , KS , KY , TN , MI , NJ , NM , UT , MN , WV , OK , WY , FL , AL , WA , SC , WI , MS , LA , TX , MO , DE , ID , IN , IA
18	Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (501(c) (3)s only) available for public inspection. Indicate how you make these available. Check all that apply. ☒ Own website ☒ Another's website ☒ Upon request	
19	Describe in Schedule O whether (and if so, how), the organization makes its governing documents, conflict of interest policy, and financial statements available to the public. See Additional Data Table.	
20	State the name, physical address, and telephone number of the person who possesses the books and records of the organization. 	the organization 801 Roeder Road No 750 silver spring, MD 20910 (301) 562-9890

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

☐ Check this box if the organization did not compensate any current or former officer, director, trustee or key employee

Form 990 (2009)

1b	Total	137,519	0	14,992
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2

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

1

		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 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		
	(A) Name and business address	(B) Description of services	(C) Compensation
2	Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 in compensation from the organization		
	0		

Part VIII

Statement of Revenue

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512, 513, or 514	
Contributions, gifts, grants and other similar amounts	1a	Federated campaigns . . .	1a					
	b	Membership dues	1b					
	c	Fundraising events	1c	1,750,127				
	d	Related organizations	1d	180,636				
	e	Government grants (contributions)	1e	90,696				
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	1,199,838				
	g	Noncash contributions included in lines 1a-1f \$ _____						
	h	Total. Add lines 1a-1f		3,221,297				
Program Service Revenue	2a	CONF REGISTRATION	Business Code	900,004	56,970	56,970		
	b							
	c							
	d							
	e							
	f	All other program service revenue						
	g	Total. Add lines 2a-2f		56,970				
	Other Revenue	3	Investment income (including dividends, interest and other similar amounts)		4,644			4,644
4		Income from investment of tax-exempt bond proceeds . .						
5		Royalties						
6a		Gross Rents	(i) Real	(ii) Personal				
b		Less rental expenses						
c		Rental income or (loss)						
d		Net rental income or (loss)						
7a		Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other	60			
b		Less cost or other basis and sales expenses						
c		Gain or (loss)	60					
d		Net gain or (loss)			60			60
8a		Gross income from fundraising events (not including \$ 1,750,127 of contributions reported on line 1c) See Part IV, line 18	a	69,859				
b		Less direct expenses	b	214,629				
c		Net income or (loss) from fundraising events . .			-144,770	-144,770		
9a		Gross income from gaming activities See Part IV, line 19	a					
b		Less direct expenses	b					
c		Net income or (loss) from gaming activities . .						
10a		Gross sales of inventory, less returns and allowances	a					
b		Less cost of goods sold . . .	b					
c		Net income or (loss) from sales of inventory . .						
	Miscellaneous Revenue	Business Code						
11a	OTHER		900,099	3,967	3,967			
b								
c								
d	All other revenue							
e	Total. Add lines 11a-11d			3,967				
12	Total revenue. See Instructions			3,142,168	-83,833	0	4,704	

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) but are not required to complete columns (B), (C), and (D).

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 governments and organizations in the U S See Part IV, line 21	855,153	855,153		
2	Grants and other assistance to individuals in the U S See Part IV, line 22				
3	Grants and other assistance to governments, organizations, and individuals outside the U S See Part IV, lines 15 and 16	63,941	63,941		
4	Benefits paid to or for members				
5	Compensation of current officers, directors, trustees, and key employees	152,511	93,199	23,821	35,491
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	638,567	390,738	99,043	148,786
8	Pension plan contributions (include section 401(k) and section 403(b) employer contributions)	17,928	10,824	2,979	4,125
9	Other employee benefits	76,100	45,945	12,645	17,510
10	Payroll taxes	65,906	39,792	10,949	15,165
11	Fees for services (non-employees)				
a	Management				
b	Legal	6,595		6,595	
c	Accounting	129,722		129,722	
d	Lobbying	98,880	98,880		
e	Professional fundraising See Part IV, line 17	96,043			96,043
f	Investment management fees	73		73	
g	Other	33,889	25,625	7,927	337
12	Advertising and promotion	20,410	20,410		
13	Office expenses	112,421	21,206	63,970	27,245
14	Information technology	14,386	14,386		
15	Royalties				
16	Occupancy	148,686	353	147,277	1,056
17	Travel	88,130	65,698	1,365	21,067
18	Payments of travel or entertainment expenses for any federal, state, or local public officials				
19	Conferences, conventions, and meetings	75,528	70,101	4,103	1,324
20	Interest				
21	Payments to affiliates				
22	Depreciation, depletion, and amortization	41,663	25,239	16,424	
23	Insurance	6,983		6,983	
24	Other expenses Itemize expenses not covered above (Expenses grouped together and labeled miscellaneous may not exceed 5% of total expenses shown on line 25 below)				
a	printing	132,090	46,759	10,915	74,416
b	naTURAL HISTORY DATABAS	97,138	97,138		
c	bank and CREDIT CARD FE	68,499	127	68,247	125
d	equipment maintenance a	52,173	640	40,748	10,785
e	Miscellaneous expenses	40,494	38,224	70	2,200
f	All other expenses		140,247	-196,850	56,603
25	Total functional expenses. Add lines 1 through 24f	3,133,909	2,164,625	457,006	512,278
26	Joint costs. Check here ☒ if following SOP 98-2 Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation	77,522	38,761	0	38,761

