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Form 990



Department of the Treasury
Internal Revenue Service

Return of Organization Exempt From Income Tax

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

Do not enter Social Security numbers on this form as it may be made public By law, the IRS generally cannot redact the information on the form

Information about Form 990 and its instructions is at [www.IRS.gov/form990](http://www.irs.gov/form990)

OMB No 1545-0047

2013

Open to Public Inspection

A For the 2013 calendar year, or tax year beginning 01-01-2013, 2013, and ending 12-31-2013

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

TUBEROUS SCLEROSIS ALLIANCE

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 province, country, and ZIP or foreign postal code

SILVER SPRING, MD 20910

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 subordinates?

☐ Yes ☒ No

H(b) Are all subordinates included?

☐ Yes ☐ No

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

H(c) Group exemption number

I Tax-exempt status

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

J Website:

WWW TSALLIANCE ORG

K Form of organization

☒ Corporation ☐ Trust ☐ Association ☐ Other

L Year of formation

1975

M State of legal domicile

CA

Part I		Summary	
Activities & Governance	1	Briefly describe the organization's mission or most significant activities THE NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, D/B/A 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)	25
	4	Number of independent voting members of the governing body (Part VI, line 1b)	25
Revenue	5	Total number of individuals employed in calendar year 2013 (Part V, line 2a)	15
	6	Total number of volunteers (estimate if necessary)	2,000
	7a	Total unrelated business revenue from Part VIII, column (C), line 12	0
	b	Net unrelated business taxable income from Form 990-T, line 34	0
	8	Contributions and grants (Part VIII, line 1h)	3,199,643
	9	Program service revenue (Part VIII, line 2g)	202,786
	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	9,669
Expenses	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	-67,798
	12	Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	3,344,300
	13	Grants and similar amounts paid (Part IX, column (A), lines 1–3)	839,957
	14	Benefits paid to or for members (Part IX, column (A), line 4)	0
	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10)	1,253,071
	16a	Professional fundraising fees (Part IX, column (A), line 11e)	16,500
	b	Total fundraising expenses (Part IX, column (D), line 25)	632,282
Net Assets or Fund Balances	17	Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e)	1,379,176
	18	Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25)	3,488,704
	19	Revenue less expenses Subtract line 18 from line 12	-144,404
		Beginning of Current Year	End of Year
	20	Total assets (Part X, line 16)	7,963,191
	21	Total liabilities (Part X, line 26)	119,036
	22	Net assets or fund balances Subtract line 21 from line 20	7,844,155

Part II

Signature Block

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

Sign Here

Signature of officer

2014-04-04

Date

KARI L ROSBECK PRESIDENT AND CEO

Type or print name and title

Paid Preparer Use Only

Print/Type preparer's name

ELIZABETH W HELLER

Preparer's signature

Date

Check ☐ if self-employed

PTIN P00397829

Firm's name

TATE & TRYON

Firm's EIN

52-1855942

Firm's address

2021 L STREET NW

WASHINGTON, DC 20036

Phone no

(202) 293-2200

May the IRS discuss this return with the preparer shown above? (see instructions)

☒ Yes ☐ No

For Paperwork Reduction Act Notice, see the separate instructions.

Cat No 11282Y

Form 990 (2013)