Part X

Balance Sheet

					(A)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing			730,732	1	320,254
	2	Savings and temporary cash investments			2,138,002	2	2,721,274
	3	Pledges and grants receivable, net			218,600	3	132,900
	4	Accounts receivable, net			21,815	4	15,130
	5	Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L				5	
	6	Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) Complete Part II of Schedule L				6	
	7	Notes and loans receivable, net				7	
	8	Inventories for sale or use			23,841	8	17,793
	9	Prepaid expenses and deferred charges			47,609	9	85,652
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a	373,250	186,415	10c	158,842
	b	Less accumulated depreciation	10b	214,408			
	11	Investments—publicly traded securities				11	
	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			4,041,492	15	4,059,328
	16	Total assets. Add lines 1 through 15 (must equal line 34)			7,408,506	16	7,511,173
Liabilities	17	Accounts payable and accrued expenses			82,134	17	53,655
	18	Grants payable				18	
	19	Deferred revenue			3,900	19	
	20	Tax-exempt bond liabilities				20	
	21	Escrow or custodial account liability Complete Part IV of Schedule D				21	
	22	Payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L				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 Complete Part X of Schedule D			46,768	25	57,359
	26	Total liabilities. Add lines 17 through 25			132,802	26	111,014
Net Assets or Fund Balances	Organizations that follow SFAS 117, check here ☒ and complete lines 27 through 29, and lines 33 and 34.						
	27	Unrestricted net assets			4,897,311	27	4,852,458
	28	Temporarily restricted net assets			1,473,949	28	1,643,257
	29	Permanently restricted net assets			904,444	29	904,444
	Organizations that do not follow SFAS 117, check here ☐ and complete lines 30 through 34.						
	30	Capital stock or trust principal, or current funds				30	
	31	Paid-in or capital surplus, or land, building or equipment fund				31	
	32	Retained earnings, endowment, accumulated income, or other funds				32	
	33	Total net assets or fund balances			7,275,704	33	7,400,159
	34	Total liabilities and net assets/fund balances			7,408,506	34	7,511,173

Part XI Financial Statements and Reporting

	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? . . .		No
b Were the organization's financial statements audited by an independent accountant?	Yes	
c If "Yes," to 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	
d If "Yes" to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued on a consolidated basis, separate basis, or both ☐ Separate basis ☒ Consolidated basis ☐ Both consolidated and separated basis		
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 . . .		

SCHEDULE A
(Form 990 or 990EZ)

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. ▶ See separate instructions.

OMB No 1545-0047

2009

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 11, check only one box)

- 1

☐

A church, convention of churches, or association of churches **section 170(b)(1)(A)(i).**
- 2

☐

A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E)
- 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 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)
- 10

☐

An organization organized and operated exclusively to test for public safety See**section 509(a)(4).**
- 11

☐

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 that describes the type of supporting organization and complete lines 11e through 11h

a

☐

Type I

b

☐

Type II

c

☐

Type III - Functionally integrated

d

☐

Type III - Other

e

☐

By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2)

f

☐

If the organization received a written determination from the IRS that it is a Type I, Type II or Type III supporting organization, check this box

g

☐

Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

(i)

a person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the the supported organization?

(ii)

a family member of a person described in (i) above?

(iii)

a 35% controlled entity of a person described in (i) or (ii) above?

h

☐

Provide the following information about the supported organization(s)

	Yes	No
11g(i)		
11g(ii)		
11g(iii)		

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1- 9 above or IRC section (see instructions))	(iv) Is the organization in col (i) listed in your governing document?		(v) Did you notify the organization in col (i) of your support?		(vi) Is the organization in col (i) organized in the U S ?		(vii) Amount of support?
			Yes	No	Yes	No	Yes	No	
Total									

Part II

Support Schedule for Organizations Described in IRC 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.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	2,972,746	3,272,110	3,524,716	3,324,865	3,221,297	16,315,734
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	2,972,746	3,272,110	3,524,716	3,324,865	3,221,297	16,315,734
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)						
6 Public Support. Subtract line 5 from line 4						16,315,734

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
7 Amounts from line 4	2,972,746	179,275	3,524,716	3,324,865	3,221,297	16,315,734
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	107,458	179,275	128,476	35,978	4,704	455,891
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income (Explain in Part IV) Do not include gain or loss from the sale of capital assets	18,035	27,962	2,467	13,767	3,967	66,198
11 Total support (Add lines 7 through 10)						16,837,823

12

Gross receipts from related activities, etc (See instructions)

12

5,185,255

13

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

Section C. Computation of Public Support Percentage

14	Public Support Percentage for 2009 (line 6 column (f) divided by line 11 column (f))	14	96.900 %
15	Public Support Percentage for 2008 Schedule A, Part II, line 14	15	96.590 %

16a

33 1/3% support test—2009. 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—2008. If the organization did not check the 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—2009. 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 IV how the organization meets the "facts and circumstances" test The organization qualifies as a publicly supported organization

b

10%-facts-and-circumstances test—2008. 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 IV how the organization meets the "facts and circumstances" test The organization qualifies as a publicly supported organization

18

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

Part IIISupport Schedule for Organizations Described in IRC 509(a)(2)
(Complete only if you checked the box on line 9 of Part I.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
1Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3Gross receipts from activities that are not an unrelated trade or business under section 513						
4Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5The value of services or facilities furnished by a governmental unit to the organization without charge						
6Total. Add lines 1 through 5						
7aAmounts included on lines 1, 2, and 3 received from disqualified persons						
bAmounts 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						
cAdd lines 7a and 7b						
8Public Support (Subtract line 7c from line 6)						

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2005	(b) 2006	(c) 2007	(d) 2008	(e) 2009	(f) Total
9Amounts from line 6						
10aGross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
bUnrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
cAdd lines 10a and 10b						
11Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13Total support (Add lines 9, 10c, 11 and 12.)						
14First Five Years If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here						

Section C. Computation of Public Support Percentage

15Public Support Percentage for 2009 (line 8 column (f) divided by line 13 column (f))	15	
16Public support percentage from 2008 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17Investment income percentage for 2009 (line 10c column (f) divided by line 13 column (f))	17	
18Investment income percentage from 2008 Schedule A, Part III, line 17	18	
19a33 1/3% support tests—2009. 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		
b33 1/3% support tests—2008. 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		
20Private Foundation If the organization did not check a box on line 14, 19a or 19b, check this box and see instructions		

Part IV

Supplemental Information. Supplemental Information. Complete this part to provide the explanation required by Part II, line 10; Part II, line 17a or 17b; or Part III, line 12. Provide any other additional information. See instructions

Explanation	
Schedule A, Part II, Line 10, Explanation of Other Income	INCOME FROM OTHER PROGRAM RELATED ACTIVITIES

Additional Data

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

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

4d. Other program services				
(Code	) (Expenses \$		including grants of \$	) (Revenue \$
	152,958			
GOVERNMENT RELATIONS FOCUSES ON EDUCATING MEMBERS OF CONGRESS ABOUT TSC TO OBTAIN FEDERAL RESOURCES TO FURTHER TSC RESEARCH AND CLINICAL CARE IN 2010, THE TS ALLIANCE GRASSROOTS VOLUNTEERS CONDUCTED A MARCH ON CAPITOL HILL RESULTING IN MORE THAN 390 PERSONAL CONGRESSIONAL VISITS AND THE DELIVERY OF INFORMATION TO EVERY CONGRESSIONAL OFFICE THESE EFFORTS RESULTED IN 90 MEMBERS OF THE HOUSE OF REPRESENTATIVES SIGNING A LETTER OF SUPPORT CIRCULATED BY REPRESENTATIVES LORETTA SANCHEZ (D-CA) AND GARY MILLER (R-CA) AND 22 SENATORS SIGNING A BIPARTISAN LETTER OF SUPPORT CIRCULATED BY SENATORS SHERROD BROWN (D-OH) AND MIKE CRAPO (R-ID) FROM SIMILAR EFFORTS OF THESE VOLUNTEERS THE PRIOR YEAR, THE US CONGRESS APPROPRIATED \$6 MILLION TO TSC RESEARCH THROUGH THE DEPARTMENT OF DEFENSE CONGRESSIONAL DIRECTED MEDICAL RESEARCH PROGRAM IN 2010 THE TS ALLIANCE BELIEVES THE INVESTMENT IN THIS PROGRAM HAS A PROFOUND IMPACT ON MOVING NEW TREATMENTS, AND ULTIMATELY A CURE FOR TSC, FORWARD THE RESEARCH PROGRAM ADMINISTERED FROM THE APPROPRIATION IS A COMPETITIVE GRANT REVIEW PROGRAM AT THE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM IN THE DEPARTMENT OF DEFENSE WHILE THE TS ALLIANCE RECEIVES NO DIRECT FUNDING, THESE FEDERAL RESEARCH DOLLARS ARE CENTRAL TO THE MISSION OF THE ORGANIZATION PROFESSIONAL EDUCATION EXPANDS PROGRAMS TARGETING HEALTH CARE PROVIDERS WHO PROVIDE CARE FOR INDIVIDUALS WITH TSC, MEDICAL STUDENTS, GENETIC COUNSELORS AND EDUCATORS TO MINIMIZE THE CONSEQUENCES OF IGNORANCE AND MISINFORMATION IN 2010, THE TS ALLIANCE PRESENTED AND PARTICIPATED IN PROFESSIONAL CONFERENCES THAT ASSISTED IN EDUCATING THESE PROFESSIONALS, INCLUDING THE CHILD NEUROLOGY SOCIETY, THE AMERICAN EPILEPSY SOCIETY (AES), AND THE AMERICAN THORACIC SOCIETY IN ADDITION, AN ANNUAL MEETING OF TSC CLINIC DIRECTORS WAS HELD DURING THE INTERNATIONAL RESEARCH CONFERENCE FOR UPDATES IN RESEARCH, CLINICAL CARE, AND THE TSC NATURAL HISTORY DATABASE THE TS ALLIANCE CONTINUED TO MONITOR A LISTSERV/ONLINE DISCUSSION GROUP IN 2010 THAT CONNECTS PROFESSIONALS IN THE FIELD OF TSC CARE, RESEARCH AND SCIENCE THERE ARE CURRENTLY 50 PROFESSIONALS ON THIS LIST, WHICH ALSO SERVES AS A RESOURCE FOR PROFESSIONALS NOT FAMILIAR WITH TSC SEEKING GUIDANCE FROM PEERS IN ADDITION, A MONTHLY ONLINE NEWSLETTER CALLED TSC ALERT WAS SENT TO NEARLY 1,000 MEDICAL PROFESSIONALS AND SCIENTISTS FURTHER, THE DIRECTOR OF ADVOCACY AND EDUCATION COLLABORATED WITH NATIONAL EDUCATIONAL NETWORKS, SUCH AS THE NATIONAL ASSOCIATION OF MIDDLE SCHOOLS, IN OUTREACH TO EDUCATORS IN THE AREA OF TSC AND SERVICES NEEDED FOR APPROPRIATE EDUCATIONAL REQUIREMENTS THE DIRECTOR PRESENTED AT FIVE PROFESSIONAL CONFERENCES IN OHIO, PENNSYLVANIA AND TEXAS THESE PROFESSIONAL PRESENTATIONS PROVIDED OUTREACH TO MORE THAN 389 TEACHERS AND ADMINISTERS IN THE EDUCATIONAL NEEDS OF CHILDREN WITH TSC PROVIDING CHILDREN WITH APPROPRIATE EDUCATIONS IS THE KEY TO INDIVIDUALS HAVING A GOOD QUALITY OF LIFE				
(Code	) (Expenses \$		including grants of \$	) (Revenue \$
	11,778			56,970
Professional Education expands programs targeting health care providers who treat individuals with TSC , medical students, genetic counselors and educators to minimize the consequences of ignorance and misinformation In 2010, the TS Alliance presented and participated in professional conferences that assisted in educating these professionals These include the International Research Conference held in Brighton, UK, American Society of Nephrology, the American Epilepsy Society (AES), and American Association of Neurology In addition, an annual meeting of TSC Clinic Directors was held during the AES meeting for updates in research, clinical care, the TSC Natural History Database and new technology, www.seizuretracker.com The TS Alliance also created a professional listserv in 2009 to connect professionals in order to provide access to the most updated information on treatment and education options Further, the Director of Advocacy and Education collaborated with national educational networks, such as the National Association of Middle Schools, in outreach to educators in the area of TSC and services needed for appropriate educational requirements The Director presented at five professional conferences in Ohio, Pennsylvania and Texas				