Part III

Statement of Program Service Accomplishments

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



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 organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.				
4a	(Code)	(Expenses \$ 2,037,048	including grants of \$ 903,892)	(Revenue \$ 1,825,634)	
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. THE TS ALLIANCE HAS FUNDED MORE THAN \$17.4 MILLION IN RESEARCH ON TSC SINCE 1984. DIRECTED BY STEVEN L. ROBERTS, PH.D., CHIEF SCIENTIFIC OFFICER, THE TS ALLIANCE RESEARCH GRANTS PROGRAM FUNDS RESEARCH FOCUSED ON TSC THAT IS PROPOSED BY RESEARCHERS AND ALIGNED WITH THE RESEARCH PRIORITIES OF THE TS ALLIANCE. COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS ARE ENCOURAGED AND FOSTERED, FOR EXAMPLE, BY BIENNIAL INTERNATIONAL TSC RESEARCH CONFERENCES. THROUGH THE TS ALLIANCE RESEARCH GRANTS PROGRAM, APPLICATIONS CAN BE SUBMITTED FOR POSTDOCTORAL FELLOWSHIPS, RESEARCH GRANTS, ROTHBERG COURAGE AWARDS, AND THE DRUG SCREENING PROGRAM. GRANTS ARE REVIEWED IN A THREE-STEP PROCESS: (1) ALL GRANT APPLICATIONS ARE REVIEWED BY A COMMITTEE COMPRISED OF SCIENTISTS KNOWLEDGEABLE ABOUT THE TOPIC AREA FOR SCIENTIFIC MERIT AND OF ADULTS AFFECTED BY TSC FOR POTENTIAL IMPACT ON THE LIVES OF THOSE AFFECTED BY TSC, (2) THE SCIENCE AND MEDICAL COMMITTEE OF THE BOARD OF DIRECTORS EVALUATES THE GRANT REVIEW COMMITTEE'S RECOMMENDATIONS AND THE RELEVANCE OF THE APPLICATIONS TO THE TS ALLIANCE'S FUNDING PRIORITIES, AND (3) THE BOARD OF DIRECTORS THEN REVIEWS THE RECOMMENDATIONS OF THE SCIENCE AND MEDICAL COMMITTEE AND MAKES FINAL APPROVAL FOR FUNDING. IMPLEMENTED IN 2006, THE TSC NATURAL HISTORY DATABASE CAPTURES CLINICAL DATA TO DOCUMENT THE IMPACT OF THE DISEASE ON A PERSON'S HEALTH OVER THEIR LIFETIME. AS OF DECEMBER 2013, 1,300 PEOPLE WITH TUBEROUS SCLEROSIS COMPLEX WERE ENROLLED IN THE PROJECT FROM AMONG 15 U.S.-BASED SITES. THE TS ALLIANCE PROVIDES FUNDING TO PARTICIPATING CLINICS TO PERFORM DATA ENTRY, MONITORS THE INTEGRITY OF THE DATABASE, AND MAKES DATA AVAILABLE TO INVESTIGATORS TO ANSWER SPECIFIC RESEARCH QUESTIONS AND IDENTIFY POTENTIAL PARTICIPANTS FOR CLINICAL TRIALS AND STUDIES. IN 2013, THE TS ALLIANCE INVESTED \$484,160 IN THE TSC DATABASE. THIS REPRESENTS A CONSIDERABLE INCREASE OVER PRIOR YEARS FOR TWO REASONS: FIRST, THE TS ALLIANCE BEGAN DEVELOPMENT AND TESTING OF A NEW DATABASE PLATFORM THAT IS BETTER SUITED FOR RESEARCH QUERIES, CAN ACCEPT PATIENT-REPORTED DATA ON QUALITY OF LIFE, AND WILL BE MORE COST EFFECTIVE TO USE. SECOND, MORE FUNDING WAS PROVIDED TO THE 15 PARTICIPATING SITES TO INCREASE ENROLLMENT AND COMPLETENESS OF RECORDS PRIOR TO MOVING TO THE NEW PLATFORM. THE TS ALLIANCE RECEIVED A ONE-YEAR \$70,000 GRANT AWARD FROM THE PEDIATRIC EPILEPSY RESEARCH FOUNDATION IN FALL 2013, WHICH WILL UNDERWRITE A PORTION OF THE OPERATIONAL EXPENSES OF THE TSC DATABASE THROUGH 2014. A CONTRACT WITH NOVARTIS WAS EXECUTED IN NOVEMBER 2012 TO PROVIDE TS ALLIANCE WITH FUNDING TO ENHANCE AND GROW THE TSC DATABASE THROUGH 2015. THE TS ALLIANCE HOSTED THE 2013 INTERNATIONAL RESEARCH CONFERENCE ON TSC AND RELATED DISORDERS: MOLECULES TO MEDICINES ON JUNE 20-23, 2013, AT THE OMNI SHOREHAM HOTEL IN WASHINGTON, DC. NEARLY 200 RESEARCHERS, CLINICIANS AND OTHER CONSTITUENTS ATTENDED THIS SUCCESSFUL AND PRODUCTIVE CONFERENCE. THE CONFERENCE'S OPENING SESSION REVEALED NEW DATA ON MULTIPLE CELLULAR MECHANISMS THAT IMPACT MTOR ACTIVITY, WHICH IS ELEVATED IN TSC. SOME OF THESE MECHANISMS ARE ASSOCIATED WITH DRUGS BEING TESTED IN ANIMAL MODELS OF TSC. THE CONFERENCE'S KEYNOTE ADDRESS BY DR. MUSTAFA SAHIN OF BOSTON CHILDREN'S HOSPITAL DISCUSSED HOW ALTERATIONS IN CONNECTIONS BETWEEN NEURONS IN THE BRAIN OF INDIVIDUALS WITH TSC MAY BE RESPONSIBLE FOR THE NEUROLOGIC AND NEUROPSYCHIATRIC PROBLEMS THAT SO FREQUENTLY OCCUR IN TSC. A SESSION ON CLINICAL STUDIES COVERED LESSONS LEARNED FROM PAST CLINICAL TRIALS IN TSC AND IDEAS FOR FUTURE CLINICAL TRIALS IN TSC. THE SESSION ON GENETICS REVEALED THAT NO THIRD GENE HAS YET BEEN IDENTIFIED TO CAUSE TSC AND THAT MANY INDIVIDUALS IN WHOM MUTATIONS COULD NOT BE IDENTIFIED ARE NOW BEING FOUND TO BE MOSAIC FOR TSC1 OR TSC2 MUTATIONS, MEANING ONLY SOME OF THOSE PERSONS' CELLS CARRY MUTATIONS. THE FINAL TWO SESSIONS OF THE CONFERENCE DISCUSSED BOTH ANIMAL MODELS AND CLINICAL DATA FROM WHICH WE ARE LEARNING MORE ABOUT THE TSC DISEASE PROCESS AND HOW WE MIGHT IDENTIFY NEW TREATMENTS OR HOW WE MIGHT MORE EFFECTIVELY DELIVER CARE USING EXISTING TREATMENTS. WORKING GROUPS HELD DURING THE CONFERENCE ENABLED ATTENDEES FROM ALL DIFFERENT BACKGROUNDS TO TACKLE SPECIFIC QUESTIONS OR PROBLEMS, INCLUDING HOW TO ACHIEVE THE BEST COMPREHENSIVE CLINICAL CARE FOR INDIVIDUALS WITH TSC AND HOW TO UTILIZE AND DEVELOP A BIOBANK OF TISSUE AND BLOOD OR URINE SAMPLES FROM PEOPLE WITH TSC. A TOTAL OF 16 RESEARCH AWARDS WERE FUNDED DURING 2013 FOR \$903,892. THE TS ALLIANCE ROTHBERG COURAGE AWARD FOR RESEARCH CONTINUED SUPPORTING THREE ONGOING PROJECTS: (1) THE DEVELOPMENT OF SEIZURE TRACKER AS AN EPILEPSY CLINICAL TRIAL TOOL, (2) THE TSC NEUROCOGNITIVE TRIAL, A CLINICAL STUDY OF EVEROLIMUS EFFECTS ON NEUROCOGNITION AT CHILDREN'S HOSPITAL BOSTON AND CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER, (3) A STUDY BY DR. ELIZABETH HENSKE (BRIGHAM & WOMEN'S HOSPITAL) TO DETERMINE WHETHER INHIBITION OF AUTOPHAGY MIGHT KILL ABNORMALLY GROWING CELLS IN TSC. THE TS ALLIANCE CONTINUED TO SUPPORT NINE RESEARCH GRANTS AWARDED IN PREVIOUS YEARS. ADDITIONALLY, FIVE NEW RESEARCH AWARDS WERE ANNOUNCED THIS YEAR, FUNDING BEGAN IN 2013 FOR THREE OF THESE, AND FUNDING OF THE OTHERS WILL BEGIN IN 2014. THE THREE NEWLY FUNDED AWARDS BEGINNING IN 2013 WERE TO: (1) DR. CARMEN PRIOLO (BRIGHAM AND WOMEN'S HOSPITAL) TO STUDY POTENTIAL BIOMARKERS IN BLOOD TO ASSESS PROGRESSION OF LAM, (2) DR. REBECCA IHRLE (VANDERBILT UNIVERSITY) TO STUDY THE CELLULAR ORIGIN OF SUBEPENDYMAL GIANT CELL ASTROCYTOMAS IN TSC TO DETERMINE NEW APPROACHES TO TREATMENT, AND (3) DR. DAVID KWIATKOWSKI (BRIGHAM AND WOMEN'S HOSPITAL) TO COLLECT AND ANALYZE BIOSAMPLES FROM A NEW EUROPEAN CLINICAL TRIAL TO TREAT OR PREVENT INFANTILE SPASMS IN TSC. AMONG THE NINE ONGOING GRANTS, THE TSC DRUG SCREENING PROGRAM CONTINUED SPONSORING RESEARCH BY DR. JEANNIE LI (HARVARD UNIVERSITY) TO IDENTIFY NEW WAYS OF TREATING TSC BY BLOCKING THE ABILITY OF CELLS WITH TSC1/TSC2 LOSS TO USE SPECIAL