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	(C) Position (check all that apply)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099- MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
CELIA MASTBAUM CHAIR	5 00	X		X				0	0	0
DAVID PARKES VICE-CHAIR	5 00	X		X				0	0	0
HENRY SHAPIRO SECRETARY	5 00	X		X				0	0	0
ITA DIDOMENICO TREASURER	5 00	X		X				0	0	0
CATHY KRINSKY IMMEDIATE PAST CHAIR	5 00	X		X				0	0	0
JULIE BLUM BOARD MEMBER	2 00	X						0	0	0
MATT BOLGER BOARD MEMBER	2 00	X						0	0	0
MARK CARROLL BOARD MEMBER	2 00	X						0	0	0
WILL COOPER SR BOARD MEMBER	4 00	X						0	0	0
PETER CRINO MD PHD BOARD MEMBER	1 00	X						0	0	0
REIKO DONATO BOARD MEMBER	4 00	X						0	0	0
TERRY ELLING BOARD MEMBER	4 00	X						0	0	0
WILLIAM FORD BOARD MEMBER	2 00	X						0	0	0
JANIE FROST RN BOARD MEMBER	4 00	X						0	0	0
JENNIFER GLASSMAN BOARD MEMBER	2 00	X						0	0	0
STEVEN GOLDSTEIN BOARD MEMBER	2 00	X						0	0	0
RON HEFFRON BOARD MEMBER	4 00	X						0	0	0
ELIZABETH HENSKE MD BOARD MEMBER	2 00	X						0	0	0
LINDA JACKSON BOARD MEMBER	4 00	X						0	0	0
TOMMY LINDSEY BOARD MEMBER	2 00	X						0	0	0
ALAN MARSHALL BOARD MEMBER	2 00	X						0	0	0
KATHY MAYRSOHN BOARD MEMBER	2 00	X						0	0	0
JOHN NICHOLSON MD M BOARD MEMBER	2 00	X						0	0	0
COURTNEY O'MALLEY BOARD MEMBER	2 00	X						0	0	0
DAVID SCHENKEIN MD BOARD MEMBER	2 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	(C) Position (check all that apply)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
CHRIS SHEFFIELD BOARD MEMBER	1 00	X						0	0	0
JUDITH SHOULAK BOARD MEMBER	5 00	X						0	0	0
ELIZABETH THIELE MD BOARD MEMBER	2 00	X						0	0	0
ROB THURSTON BOARD MEMBER	2 00	X						0	0	0
KARI L ROSBECK PRESIDENT & CEO	65 00			X				137,519	0	14,992

Form 990, Part IX - Statement of Functional Expenses - 24a - 24e Other Expenses

<i>Do not include amounts reported on line 6b, 8b, 9b, and 10b of Part VIII.</i>	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
printing	132,090	46,759	10,915	74,416
naTURAL HISTORY DATABAS	97,138	97,138		
bank and CREDIT CARD FE	68,499	127	68,247	125
equipment maintenance a	52,173	640	40,748	10,785
Miscellaneous expenses	40,494	38,224	70	2,200

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. ▶ See separate instructions.**

OMB No 1545-0047

2009

Open to Public
Inspection

If the organization answered “Yes,” to Form 990, Part IV, Line 3, or Form 990-EZ, Part VI, 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,” to 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,” to Form 990, Part IV, Line 5 (Proxy Tax) or Form 990-EZ, line 35a (regarding proxy tax), 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
- 2
- Political expenditures
- ▶
- \$
- 3
- Volunteer hours

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 funtion 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
- State the names, addresses and employer identification number (EIN) of all section 527 political organizations to which payments were made For each organization listed, enter the amount paid from the filing organization's funds Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC) If additional space is needed, provide information in Part IV

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

Part II-A

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

A

Check

☐

if the filing organization belongs to an affiliated group

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)		34,107													
b Total lobbying expenditures to influence a legislative body (direct lobbying)		118,851													
c Total lobbying expenditures (add lines 1a and 1b)		152,958													
d Other exempt purpose expenditures		3,383,909													
e Total exempt purpose expenditures (add lines 1c and 1d)		3,536,867													
f Lobbying nontaxable amount Enter the amount from the following table in both columns		326,843													
<table><thead><tr><th>If the amount on line 1e, column (a) or (b) is:</th><th>The lobbying nontaxable amount is:</th></tr></thead><tbody><tr><td>Not over \$500,000</td><td>20% of the amount on line 1e</td></tr><tr><td>Over \$500,000 but not over \$1,000,000</td><td>\$100,000 plus 15% of the excess over \$500,000</td></tr><tr><td>Over \$1,000,000 but not over \$1,500,000</td><td>\$175,000 plus 10% of the excess over \$1,000,000</td></tr><tr><td>Over \$1,500,000 but not over \$17,000,000</td><td>\$225,000 plus 5% of the excess over \$1,500,000</td></tr><tr><td>Over \$17,000,000</td><td>\$1,000,000</td></tr></tbody></table>		If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:	Not over \$500,000	20% of the amount on line 1e	Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000	Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000	Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000	Over \$17,000,000	\$1,000,000		
If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:														
Not over \$500,000	20% of the amount on line 1e														
Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000														
Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000														
Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000														
Over \$17,000,000	\$1,000,000														
g Grassroots nontaxable amount (enter 25% of line 1f)		81,711													
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 instructions for lines 2a through 2f on page 4.)

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2006	(b) 2007	(c) 2008	(d) 2009	(e) Total
2a Lobbying non-taxable amount	339,627	327,641	296,364	326,843	1,290,475
b Lobbying ceiling amount (150% of line 2a, column(e))					1,935,713
c Total lobbying expenditures	104,052	186,704	142,286	152,958	586,000
d Grassroots non-taxable amount	84,907	81,910	74,091	81,711	322,619
e Grassroots ceiling amount (150% of line 2d, column (e))					483,929
f Grassroots lobbying expenditures	8,048	4,000	16,771	34,107	62,926

Part II-B

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

		(a)		(b)
		Yes	No	Amount
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? If "Yes," describe in Part IV			
	j Total 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 carryover 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) if BOTH Part III-A, lines 1 and 2 are answered "No" OR if Part III-A, line 3 is answered "Yes".

1	Dues, assessments and similar amounts from members	1	
2	Section 162(e) non-deductible 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

Complete this part to provide the descriptions required for Part I-A, line 1, Part I-B, line 4, Part I-C, line 5, and Part II-B, line 1i. Also, complete this part for any additional information.

Identifier	Return Reference	Explanation

SCHEDULE D
(Form 990)

Supplemental Financial Statements

▶ Complete if the organization answered "Yes," to Form 990, Part IV, line 6, 7, 8, 9, 10, 11, or 12.
▶ Attach to Form 990. ▶ See separate instructions.

OMB No 1545-0047

2009

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

	(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year	
2	Aggregate contributions to (during year)	
3	Aggregate 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 may 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" to 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 pleasure)

☐ Preservation of an historically importantly land area

☐ Protection of natural habitat

☐ Preservation of a certified historic structure

☐ Preservation of open space

2

Complete lines 2a–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
2a	Total number of conservation easements
2b	Total acreage restricted by conservation easements
2c	Number of conservation easements on a certified historic structure included in (a)
2d	Number of conservation easements included in (c) acquired after 8/17/06

3

Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the taxable 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 and enforcing conservation easements during the year ▶ _____

7

Amount of expenses incurred in monitoring, inspecting, 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 170(h)(4)(B)(ii)?

☐ Yes ☐ No

9

In Part XIV, 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" to Form 990, Part IV, line 8.

1a

If the organization elected, as permitted under SFAS 116, 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 XIV, the text of the footnote to its financial statements that describes these items

b

If the organization elected, as permitted under SFAS 116, 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) Revenues included in 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 relating to these items

a

Revenues included in Form 990, Part VIII, line 1 ▶ \$ _____

b

Assets included in Form 990, Part X ▶ \$ _____

For Privacy Act and Paperwork Reduction Act Notice, see the Intructions for Form 990

Cat No 52283D

Schedule D (Form 990) 2009

Part III

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

3

Using the organization's 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 XIV

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" to 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 XIV 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?

☐ Yes

☐ No

b

If "Yes," explain the arrangement in Part XIV

Part V

Endowment Funds. Complete if the organization answered "Yes" to 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	3,750,509	4,856,856			
b Contributions	13,523	6,722			
c Investment earnings or losses	312,223	-832,060			
d Grants or scholarships					
e Other expenditures for facilities and programs	210,174	281,009			
f Administrative expenses					
g End of year balance	3,866,081	3,750,509			

2

Provide the estimated percentage of the year end balance held as

a

Board designated or quasi-endowment 76 600 % %

b

Permanent endowment 23 400 % %

c

Term endowment %

3a

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

(i) unrelated organizations

3a(i)

No

(ii) related organizations

3a(ii)

No

b

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

3b

4

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

Part VI

Investments—Land, Buildings, and Equipment. See Form 990, Part X, line 10.

Description of investment	(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		27,000		27,000
d Equipment		33,021		33,021
e Other		313,229	214,408	98,821
Total. Add lines 1a-1e (Column (d) should equal Form 990, Part X, column (B), line 10(c).)				158,842

Schedule D (Form 990) 2009

Part XI Reconciliation of Change in Net Assets from Form 990 to Financial Statements		
1	Total revenue (Form 990, Part VIII, column (A), line 12)	13,142,168
2	Total expenses (Form 990, Part IX, column (A), line 25)	3,133,909
3	Excess or (deficit) for the year Subtract line 2 from line 1	8,259
4	Net unrealized gains (losses) on investments	623
5	Donated services and use of facilities	
6	Investment expenses	
7	Prior period adjustments	
8	Other (Describe in Part XIV)	115,572
9	Total adjustments (net) Add lines 4 - 8	116,195
10	Excess or (deficit) for the year per financial statements Combine lines 3 and 9	124,454

Part XII Reconciliation of Revenue per Audited Financial Statements With Revenue per Return		
1	Total revenue, gains, and other support per audited financial statements	13,264,052
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12	
a	Net unrealized gains on investments2a623	
b	Donated services and use of facilities2b5,689	
c	Recoveries of prior year grants2c	
d	Other (Describe in Part XIV)2d115,572	
e	Add lines 2a through 2d2e121,884	
3	Subtract line 2e from line 13	3,142,168
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 7b4a	
b	Other (Describe in Part XIV)4b	
c	Add lines 4a and 4b4c0	
5	Total Revenue Add lines 3 and 4c. (This should equal Form 990, Part I, line 12)5	3,142,168

Part XIII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return		
1	Total expenses and losses per audited financial statements	13,139,597
2	Amounts included on line 1 but not on Form 990, Part IX, line 25	
a	Donated services and use of facilities2a5,689	
b	Prior year adjustments2b	
c	Other losses2c	
d	Other (Describe in Part XIV)2d	
e	Add lines 2a through 2d2e5,689	
3	Subtract line 2e from line 13	3,133,908
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 7b4a	
b	Other (Describe in Part XIV)4b	
c	Add lines 4a and 4b4c0	
5	Total expenses Add lines 3 and 4c. (This should equal Form 990, Part I, line 18)5	3,133,908

Part XIV Supplemental Information

Complete this part to 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, Part XI, line 8, Part XII, lines 2d and 4b, and Part XIII, lines 2d and 4b. Also complete this part to provide any additional information.

Identifier	Return Reference	Explanation
Part V, Line 4	Description of Intended Use of Endowment Funds	The Alliance's Endowments consist of three funds established for different purposes. The Alliance's endowments include two traditional donor-restricted endowment funds and one board-designated endowment fund. The board-designated endowment fund solely consists of The Endowment Fund's unrestricted net asset balance.
Part XI, Line 8 - Other Adjustments		change in interest in affiliate 115572
Part XII, Line 2d - Other Adjustments		CHANGE IN INTEREST IN ENDOWMENT FUND 115572

Part II

Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Check this box if no one recipient received more than \$5,000 ☒

Use Schedule F-1 (Form 990) if additional space is needed.

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			europe	research grant	33,000	check			cash
			europe	research grant	30,941	check			cash

2

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

2

3

Enter total number of other organizations or entities

0

Part III **Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 16.
Use Schedule F-1 (Form 990) if additional space is needed.

[illegible]

Complete this part to provide the information required in Part I, line 2, and any additional information.

Schedule F (Form 990) 2009

SCHEDULE G
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding
Fundraising or Gaming Activities

Complete if the organization answered "Yes" to 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. ▶ See separate instructions.

OMB No. 1545-0047

2009

Open to Public
Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

Employer identification number
95-3018799

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

- 1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- a ☒ Mail solicitations

b ☒ Internet and e-mail solicitations

c ☒ Phone solicitations

d ☒ In-person solicitations

e ☒ Solicitation of non-government grants

f ☒ Solicitation of government grants

g ☒ Special fundraising events
- 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 activities? ☒ Yes ☐ No
- b If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization. Form 990-EZ filers are not required to complete this table.