NUTRIENT SOURCES AND, THEREFORE, SELECTIVELY KILL THESE CELLS WITHOUT KILLING NORMAL CELLS. THE DRUG SCREENING PROGRAM ALSO CONTINUED TO SUPPORT PROJECTS TESTING DRUGS FOR THEIR POTENTIAL TO INFLUENCE NEUROLOGIC MANIFESTATIONS OF TSC. DR. MUSTAFA SAHIN (CHILDREN'S HOSPITAL BOSTON) IS WORKING TO IDENTIFY COMPOUNDS THAT REVERSE CHANGES INDUCED BY LOSS OF TSC2 IN CULTURED NEURONS AND TO UNDERSTAND THEIR IMPACT ON LEARNING AND BEHAVIORAL DEFECTS IN MICE DEFICIENT IN TSC1 OR TSC2. DR. SEOK-HYUNG KIM (VANDERBILT UNIVERSITY) IS SCREENING COMPOUNDS TO REVERSE ABNORMAL NEURONAL PHENOTYPES IN TSC2 MUTANT ZEBRAFISH. THE FINAL RESEARCH AWARD CONSISTED OF \$240,252 TO HELP SUPPORT THE TSC CLINICAL RESEARCH CONSORTIUM AND LEVERAGE NIH FUNDING. THE FIVE CLINICS COMPRISING THIS CONSORTIUM RECEIVED NIH GRANTS TO CONDUCT TWO CLINICAL STUDIES INITIATED IN 2013 THAT ARE ENROLLING PARTICIPANTS AHEAD OF SCHEDULE. THESE TWO CLINICAL STUDIES WILL: (1) DETERMINE WHAT EARLY SIGNS OR TESTS CAN IDENTIFY INFANTS WITH TSC AT HIGHEST RISK OF DEVELOPING AUTISM BY AGE THREE, AND (2) MEASURE THE ABILITY OF EEG AND BRAIN IMAGING TO ASSESS THE RISK OF NEWLY DIAGNOSED INFANTS WITH TSC TO DEVELOP INFANTILE SPASMS. THE BIOMARKERS RESULTING FROM STUDIES WILL HAVE A MAJOR IMPACT ON OUR ABILITY TO INTERVENE VERY EARLY TO PREVENT SOME OF THE MOST DEVASTATING MANIFESTATIONS OF TSC. ADDITIONALLY, THE COORDINATED WORK TO EXECUTE BOTH OF THESE STUDIES WILL DEVELOP INFRASTRUCTURE AND PROCESSES TO FORM THE BASIS OF AN ONGOING AND GROWING TSC CLINICAL RESEARCH NETWORK. AS TRANSLATIONAL RESEARCH IN TSC PRODUCES ADDITIONAL IDEAS FOR CLINICAL STUDIES, THE EFFICIENT INITIATION AND CONDUCT OF FUTURE CLINICAL TRIALS WILL BENEFIT FROM HAVING THIS INFRASTRUCTURE IN PLACE TO ENABLE INVESTIGATORS TO QUICKLY AND AFFORDABLY EXECUTE STUDIES. THE TS ALLIANCE'S CHIEF SCIENTIFIC OFFICER IS ON THE LEADERSHIP TEAM OF THE CONSORTIUM.					
4b	(Code)	(Expenses \$ 714,679	including grants of \$)	(Revenue \$ 118,000)	
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. THE OUTREACH DEPARTMENT PROVIDED SUPPORT AND RESOURCES TO 2,272 INDIVIDUALS AND FAMILIES DEALING WITH TSC. THE DIRECTOR OF ADVOCACY AND EDUCATION ATTENDED 26 INDIVIDUAL EDUCATION PROGRAM (IEP) MEETINGS IN PERSON, THROUGH SKYPE, AND VIA CONFERENCE CALLS TO SUPPORT FAMILIES IN GETTING EDUCATIONAL SERVICES FOR THEIR CHILDREN THROUGHOUT THE COUNTRY. IN 2013 THERE WERE THERE ARE 23 EDUCATIONAL LIAISON VOLUNTEERS, WORKING IN 23 STATES, TO CONNECT FAMILIES TO FREE EDUCATIONAL ADVOCACY TRAININGS IN COLLABORATION WITH THE STATES' PARENT TRAINING AND INFORMATION CENTERS. OVER THE PAST YEAR THERE HAVE BEEN MORE THAN 1,000 FREE PARENT TRAININGS AND WEBINARS ON EDUCATIONAL ADVOCACY OFFERED TO FAMILIES DEALING WITH EDUCATIONAL ISSUES FOR THEIR CHILDREN. A NEW EDUCATIONAL ADVOCACY PUBLICATION WAS DEVELOPED TO HELP YOUNG ADULTS SELF-ADVOCATE AT THE COLLEGE LEVEL. "WHAT COLLEGE PROFESSORS NEED TO KNOW ABOUT TSC." THERE WERE 9 ADULT TOPIC CALLS HELD ON TOPICS SPECIFIC TO INDEPENDENT AND SEMI-INDEPENDENT ADULTS WITH TSC. A PILOT ADULT TOPIC CALL WAS HELD FOR PARENTS OF DEPENDENT ADULTS AND A DEPENDENT ADULT TASK FORCE DEVELOPED TO ADDRESS THE NEEDS OF THIS POPULATION. THE ADULT REGIONAL COORDINATOR PROGRAM DEVELOPED TO SUPPORT ADULTS ONE ON ONE SUPPORTED 1,077 ADULTS WITH TSC THROUGHOUT THE COUNTRY. FINALLY, THE TS ALLIANCE ONLINE SOCIAL NETWORK THROUGH "INSPIRE" HELPS TO CONNECT INDIVIDUALS AND FAMILIES DEALING WITH TSC AND GET SUPPORT FROM EACH OTHER'S EXPERIENCE. PRESENTLY THE TSC POPULATION THROUGH INSPIRE INCLUDES 2,154 MEMBERS FROM 79 COUNTRIES AS OF DECEMBER 31, 2013. IN ADDITION, THE TSC CLINIC AMBASSADORS PROGRAM SUPPORTED 238 INDIVIDUALS AND FAMILIES ONE ON ONE IN EIGHT TSC CLINICS LOCATED IN MIAMI, FL, CINCINNATI, OH, COLUMBUS, OH, ATLANTA, GA, NASHVILLE, TN, BIRMINGHAM, AL, DENVER, CO, AND DALLAS, TX THROUGH THE NETWORK OF 32 VOLUNTEER BRANCHES OF THE ORGANIZATION, CALLED COMMUNITY ALLIANCES, LOCAL EDUCATION AND SUPPORT GROUP MEETINGS ARE HELD THROUGHOUT THE COUNTRY. THE TS ALLIANCE HOSTED 20 EDUCATIONAL MEETINGS AND 33 GATHERINGS HELD AT COMMUNITY ALLIANCE LOCATIONS DURING THE FISCAL YEAR 2013. THESE MEETINGS FACILITATED STRONGER CONNECTIONS AND PEERS, RESEARCHERS, AND CLINICIANS IN THE COMMUNITY AND EDUCATED THE TSC COMMUNITY ABOUT CLINICAL TRIALS, RESEARCH AND TREATMENT OPTIONS FOR THOSE LIVING WITH TSC.					
4c	(Code)	(Expenses \$ 196,950	including grants of \$)	(Revenue \$)	
PUBLIC HEALTH EDUCATION HEIGHTENS AWARENESS OF TSC THROUGHOUT THE GENERAL PUBLIC TO BROADEN THE SCOPE OF SUPPORT AND UNDERSTANDING BEYOND TSC INDIVIDUALS AND THEIR FAMILIES. DURING 2013, THE TS ALLIANCE PRODUCED THREE ISSUES OF ITS NATIONAL MAGAZINE, PERSPECTIVE, WHICH IS MAILED TO MORE THAN 13,700 CONSTITUENTS AS WELL AS POSTED ON THE WEBSITE. THE TS ALLIANCE'S WEBSITE INCREASES AWARENESS AND PROVIDES EXTENSIVE EDUCATION THROUGH ITS WEBSITE VIA 950,000 TO 1.2 MILLION HITS MONTHLY FROM AN AVERAGE OF MORE THAN 35,000 UNIQUE VISITORS. THE SITE'S ONLINE MAIL LIST FORM CONTINUES TO CAPTURE 50 OR MORE NEW CONSTITUENTS EVERY MONTH. THE TS ALLIANCE RELIES HEAVILY ON SOCIAL MEDIA TO EDUCATE CONSTITUENTS AND PROMOTE NEW RESOURCES AND EVENTS. ITS FACEBOOK GROUP BOASTS MORE THAN 5,300 MEMBERS, WHILE ITS TWITTER ACCOUNT HAS 800+ FOLLOWERS. THE TS ALLIANCE ALSO PROVIDES PUBLIC EDUCATION THROUGH A SERIES OF REGIONAL TSC CONFERENCES, FOUR WERE HELD IN 2013 INCLUDING GRAND RAPIDS, MI, NEW YORK, NY, BIRMINGHAM, AL, AND KANSAS CITY, MO. TO INCREASE PUBLIC AWARENESS, THE TS ALLIANCE HEAVILY PROMOTED TSC GLOBAL AWARENESS DAY ON MAY 15. THIS YEAR'S EVENT INTRODUCED A DEDICATED WEBSITE - TSGLOBALDAY.ORG, TO HOUSE A "WHERE IN THE WORLD IS TSC?" SOCIAL MEDIA/PHOTO CAMPAIGN WHICH GARNERED 473 PICTURES FROM 34 COUNTRIES AS WELL AS A HUGE FACEBOOK/TWITTER PUSH. IN ADDITION, THE TS ALLIANCE PRESIDENT & CEO AND ITS CHIEF SCIENTIFIC OFFICER PARTICIPATED IN 10 RADIO INTERVIEWS, WHICH ULTIMATELY AIRED ON 735 STATIONS REACHING MORE THAN 9.7 MILLION LISTENERS. FINALLY, LONG-TIME TS ALLIANCE SUPPORTER AND FAMED ACTRESS JULIANNE MOORE RECORDED A TSC GLOBAL AWARENESS DAY PSA, WHICH WAS PLAYED 1,326 TIMES ON 154 DIFFERENT STATIONS, REACHING 4.9 MILLION. THE TS ALLIANCE ALSO PARTICIPATED IN A MEDIA TOURS IN PARTNERSHIP WITH NOVARTIS AND THE SPECIAL OLYMPICS, SHARING THE STORY OF TWO TSC SPECIAL OLYMPIANS. IN MAY, TS ALLIANCE PRESIDENT AND CEO PARTICIPATED IN 10 INTERNET MEDIA BASED INTERVIEWS WITH KATHY GROVES WHO TALKED ABOUT HER FAMILY, LIFE WITH TSC, AND HER SON RYAN AND HIS PARTICIPATION IN THE SPECIAL OLYMPICS. THE CSO PARTICIPATED IN A RADIO MEDIA TOUR IN NOVEMBER REACHING A TOTAL LISTENERSHIP OF 3,376,000 WITH PLACEMENT ON 17 NETWORKS. THE MEDIA TOUR INCLUDED MANDY AND SCOTT STRIEGEL, WHO ADDRESSED THE FAMILY'S EXPERIENCES LIVING WITH TSC, ESPECIALLY THEIR SON STEVEN'S PARTICIPATION IN THE SPECIAL OLYMPICS. TO HELP EDUCATE PEOPLE WITH TSC, PHYSICIANS AND THE GENERAL PUBLIC, THE TS ALLIANCE PRODUCED AND RELEASED EIGHT NEW EDUCATIONAL VIDEOS IN 2013.					
	(Code)	(Expenses \$ 142,520	including grants of \$)	(Revenue \$)	
GOVERNMENT RELATIONS FOCUSES ON EDUCATING MEMBERS OF CONGRESS ABOUT TSC TO FURTHER TSC RESEARCH, AWARENESS AND CLINICAL CARE. IN 2013, THE TS ALLIANCE GRASSROOTS VOLUNTEERS CONDUCTED A MARCH ON CAPITOL HILL RESULTING IN 74 MEMBERS OF THE HOUSE OF REPRESENTATIVES SIGNING A LETTER OF SUPPORT CIRCULATED BY REPRESENTATIVE LORETTA SANCHEZ (D-CA) AND 10 SENATORS SIGNING A BIPARTISAN LETTER OF SUPPORT CIRCULATED BY SENATOR RON WYDEN (D-OR) FOR FY14 APPROPRIATIONS. THE US CONGRESS APPROPRIATED \$6 MILLION FOR FY14 TO TSC RESEARCH THROUGH THE DEPARTMENT OF DEFENSE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM. THE TSC RESEARCH PROGRAM (TSCRP) ADMINISTERED FROM THE APPROPRIATION IS A COMPETITIVE PEER REVIEW GRANT PROGRAM. ACCORDING TO THE U.S. ARMY MEDICAL RESEARCH AND MATERIAL COMMAND, CDMRP, TUBEROUS SCLEROSIS COMPLEX RESEARCH PROGRAM REPORT "TODAY, THE TSCRP IS ONE OF THE LEADING SOURCES OF EXTRAMURAL TSC RESEARCH FUNDING IN THE UNITED STATES. THE TSCRP FILLS IMPORTANT GAPS IN TSC RESEARCH NOT ADDRESSED BY OTHER FUNDING AGENCIES." A HALLMARK ACHIEVEMENT IS TSCRP-SUPPORTED RESEARCH THAT EXAMINED THE ROLE THAT TSC GENES PLAY IN CELL GROWTH AND PROLIFERATION-SPECIFICALLY IN CONTROLLING THE MAMMALIAN TARGET OF RAPAMYCIN (MTOR) SIGNALING PATHWAY IN CELLS. THIS RESEARCH RAPIDLY LED TO CLINICAL TRIALS, RESULTING IN THE FIRST DRUG APPROVED BY THE FDA SPECIFICALLY FOR TREATMENT OF INDIVIDUALS WITH TSC. RESEARCH DONE THROUGH THIS PROGRAM HAS RECENTLY LED TO ADDITIONAL CLINICAL TRIALS INCLUDING, TESTING A COMBINATION OF TWO DRUGS TO TREAT LYMPHANGIOLEIOMYOMATOSIS (LAM), A LIFE-THREATENING LUNG MANIFESTATION OF TSC FUNDED IN FY2012, A MULTI-SITE CLINICAL TRIAL TESTING THE EFFICACY OF AN EXPERIMENTAL TOPICAL RAPAMYCIN CREAM TO TREAT THE DISFIGURING FACIAL TUMORS, FACIAL ANGIOFIBROMAS, CAUSED BY TSC FUNDED IN FY2010, A CLINICAL RESEARCH NETWORK WAS CREATED TO TEST POTENTIAL NEW THERAPIES, TO VALIDATE BIOMARKERS, AND TO LEARN THE NATURAL HISTORY OF LEADING TO A CLINICAL TRIAL FUNDED IN FY2012. BUILDING UPON FY2010-FUNDED RESEARCH ON GLUTAMATE RECEPTORS (MGLUR5), SEVERAL COMPANIES ARE NOW LOOKING DEVELOPING DRUGS TO THE LINK BETWEEN COGNITIVE IMPAIRMENTS IN TSC TO AUTISM, ANXIETY, AND OTHER MENTAL DISORDERS. THE TSCRP HAS ALSO FUNDED RESEARCH TO DEVELOP ANIMAL MODELS OF TSC THAT HAVE SEIZURES, ENABLING A BETTER UNDERSTANDING OF THE ETIOLOGY OF TSC. IN 2013 A CLINICAL TRIAL BEGAN TO TEST MTOR INHIBITORS TO TREAT EPILEPSY IN INDIVIDUALS WITH TSC. NONE OF THIS PROGRESS WOULD HAVE BEEN POSSIBLE WITHOUT THE CRITICAL SUPPORT PROVIDED THROUGH THE TSCRP. ADDITIONAL GOVERNMENT RELATIONS EFFORTS INCLUDED A CONGRESSIONAL BRIEFING ON CAPITOL HILL TO COMMEMORATE TSC GLOBAL AWARENESS DAY ON MAY 15, 2013. CONGRESSIONAL STAFF AND KEY MEMBERS OF THE TSC RESEARCH AND GRASSROOTS COMMUNITIES ATTENDED THE EVENT.					
	(Code)	(Expenses \$ 22,826	including grants of \$)	(Revenue \$)	
PROFESSIONAL EDUCATION EXPANDS PROGRAMS TO TARGET RESEARCHERS AND HEALTHCARE PROVIDERS CARING FOR INDIVIDUALS WITH TSC, MEDICAL STUDENTS, GENETIC COUNSELORS AND EDUCATORS TO MINIMIZE THE CONSEQUENCES OF IGNORANCE AND MISINFORMATION. THE TS ALLIANCE FUNDED THE OPEN-ACCESS PUBLICATION OF TWO PEER-REVIEWED ARTICLES IN THE JOURNAL PEDIATRIC NEUROLOGY TO MAKE AVAILABLE TO HEALTHCARE PROVIDERS WORLDWIDE THE LATEST RECOMMENDATIONS ON THE DIAGNOSIS, SURVEILLANCE, AND MANAGEMENT OF TSC FROM THE 2012 TSC CLINICAL CONSENSUS CONFERENCE. THE TS ALLIANCE ALSO CO-SPONSORED A CONTINUING MEDICAL EDUCATION PROGRAM WITH PEERVIEW INSTITUTE AND THE UNIVERSITY OF FLORIDA THAT IS AVAILABLE FREE TO PHYSICIANS TO EDUCATE THEM ON THE PUBLISHED CONSENSUS RECOMMENDATIONS. ADDITIONALLY, THE TS ALLIANCE WORKED WITH OTHER ADVOCACY GROUPS REPRESENTING RARE EPILEPSY SYNDROMES TO HELP IMPLEMENT SOME OF THE RECOMMENDATIONS FROM AN INSTITUTE OF MEDICINE REPORT ON THE EPILEPSIES, INCLUDING BUILDING THE HERO WEBSITE TO ENABLE INDIVIDUALS WITH EPILEPSY TO LOCATE RELEVANT CLINICAL STUDIES. THE TS ALLIANCE PARTICIPATED IN AND PRESENTED AT SEVERAL PROFESSIONAL MEETINGS INCLUDING LAM FOUNDATION CONFERENCE, WORLD ORPHAN DRUG CONGRESS, ASSOCIATION OF CLINICAL RESEARCH PROFESSIONALS CONFERENCE, INTERAGENCY COLLABORATIVE TO ADVANCE RESEARCH IN EPILEPSY (ICARE), THE NINDS NONPROFIT FORUM, NORD/DIA ANNUAL CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS, PARTNERING FOR CURES, CHILD NEUROLOGY SOCIETY ANNUAL MEETING, AND TSC RESEARCH CONFERENCES IN GERMANY AND NORWAY. IN ADDITION, AT THE AMERICAN EPILEPSY SOCIETY (AES) ANNUAL MEETING THE TS ALLIANCE HOSTED A TSC RECEPTION FOR MORE THAN 50 RESEARCHERS AND PARTICIPATED IN TWO SPECIAL INTEREST GROUP SCIENTIFIC SESSIONS, ONE ON TSC AND ANOTHER ON RESEARCH RESOURCES MADE AVAILABLE BY NON-PROFIT ORGANIZATIONS ADVOCATING FOR RARE DISORDERS THAT INVOLVE EPILEPSY. THE TS ALLIANCE ALSO MANAGES AN ONLINE PORTAL FOR HEALTHCARE PROFESSIONALS CALLED "VEOMED" TO ENCOURAGE INFORMATION EXCHANGE. THERE ARE CURRENTLY 75 PROFESSIONALS USING THIS PORTAL, WHICH ALSO SERVES AS A RESOURCE FOR PROFESSIONALS NOT FAMILIAR WITH TSC SEEKING GUIDANCE FROM PEERS. A MONTHLY ONLINE NEWSLETTER CALLED TSC ALERT IS SENT TO NEARLY 1,000 MEDICAL PROFESSIONALS AND SCIENTISTS. FURTHER, THE DIRECTOR OF ADVOCACY AND EDUCATION HAS ONGOING COLLABORATION WITH NATIONAL EDUCATIONAL NETWORKS, SUCH AS THE ASSOCIATION FOR MIDDLE LEVEL EDUCATION (AMLE). SHE ALSO COLLABORATES WITH PARENT TRAINING INFORMATION CENTERS (PTIS) THROUGHOUT THE COUNTRY. PROVIDING CHILDREN WITH APPROPRIATE EDUCATION IS THE KEY TO INDIVIDUALS HAVING A GOOD QUALITY OF LIFE.					
4d	Other program services (Describe in Schedule O)				
	(Expenses \$ 165,346	including grants of \$)	(Revenue \$)		
4e	Total program service expenses 3,114,023				