(i) Name of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
TIMOTHY ROGERS	NY GALA, dc food & wine, major donors		No	659,618	65,000	594,618
BLUE ROOM EVENTS	LA COMEDY FOR A CURE	Yes		249,751	15,544	234,207
Total ▶				909,369	80,544	828,825

- 3 List all states in which the organization is registered or licensed to solicit funds or has been notified it is exempt from registration or licensing.
- AK,AL,AR,AZ,CA,CO,CT,DC,DE,FL,GA,HI,IA,ID,IL,IN,KS,KY,LA,MA,MD,ME,MI,MN,MO,MS,NC,ND,NH,NJ,NM,NV,OH,OK,OR,PA,RI,SC,TN, TX,UT,VA,WA,WI,WV,WY

Part II Fundraising Events.

Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 on Form 990-EZ, line 6a. List events with gross receipts greater than \$5,000.

		(a) Event #1	(b) Event #2	(c) Other Events	(d) Total Events
		LA COMEDY FOR A CURE (event type)	NEW YORK COMEDY FOR A CURE (event type)	54 (total number)	(Add col (a) through col (c))
Revenue	1	Gross receipts	249,751	203,204	1,367,031
	2	Less Charitable contributions	236,734	190,009	1,323,384
	3	Gross income (line 1 minus line 2)	13,017	13,195	43,647
Direct Expenses	4	Cash prizes			
	5	Non-cash prizes	22	749	26,171
	6	Rent/facility costs	61,657	22,700	62,421
	7	Food and beverages	1,742	5,000	7,782
	8	Entertainment	30	150	3,396
	9	Other direct expenses	7,969	7,675	7,165
	10	Direct expense summary Add lines 4 through 9 in column (d)			
	11	Net income summary Combine lines 3, column d, and line 10.			

Part III Gaming.

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

		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming
					(Add col (a) through col (c))
Revenue	1	Gross revenue			
	2	Cash prizes			
Direct Expenses	3	Non-cash prizes			
	4	Rent/facility costs			
	5	Other 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 Combine lines 1, column d, and line 7			

		Yes	No
9	Enter the state(s) in which the organization operates gaming activities _____		
a	Is the organization licensed to operate gaming activities in each of these states?	9a	
b	If "No," Explain _____		
10a	Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year?	10a	
b	If "Yes," Explain _____		
11	Does the organization operate gaming activities with nonmembers?	11	
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?	12	

		Yes	No
13	Indicate the percentage of gaming activity operated in		
a	The organization's facility 13a		
b	An outside facility 13b		
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?	15a	
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		
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?	17a	
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 ► \$		

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," to Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990

OMB No 1545-0047

2009

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 Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21 for any recipient that received more than \$5,000. Check this box if no one recipient received more than \$5,000. Use Part IV and Schedule I-1 (Form 990) if additional space is needed ▶ ☐

(a) Name and address of organization or government	(b) EIN	(c) IRC Code 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
See Additional Data Table							

2

Enter total number of section 501(c)(3) and government organizations

14

3

Enter total number of other organizations

1

Software ID:

Software Version:

EIN: 95-3018799

Name: NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

Form 990, Schedule I, Part II, Grants and Other Assistance to Governments and Organizations in the United States

(a) Name and address of organization or government	(b) EIN	(c) IRC Code 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 & WOMEN'S HOSPITAL75 francis street boston,MA 02115	04-2312909		179,788				clinical trials and research grants
harvard school of public health677 huntington avenue boston,MA 02115	04-2103580		12,500				Research grant
fox chase CANCER CENTER 333 COTTMAN AVA PHILADELPHIA,PA 19111	23-2003072		12,500				Research grant
vanderbilt UNIVERSITY medical centerdept of finance dept AT 40303 atlanta,GA 31192	62-0476822		50,000				Research grant
UNIVERSITY OF TEXASPO BOX 4786-750 HOUSTON,TX 77210	74-6000949		50,000				Research grant
UNIVERSITY OF WASHINGTON4326 University Way NE seattle,WA 98105	91-6001537		54,753				Research grant
md anderson cancer centerpo box 301402 houston,TX 77230	74-6000203		9,375				Research grant
washington university in st louisone brookings drive st louis,MO 63130	43-0653611		49,251				Research grant
children's hospitalPO BOX 414413 BOSTON,MA 02241	04-2774441		116,000				Research grant
yale university SCHOOL OF MEDICINE265 church street new haven,CT 06511	06-0646973		59,712				Research grant

Form 990, Schedule I, Part II, Grants and Other Assistance to Governments and Organizations in the United States

(a) Name and address of organization or government	(b) EIN	(c) IRC Code 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
HARVARD MEDICAL SCHOOL25 SHATTUCK ST SUITE 509 Boston, MA 02115	04-2103580		66,000				Research grant
columbia UNIVERSITY MEDICAL CENTERPO BOX 29789 NEW YORK, NY 10087	13-5598093		66,000				Research grant
NEW YORK UNIVERSITY MEDICAL CENTER550 1st ave new york, NY 10016	13-5562308		44,227				Research grant
MASSACHUSETTS GENERAL HOSPITALPO BOX 414876 BOSTON, MA 02241	04-2697983		31,310				Research grant
SEIZURE TRACKER LLC 4008 RONSON DRIVE ALEXANDRIA, VA 22310	26-3211059		25,000				Research grant

Schedule J
(Form 990)

Compensation Information

OMB No 1545-0047

2009

Open to Public Inspection

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

▶ Complete if the organization answered "Yes" to Form 990, Part IV, question 23.

▶ Attach to Form 990. ▶ See separate instructions.