Part IV

Checklist of Required Schedules

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

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or government 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 or 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, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	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 lines 24b through 24d and complete Schedule K. If "No," go to line 25a</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	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If so, 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 employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	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 (or a family member thereof) was an officer, director, trustee, or direct or indirect 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	Yes	
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, Part II, III, or IV, and Part V, line 1</i>	34	Yes	
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		No
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b		
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 11b and 19? Note. All Form 990 filers are required to complete Schedule O	38	Yes	

Part V

Statements Regarding Other IRS Filings and Tax Compliance

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

☐

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable.	29	
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.	0	
1c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?		Yes	
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return.	15	
2b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions).		Yes	
3a Did the organization have unrelated business gross income of \$1,000 or more during the year?			No
3b If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation in Schedule O.			
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)?			No
4b If "Yes," enter the name of the foreign country: See instructions for 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?			No
5b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?			No
5c If "Yes," to line 5a or 5b, did the organization file Form 8886-T?			
6a Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?			No
6b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?			
7 Organizations that may receive deductible contributions under section 170(c).			
7a 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?		Yes	
7b If "Yes," did the organization notify the donor of the value of the goods or services provided?		Yes	
7c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?			No
7d If "Yes," indicate the number of Forms 8282 filed during the year.			
7e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?			
7f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?			
7g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?			
7h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?			
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?			
9 Sponsoring organizations maintaining donor advised funds.			
9a Did the organization make any taxable distributions under section 4966?			
9b Did the organization make a distribution to a donor, donor advisor, or related person?			
10 Section 501(c)(7) organizations. Enter			
10a Initiation fees and capital contributions included on Part VIII, line 12.			
10b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities.			
11 Section 501(c)(12) organizations. Enter			
11a Gross income from members or shareholders.			
11b Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them).			
12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?			
12b If "Yes," enter the amount of tax-exempt interest received or accrued during the year.			
13 Section 501(c)(29) qualified nonprofit health insurance issuers.			
13a Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O.			
13b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans.			
13c Enter the amount of reserves on hand.			
14a Did the organization receive any payments for indoor tanning services during the tax year?			No
14b If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O.			

Part VI

Governance, Management, and Disclosure

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

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

Section A. Governing Body and Management

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	25	
If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O			
1b	Enter the number of voting members included in line 1a, above, who are independent	25	
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?	2	No
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person?	3	No
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4	No
5	Did the organization become aware during the year of a significant diversion of the organization's assets?	5	No
6	Did the organization have members or stockholders?	6	Yes
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?	7a	Yes
7b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	7b	No
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following		
8a	The governing body?	8a	Yes
8b	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	Did the organization have local chapters, branches, or affiliates?	10a	Yes
10b	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	10b	Yes
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	11a	Yes
11b	Describe in Schedule O the process, if any, used by the organization to review this Form 990		
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	12a	Yes
12b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Yes
12c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	12c	Yes
13	Did the organization have a written whistleblower policy?	13	Yes
14	Did 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?		
15a	The organization's CEO, Executive Director, or top management official	15a	Yes
15b	Other officers or key employees of the organization	15b	Yes
If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions)			
16a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?	16a	No
16b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?	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 made these available. Check all that apply. ☒ Own website ☐ Another's website ☒ Upon request ☐ Other (explain in Schedule O)	
19	Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year	
20	State the name, 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

Part VII

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

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

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

- 1a Complete this table for all persons required to be listed Report compensation for the calendar year ending with or within the organization's tax year
- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation Enter -0- in columns (D), (E), and (F) if no compensation was paid