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 in Form 990, Part VII, Section A, line 1a Complete Part III to provide any relevant information regarding these items		
	☐ First-class or charter travel ☐ Housing allowance or residence for personal use ☐ Travel for companions ☐ Payments for business use of personal residence ☐ Tax idemnification and gross-up payments ☐ Health or social club dues or initiation fees ☐ Discretionary spending account ☐ Personal services (e g , maid, chauffeur, chef)		
b	If any of the boxes in line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all 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 officers, directors, trustees, and the CEO/Executive Director, regarding the items checked in line 1a?	2	
3	Indicate which, if any, of the following the organization uses to establish the compensation of the organization's CEO/Executive Director Check all that apply		
	☒ Compensation committee ☒ Written employment contract ☐ Independent compensation consultant ☒ Compensation survey or study ☒ Form 990 of other organizations ☒ Approval by the board or compensation committee		
4	During the year, did any person listed in Form 990, Part VII, Section A, line 1a with respect to the filing organization or a related organization		
a	Receive a severance payment or change-of-control payment?	4a	No
b	Participate in, or receive payment from, a supplemental nonqualified retirement plan?	4b	No
c	Participate in, or receive payment from, an equity-based compensation arrangement?	4c	No
	If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III		
	Only 501(c)(3) and 501(c)(4) organizations only must complete lines 5-9.		
5	For persons listed in form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of		
a	The organization?	5a	No
b	Any related organization?	5b	No
	If "Yes," to line 5a or 5b, describe in Part III		
6	For persons listed in form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of		
a	The organization?	6a	No
b	Any related organization?	6b	No
	If "Yes," to line 6a or 6b, describe in Part III		
7	For persons listed in Form 990, Part VII, Section A, line 1a, did the organization provide any non-fixed payments not described in lines 5 and 6? If "Yes," describe in Part III	7	No
8	Were any amounts reported in Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regs section 53 4958-4(a)(3)? If "Yes," describe in Part III	8	No
9	If "Yes" to 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 in 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) must equal the applicable column (D) or column (E) amounts on Form 990, Part VII, line 1a

[illegible]

Part III

Supplemental Information

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

Identifier	Return Reference	Explanation
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SCHEDULE O
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990

Complete to provide information for responses to specific questions on Form 990 or to provide any additional information.
▶ Attach to Form 990.

OMB No 1545-0047

2009

Open to Public Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

Employer identification number
95-3018799

Identifier	Return Reference	Explanation
Form 990, Part III, line 2	New Program Services	THIS YEAR WE HELD A SERIES OF TELECONFERENCES PAIRING RESEARCHERS AND CLINICIANS TO TALK ABOUT ADVANCES MADE IN SCIENCE THAT ARE LEADING TO CHANGES IN CLINICAL CARE OR CLINICAL TRIALS THIS WAS A COST EFFECTIVE WAY TO PROVIDE UP TO DATE INFORMATION FOR OUR CONSTITUENTS FROM THE COMFORT OF THEIR LIVING ROOM THIS TELECONFERENCE SERIES REPLACED OUR REGIONAL CONFERENCE DUE TO ECONOMIC CONDITIONS
Form 990, Part VI, Section A, line 2		Tw o members of the board of directors are related Rita DiDomencio (Treasurer) and Tommy Lindsey are brother and sister
Form 990, Part VI, Section A, line 4		A RESOLUTION WAS APPROVED BY THE BOARD OF DIRECTORS TO CHANGE THE FISCAL YEAR
Form 990, Part VI, Section A, line 6		Membership is available to any person w ho subscribes to the purposes and objectives of the corporation, without regard to race, religion, gender, sexual orientation, age, color, national origin or mental or physical handicap or disability There shall be no limit to the number of members in the Corporation 1) There may be one or more classes of membership as determined by the Board 2) Membership is not transferable or assignable
Form 990, Part VI, Section A, line 7a		THE TS ALLIANCE IS A MEMBERSHIP-BASED ORGANIZATION, WHICH MEANS MEMBERS HELP ELECT THE BOARD OF DIRECTORS AS SUCH, MEMBERS HAVE A PROFOUND IMPACT ON THE FUTURE OF THE TS ALLIANCE AND ALL THOSE LIVING WITH TSC MEMBERSHIP GIVES YOU AN IMPORTANT VOICE AND YOUR INVOLVEMENT AS A TS ALLIANCE MEMBER IS IMPORTANT TO US THE TS ALLIANCE MEMBERSHIP PROGRAM IS COMPOSED OF SEVERAL LEVELS DESIGNED TO GIVE YOU A CHOICE IN HOW YOU PARTICIPATE (SEE BELOW) WHETHER YOU CHOOSE THE COMPLIMENTARY BASIC MEMBERSHIP OR THE GOLD LEVEL, BEING A MEMBER MEANS BEING A PART OF OUR UNIQUE AND VITAL COMMUNITY BECAUSE OF ALLIES LIKE YOU, WHOSE FINANCIAL SUPPORT IS VITAL, THE TS ALLIANCE HAS BEEN ABLE TO MAKE QUANTUM LEAPS FORWARD
Form 990, Part VI, Section B, line 11		THE FORM 990 IS REVIEWED, IN DETAIL, BY THE BOARD OF DIRECTORS AUDIT AND FINANCE COMMITTEES RECOMMENDATIONS ARE MADE BY THE COMMITTEE MEMBERS FOR ANY CHANGES/EDITS/ADDITIONS AFTER THOSE HAVE BEEN INCORPORATED BOTH COMMITTEES VOTE WHETHER TO APPROVE AND THEN FORWARD THE 990 TO THE EXECUTIVE COMMITTEE THE EXECUTIVE COMMITTEE PERFORMS THE FINAL REVIEW AND THEN VOTES WHETHER TO APPROVE ON BEHALF OF THE BOARD OF DIRECTORS A COPY OF THE APPROVED 990 IS SHARED WITH THE ENTIRE BOARD
Form 990, Part VI, Section B, line 12c		Annually each member of the board of directors w ill receive notice of the organization's conflict of interest statement Each member w ill be provided w ith 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 members w ill make w ritten notice of a potential conflict of interest and recuse himself or herself from any discussions and votes in connection w ith the issue identified Any time a members is recused from discussion on an issue, the minutes of committee meeting and board meeting w ill duly record such actions For fiscal year 2010 The following conflicts of interest w ere disclosed Board member Janie Frost's husband is a partner in the Minnesota Epilepsy Group, w hich received \$4,440 for database payments from TSA Board member Elizabeth Petri Henske, MD is employed at Brigham and Women's and previously by Fox Chase Center Tw o grants w ere awarded \$12,500 to Fox Chase Center for mechanisms of renal tumorigenesis in tuberous sclerosis \$28,125 to Brigham and Women's for roles of tuberin (tcs2) and rheb in cystic kidney disease Board member Elizabeth Thiele, MD, PHD is employed at Massachusetts General Hospital w hich received an \$11,000 grant for her work on Glucose Restriction on TSC and received \$13,800 for database payments Board member Peter Crino, MD, PHD is employed at University of Pennsylvania School of Medicine w hich received \$4,500 for database payments
Form 990, Part VI, Section B, line 15		The Compensation Committee review s and approves the salaries of the President/CEO, Chief Staff Executive Officer and the Chief Financial Officer, in accordance w ith the Tuberous Sclerosis Alliance Bylaw s Such review and approval occurs initially upon hiring, upon annual review s and w henever 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 betw een total remuneration and delivered business and personal performance over the short and long-terms The compensation is review ed by the Compensation Committee to ensure - Comparability, - Proper review , and - Substantiation in setting the compensation