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

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

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

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

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

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W- 2/1099-MISC)	(E) Reportable compensation from related organizations (W- 2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
(1) MATT BOLGER CHAIR	5 00	X		X				0	0	0
(2) KEITH HALL VICE CHAIR	5 00	X		X				0	0	0
(3) HENRY SHAPIRO IMMEDIATE PAST CHAIR	5 00	X		X				0	0	0
(4) DAVID MICHAELS TREASURER	5 00 1 00	X		X				0	0	0
(5) REIKO DONATO SECRETARY	5 00	X		X				0	0	0
(6) MARTINA BEBIN BOARD MEMBER	2 00	X						0	0	0
(7) DAVID PARKES BOARD MEMBER	2 00	X						0	0	0
(8) CELIA MASTBAUM BOARD MEMBER	2 00	X						0	0	0
(9) JULIE BLUM BOARD MEMBER	3 00	X						0	0	0
(10) MARK CARROLL BOARD MEMBER	2 00	X						0	0	0
(11) RITA DIDOMENICO BOARD MEMBER	2 00 1 00	X						0	0	0
(12) PETER CRINO MD PHD BOARD MEMBER	2 00	X						0	0	0
(13) DAVID FITZMAURICE BOARD MEMBER	2 00	X						0	0	0
(14) JENNIFER GLASSMAN BOARD MEMBER	2 00	X						0	0	0
(15) STEVEN GOLDSTEIN BOARD MEMBER	2 00 1 00	X						0	0	0
(16) RON HEFFRON BOARD MEMBER	2 00	X						0	0	0
(17) LINDA JACKSON BOARD MEMBER	2 00	X						0	0	0

Part VII

1b	Sub-Total			
c	Total from continuation sheets to Part VII, Section A			
d	Total (add lines 1b and 1c)	408,547	27,186	64,535

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>
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>
5	Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization Report compensation for the calendar year ending with or within the organization's tax year		
(A) Name and business address	(B) Description of services	(C) Compensation
2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization ▶0		

Part VIII

Statement of Revenue

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

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514
Contributions, Gifts, Grants and Other Similar Amounts	1a	Federated campaigns	75,476			
	b	Membership dues				
	c	Fundraising events	1,410,318			
	d	Related organizations	197,200			
	e	Government grants (contributions)				
	f	All other contributions, gifts, grants, and similar amounts not included above	1,556,054			
	g	Noncash contributions included in lines 1a-1f \$	47,984			
	h	Total. Add lines 1a-1f	3,239,048			
Program Service Revenue	2a	CONTRACT REVENUE	900099	779,327	779,327	
	b	CONFERENCE REVENUE	900099	203,800	203,800	
	c					
	d					
	e					
	f	All other program service revenue				
	g	Total. Add lines 2a-2f	983,127			
Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)	13,335			13,335
	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		
	b	Less cost or other basis and sales expenses	124,940			
	c	Gain or (loss)	124,475			
	d	Net gain or (loss)	465			465
	8a	Gross income from fundraising events (not including \$ 1,410,318 of contributions reported on line 1c) See Part IV, line 18	a			
	b	Less direct expenses	18,778			
	c	Net income or (loss) from fundraising events	109,491			
	9a	Gross income from gaming activities See Part IV, line 19	a			
	b	Less direct expenses				
	c	Net income or (loss) from gaming activities				
	10a	Gross sales of inventory, less returns and allowances	a			
	b	Less cost of goods sold				
	c	Net income or (loss) from sales of inventory				
		Miscellaneous Revenue	Business Code			
	11a	OTHER	900099	5,984		5,984
	b					
	c					
	d	All other revenue				
	e	Total. Add lines 11a-11d	5,984			
	12	Total revenue. See Instructions	4,151,246	983,127	0	-70,929

Part IX

Statement of Functional Expenses

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.		(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to governments and organizations in the United States. See Part IV, line 21.	855,892	855,892		
2	Grants and other assistance to individuals in the United States. See Part IV, line 22.				
3	Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16.	48,000	48,000		
4	Benefits paid to or for members.				
5	Compensation of current officers, directors, trustees, and key employees.	512,765	303,716	67,489	141,560
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.	736,109	436,773	96,553	202,783
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions).	21,951	12,872	2,945	6,134
9	Other employee benefits.	77,945	45,708	10,458	21,779
10	Payroll taxes.	89,867	52,693	12,060	25,114
11	Fees for services (non-employees):				
a	Management.				
b	Legal.	18,750	1,023	17,727	
c	Accounting.	32,440		32,440	
d	Lobbying.	102,517	102,517		
e	Professional fundraising services. See Part IV, line 17.	16,500			16,500
f	Investment management fees.				
g	Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O).	60,607	32,685	12,922	15,000
12	Advertising and promotion.				
13	Office expenses.	271,024	138,576	60,949	71,499
14	Information technology.	97,960	39,620	55,593	2,747
15	Royalties.				
16	Occupancy.	83,642	120	83,402	120
17	Travel.	208,463	168,588	3,066	36,809
18	Payments of travel or entertainment expenses for any federal, state, or local public officials.				
19	Conferences, conventions, and meetings.	158,908	141,024	16,568	1,316
20	Interest.				
21	Payments to affiliates.				
22	Depreciation, depletion, and amortization.	110,683	90,422	20,261	
23	Insurance.	8,421		8,421	
24	Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O):				
a	NATURAL HISTORY DATABAS	484,160	484,160		
b	BANK AND CREDIT CARD FE	50,182	0	35,130	15,052
c	EQUIPMENT & MAINTENANCE	20,593	697	18,959	937
d	ALLOCATIONS	0	156,156	-229,921	73,765
e	All other expenses	18,602	2,781	14,654	1,167
25	Total functional expenses. Add lines 1 through 24e.	4,085,981	3,114,023	339,676	632,282
26	Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ☒ if following SOP 98-2 (ASC 958-720).	79,936	39,968	0	39,968

Part X

Balance Sheet

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

					(A)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing			2,334,967	1	3,054,646
	2	Savings and temporary cash investments			492,140	2	248,045
	3	Pledges and grants receivable, net			336,000	3	162,675
	4	Accounts receivable, net			86,517	4	326,326
	5	Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L				5	
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions) Complete Part II of Schedule L				6	
	7	Notes and loans receivable, net				7	
	8	Inventories for sale or use			4,395	8	0
	9	Prepaid expenses and deferred charges			155,998	9	181,502
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a	553,970	100,412	10c	203,501
	b	Less accumulated depreciation	10b	350,469			
	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			4,452,762	15	4,995,018
16	Total assets. Add lines 1 through 15 (must equal line 34)			7,963,191	16	9,171,713	
Liabilities	17	Accounts payable and accrued expenses			117,408	17	230,387
	18	Grants payable				18	
	19	Deferred revenue			1,628	19	494,483
	20	Tax-exempt bond liabilities				20	
	21	Escrow or custodial account liability Complete Part IV of Schedule D				21	
	22	Loans and other payables to 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 (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24) Complete Part X of Schedule D				25	
	26	Total liabilities. Add lines 17 through 25			119,036	26	724,870
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here ☒ and complete lines 27 through 29, and lines 33 and 34.						
	27	Unrestricted net assets			5,255,154	27	5,953,119
	28	Temporarily restricted net assets			1,709,557	28	1,614,280
	29	Permanently restricted net assets			879,444	29	879,444
	Organizations that do not follow SFAS 117 (ASC 958), 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			7,844,155	33	8,446,843
	34	Total liabilities and net assets/fund balances			7,963,191	34	9,171,713

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	4,151,246
2	Total expenses (must equal Part IX, column (A), line 25)	2	4,085,981
3	Revenue less expenses Subtract line 2 from line 1	3	65,265
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	7,844,155
5	Net unrealized gains (losses) on investments	5	21
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	537,401
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	8,446,843

Part XII Financial Statements and Reporting

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

		Yes	No
1	Accounting method used to prepare the Form 990 ☐ Cash ☒ Accrual ☐ Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O		
2a	Were the organization's financial statements compiled or reviewed by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		No
2b	Were the organization's financial statements audited by an independent accountant? If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both ☐ Separate basis ☒ Consolidated basis ☐ Both consolidated and separate basis	Yes	
2c	If "Yes," to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O	Yes	
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		No
3b	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.