Identifier	Return Reference	Explanation
Form 990, Part VI, Section C, line 19		All governing documents, conflict of interest policy and financial statements are available upon w ritten request

FORM 990, PART XI, LINE 2C THE AUDIT REVIEW PROCESS HAS REMAIN UNCHANGED FROM THE PRIOR YEAR part ix, column b - program service expenses PROGRAM SERVICE EXPENSES AND OVERHEAD RATIOS IN CONSIDERING THE COMBINED MANAGEMENT AND FUNDRAISING COSTS FOR THE TS ALLIANCE, IT IS IMPORTANT TO NOTE THAT TS ALLIANCE SECURES \$6 MILLION ANNUALLY FROM THE US DEPARTMENT OF DEFENSE TO DIRECTLY SUPPORT RESEARCH ON TUBEROUS SCLEROSIS COMPLEX TS ALLIANCE IS THE ONLY ORGANIZATION THAT ACTIVELY SOLICITS THESE FUNDS AND WITHOUT TS ALLIANCE'S INVOLVEMENT, THE APPROPRIATION WOULD BE ELIMINATED BECAUSE THE FUNDS GO DIRECTLY FROM THE DEPARTMENT OF DEFENSE TO INDIVIDUAL RESEARCH LABS, THE ATTENDANT REVENUES AND EXPENSES NEVER SHOW UP ON TS ALLIANCE'S INCOME STATEMENT AS A RESULT, TS ALLIANCE'S OVERALL PROGRAMMATIC EXPENSES REMAIN MISLEADINGLY LOW, WHILE OVERHEAD EXPENSES APPEAR EXCESSIVE IN FACT, IF THE \$6 MILLION OF REVENUE AND ASSOCIATED EXPENSES WERE INCLUDED IN TS ALLIANCE'S BUDGET, OVERHEAD EXPENSES WOULD TOTAL APPROXIMATELY 11% SINCE THE PROGRAMMATIC BUDGET WOULD INCREASE BY \$6 MILLION IT IS UNUSUAL FOR A NONPROFIT ORGANIZATION TO WORK SO DILIGENTLY TO RAISE MONEY TO HELP ANOTHER ENTITY'S BOTTOM LINE, AND IT WOULD BE UNFORTUNATE IF THE ORGANIZATION WERE UNFAIRLY PENALIZED FOR WHAT IS ACTUALLY A COMMENDABLE, AND GENEROUS, PRACTICE ON BEHALF OF THE FIELD

Related Organizations and Unrelated Partnerships

OMB No 1545-0047

2009

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

▶ **Complete if the organization answered "Yes" to Form 990, Part IV, line 33, 34, 35, 36, or 37.**
▶ **Attach to Form 990.** ▶ **See separate instructions.**

Name of the organization

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 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

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

TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FUND

801 ROEDER ROAD 750

SILVER SPRING, MD 20910
52-1926919

TO RECEIVE GIFTS THAT
WILL BE INVESTED TO
GENERATE PERMANENT
INCOME FOR TSA

MD

501(C)(3)

509(A)(3)

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?	
							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
---	-------------------------	---	-------------------------------------	--	---------------------------------	--	--------------------------------

Part V

Transactions With Related Organizations

(Complete if the organization answered "Yes" on Form 990, Part IV, line 34, 35, or 36.)

Note. Complete line 1 if any entity is listed in Parts II, III or IV		Yes	No
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?			
a Receipt of (i) interest (ii) annuities (iii) royalties (iv) rent from a controlled entity	1a		No
b Gift, grant, or capital contribution to other organization(s)	1b		No
c Gift, grant, or capital contribution from other organization(s)	1c	Yes	
d Loans or loan guarantees to or for other organization(s)	1d		No
e Loans or loan guarantees by other organization(s)	1e		No
f Sale of assets to other organization(s)	1f		No
g Purchase of assets from other organization(s)	1g		No
h Exchange of assets	1h		No
i Lease of facilities, equipment, or other assets to other organization(s)	1i		No
j Lease of facilities, equipment, or other assets from other organization(s)	1j		No
k Performance of services or membership or fundraising solicitations for other organization(s)	1k		No
l Performance of services or membership or fundraising solicitations by other organization(s)	1l		No
m Sharing of facilities, equipment, mailing lists, or other assets	1m	Yes	
n Sharing of paid employees	1n		No
o Reimbursement paid to other organization for expenses	1o		No
p Reimbursement paid by other organization for expenses	1p		No
q Other transfer of cash or property to other organization(s)	1q		No
r Other transfer of cash or property from other organization(s)	1r		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 other organization	(b) Transaction type(a-r)	(c) Amount involved
(1)	TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FUND	R	180,636
(1)	See Additional Data Table		
(2)			
(3)			
(4)			
(5)			
(6)			

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

(a) Name, address, and EIN of entity	(b) Primary activity	(c) Legal domicile (state or foreign country)	(d) Are all partners section 501(c)(3) organizations?		(e) Share of end-of-year assets	(f) Disproportionate allocations?		(g) Code V—UBI amount in box 20 of Schedule K-1 (Form 1065)	(h) General or managing partner?	
			Yes	No		Yes	No		Yes	No