▶ Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public Inspection

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

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

The organization is not a private foundation because it is (For lines 1 through 11, check only one box)

- 1

☐

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

☐

A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E)
- 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 33¹/₃% 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 33¹/₃% 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 - Non-functionally integrated

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 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 monetary support
			Yes	No	Yes	No	Yes	No	
Total									

Part II

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

Section A. Public Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")	3,221,297	1,449,542	3,812,563	3,199,643	3,239,048	14,922,093
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	3,221,297	1,449,542	3,812,563	3,199,643	3,239,048	14,922,093
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)						1,461,893
6 Public support. Subtract line 5 from line 4						13,460,200

Section B. Total Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
7 Amounts from line 4	3,221,297	1,449,542	3,812,563	3,199,643	3,239,048	14,922,093
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	4,704	7,821	9,722	9,794	13,335	45,376
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income Do not include gain or loss from the sale of capital assets (Explain in Part IV.)	3,967	5,728	13,037	23,048	5,984	51,764
11 Total support (Add lines 7 through 10)						15,019,233
12 Gross receipts from related activities, etc. (see instructions)					12	1,517,705
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 2013 (line 6, column (f) divided by line 11, column (f))	14 89 620 %
15	Public support percentage for 2012 Schedule A, Part II, line 14	15 97 490 %
16a	33 1/3% support test—2013. 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—2012. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization	☐
17a	10%-facts-and-circumstances test—2013. 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—2012. 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 Section 509(a)(2)
(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support (Subtract line 7c from line 6)						

Section B. Total Support						
Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						
14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a 501(c)(3) organization, check this box and stop here ▶						

Section C. Computation of Public Support Percentage		
15 Public support percentage for 2013 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2012 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2013 (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from 2012 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2013. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization ▶		
b 33 1/3% support tests—2012. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3% and line 18 is not more than 33 1/3%, check this box and stop here. The organization qualifies as a publicly supported organization ▶		
20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ▶		

Part IV

Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12. Also complete this part for any additional information. (See instructions).

Facts And Circumstances Test	
Return Reference	Explanation
SCHEDULE A, PART II, LINE 10, EXPLANATION OF OTHER INCOME	INCOME FROM OTHER PROGRAM RELATED ACTIVITIES - 2009 AMOUNT \$ 3,967 2010 AMOUNT \$ 5,728 2011 AMOUNT \$ 13,037 2012 AMOUNT \$ 23,048 2013 AMOUNT \$ 5,984

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.** ▶ **Information about Schedule C (Form 990 or 990-EZ) and its instructions is at *www.irs.gov/form990*.**

OMB No 1545-0047

2013

Open to Public Inspection

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

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

If the organization answered "Yes" 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, Part V, line 35c (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
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Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

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

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

Part II-A

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

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

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)		919													
b Total lobbying expenditures to influence a legislative body (direct lobbying)		141,601													
c Total lobbying expenditures (add lines 1a and 1b)		142,520													
d Other exempt purpose expenditures		3,940,692													
e Total exempt purpose expenditures (add lines 1c and 1d)		4,083,212													
f Lobbying nontaxable amount Enter the amount from the following table in both columns		354,161													
<table><tr><th>If the amount on line 1e, column (a) or (b) is:</th><th>The lobbying nontaxable amount is:</th></tr><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></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)		88,540													
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) 2010	(b) 2011	(c) 2012	(d) 2013	(e) Total
2a Lobbying nontaxable amount	226,416	334,138	323,610	354,161	1,238,325
b Lobbying ceiling amount (150% of line 2a, column(e))					1,857,488
c Total lobbying expenditures	74,182	163,120	141,410	142,520	521,232
d Grassroots nontaxable amount	56,604	83,535	80,903	88,540	309,582
e Grassroots ceiling amount (150% of line 2d, column (e))					464,373
f Grassroots lobbying expenditures	7,007	7,688	16,179	919	31,793

Part II-B

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

For each "Yes" response to lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.		(a)		(b)
		Yes	No	Amount
1	During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of			
a	Volunteers?			
b	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?			
c	Media advertisements?			
d	Mailings to members, legislators, or the public?			
e	Publications, or published or broadcast statements?			
f	Grants to other organizations for lobbying purposes?			
g	Direct contact with legislators, their staffs, government officials, or a legislative body?			
h	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?			
i	Other activities?			
j	Total. Add lines 1c through 1i.			
2a	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?			
b	If "Yes," enter the amount of any tax incurred under section 4912.			
c	If "Yes," enter the amount of any tax incurred by organization managers under section 4912.			
d	If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

Part III-A

Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

1	Were substantially all (90% or more) dues received nondeductible by members?	1	Yes	No
2	Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2		
3	Did the organization agree to carry over lobbying and political expenditures from the prior year?	3		

Part III-B

Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes."

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

Part IV

Supplemental Information

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

Return Reference	Explanation

Part IV

Explanation

SCHEDULE D
(Form 990)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

▶ Complete if the organization answered "Yes," to Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b
▶ Attach to Form 990. ▶ See separate instructions. ▶ Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public Inspection

Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC	Employer identification number 95-3018799
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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 can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? ☐ Yes ☐ No	

Part II

Conservation Easements. Complete if the organization answered "Yes" 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 education) ☐ Preservation of an historically important land area
☐ Protection of natural habitat ☐ Preservation of a certified historic structure
☐ Preservation of open space

2

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

	Held at the End of the Year
a	Total number of conservation easements
b	Total acreage restricted by conservation easements
c	Number of conservation easements on a certified historic structure included in (a)
d	Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register

3

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

4

Number of states where property subject to conservation easement is located ▶ _____

5

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

☐ Yes ☐ No

6

Staff and volunteer hours devoted to monitoring, inspecting, 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 section 170(h)(4)(B)(ii)?

☐ Yes ☐ No

9

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

Part III

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

1a

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

b

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

(i) 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 (ASC 958) relating to these items

a

Revenues included in Form 990, Part VIII, line 1

▶ \$ _____

b

Assets included in Form 990, Part X

▶ \$ _____

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

- 3

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

☐ Public exhibition

b

☐ Scholarly research

c

☐ Preservation for future generations

d

☐ Loan or exchange programs

e

☐ Other
- 4

Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII
- 5

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

☐ Yes

☐ No

Part IV Escrow and Custodial Arrangements. Complete if the organization answered "Yes" 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 XIII and complete the following table
- c

Beginning balance

d

Additions during the year

e

Distributions during the year

f

Ending balance
- | | |
|----|--------|
| | Amount |
| 1c | |
| 1d | |
| 1e | |
| 1f | |
- 2a

Did the organization include an amount on Form 990, Part X, line 21?

☐ Yes

☐ No
- b

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

☐

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

	(a)Current year	(b)Prior year	b (c)Two years back	(d)Three years back	(e)Four years back
1a Beginning of year balance	4,457,365	4,221,150	4,443,045	3,866,081	3,750,509
b Contributions	42,690	43,996	29,825	13,835	13,523
c Net investment earnings, gains, and losses	718,381	420,983	-47,583	584,775	312,223
d Grants or scholarships					
e Other expenditures for facilities and programs	197,200	202,000	175,000		210,174
f Administrative expenses	26,470	26,764	29,137	21,646	
g End of year balance	4,994,766	4,457,365	4,221,150	4,443,045	3,866,081

- 2

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

Board designated or quasi-endowment

78 070 %
- b

Permanent endowment

17 610 %
- c

Temporarily restricted endowment

4 320 %
- The percentages in lines 2a, 2b, and 2c should equal 100%
- 3a

Are there endowment funds not in the possession of the organization that are held and administered for the organization by
- (i) unrelated organizations

3a(i)

Yes

No

(ii) related organizations

3a(ii)

Yes
- b

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

3b

Yes
- 4

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

Part VI Land, Buildings, and Equipment. Complete if the organization answered 'Yes' to Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b)Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements		150,655	16,142	134,513
d Equipment		14,829	9,112	5,717
e Other		388,486	325,215	63,271
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				203,501

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return Complete if the organization answered 'Yes' to Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements	1	4,186,343
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains on investments	2a	21
b	Donated services and use of facilities	2b	35,076
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII)	2d	
e	Add lines 2a through 2d	2e	35,097
3	Subtract line 2e from line 1	3	4,151,246
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	4b	
c	Add lines 4a and 4b	4c	0
5	Total revenue Add lines 3 and 4c . (This must equal Form 990, Part I, line 12)	5	4,151,246

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return. Complete if the organization answered 'Yes' to Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements	1	4,121,056
2	Amounts included on line 1 but not on Form 990, Part IX, line 25		
a	Donated services and use of facilities	2a	35,076
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII)	2d	
e	Add lines 2a through 2d	2e	35,076
3	Subtract line 2e from line 1	3	4,085,980
4	Amounts included on Form 990, Part IX, line 25, but not on line 1 :		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII)	4b	
c	Add lines 4a and 4b	4c	0
5	Total expenses Add lines 3 and 4c . (This must equal Form 990, Part I, line 18)	5	4,085,980

Part XIII Supplemental Information

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

Return Reference	Explanation
PART V, LINE 4	THE ALLIANCE'S ENDOWMENTS CONSIST OF TWO FUNDS ESTABLISHED FOR DIFFERENT PURPOSES. THE ALLIANCE'S ENDOWMENT INCLUDE ONE TRADITIONAL DONOR-RESTRICTED ENDOWMENT FUNDS AND ONE BOARD-DESIGNATED ENDOWMENT FUND. THE BOARD-DESIGNATED ENDOWMENT FUND SOLELY CONSISTS OF THE ENDOWMENT FUND'S UNRESTRICTED NET ASSET BALANCE.
PART X, LINE 2	THE ALLIANCE BELIEVES THAT IT HAS APPROPRIATE SUPPORT FOR INCOME TAX POSITIONS TAKEN. THEREFORE, MANAGEMENT HAS NOT IDENTIFIED ANY UNCERTAIN INCOME TAX POSITIONS. GENERALLY, INCOME TAX RETURNS RELATED TO THE CURRENT AND THREE PRIOR YEARS REMAIN OPEN FOR EXAMINATION BY TAXING AUTHORITIES.

[illegible]

SCHEDULE F
(Form 990)

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

► Complete if the organization answered "Yes" to Form 990,
Part IV, line 14b, 15, or 16.
► Attach to Form 990. ► See separate instructions.
► Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

Employer identification number
95-3018799

Part I

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

1

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

☒ Yes

☐ No

2

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

3

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

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e g , fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for and investments in region
EUROPE	0	0	GRANTS TO RECIPIENTS	RESEARCH AWARDS	48,000
3a Sub-total	0	0			48,000
b Total from continuation sheets to Part I	0	0			0
c Totals (add lines 3a and 3b)	0	0			48,000

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. Part II can be duplicated if additional space is needed.

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			EUROPE	RESEARCH GRANT	48,000	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 ▶
- 3 Enter total number of other organizations or entities ▶

Part III

[illegible]

Part IV Foreign Forms

- 1

Was the organization a U S transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)*

☐

Yes

☒

No
- 2

Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to file Form 3520, Annual Return to Report Transactions with Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A)*

☐

Yes

☒

No
- 3

Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons with Respect to Certain Foreign Corporations. (see Instructions for Form 5471)*

☐

Yes

☒

No
- 4

Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621)*

☐

Yes

☒

No
- 5

Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons with Respect to Certain Foreign Partnerships. (see Instructions for Form 8865)*

☐

Yes

☒

No
- 6

Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to file Form 5713, International Boycott Report (see Instructions for Form 5713).*

☐

Yes

☒

No

Supplemental Information

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

[illegible]

OMB No 1545-0047

Information about Schedule G (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

Open to Public Inspection

95-3018799

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

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

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		WALKS (event type)	LA COMEDY FOR CURE (event type)	2 (total number)	(add col (a) through col (c))
Revenue	1	Gross receipts	1,032,055	237,663	159,378
	2	Less Contributions . . .	1,032,055	222,318	155,945
	3	Gross income (line 1 minus line 2)		15,345	3,433
Direct Expenses	4	Cash prizes			
	5	Noncash prizes			
	6	Rent/facility costs . . .			
	7	Food and beverages . .			
	8	Entertainment			
	9	Other direct expenses .	54,806	41,345	13,340
	10	Direct expense summary Add lines 4 through 9 in column (d) ▶			
	11	Net income summary Subtract line 10 from line 3, column (d) ▶			

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			
	3	Non-cash prizes			
	4	Rent/facility costs			
	5	Other direct expenses . . .			
Direct Expenses	6	Volunteer labor			
	7	Direct expense summary Add lines 2 through 5 in column (d) ▶			
	8	Net gaming income summary Subtract line 7 from line 1, column (d) ▶			

9 Enter the state(s) in which the organization operates gaming activities _____

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

b If "No," explain _____

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

b If "Yes," explain _____

Does the organization operate gaming activities with nonmembers? ☐ **Yes** ☐ **No**

12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? ☐ **Yes** ☐ **No**

13 Indicate the percentage of gaming activity 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? ☐ **Yes** ☐ **No**

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

c If "Yes," enter name and address of the third party

Name ►

Address ►

16 Gaming manager information

Name ►

Gaming manager compensation ► \$

Description of services provided ►

☐ Director/officer ☐ Employee ☐ Independent contractor

17 Mandatory distributions

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? ☐ **Yes** ☐ **No**

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

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

Return Reference	Explanation
PART I, LINE 2B	THE TS ALLIANCE DOES NOT CONTRACT WITH ADDITIONAL PROFESSIONAL FUNDRAISERS

Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

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

▶ Information about Schedule I (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public
Inspection

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. Part II can be duplicated 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
(1) BRIGHAM & WOMEN'S HOSPITAL 75 FRANCIS STREET BOSTON,MA 02115	04-2312909	501(C)(3)	240,717				CLINICAL TRIALS AND RESEARCH GRANTS
(2) VANDERBILT UNIVERSITY MEDICAL CENTER DEPT OF FINANCE DEPT AT 40303 ATLANTA,GA 31192	62-0476822	501(C)(3)	86,938				RESEARCH GRANT
(3) CHILDREN'S HOSPITAL PO BOX 414413 BOSTON,MA 02241	04-2774441	501(C)(3)	122,567				RESEARCH GRANT
(4) MASSACHUSETTS GENERAL HOSPITAL PO BOX 414876 BOSTON,MA 02241	04-2697983	501(C)(3)	33,000				RESEARCH GRANT
(5) CINCINNATI CHILDREN'S HOSPITAL 3333 BURNET AVE ML 7030 CINCINNATI,OH 452293039	31-0833936	501(C)(3)	66,000				RESEARCH GRANT
(6) HARVARD UNIVERSITY PO BOX 415649 BOSTON,MA 022415649	04-2103580	501(C)(3)	66,000				RESEARCH GRANT

2

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

6

3

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

0

Part III

Grants and Other Assistance to Individuals in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 22.
Part III can be duplicated if additional space is needed.

(a)Type of grant or assistance	(b)Number of recipients	(c)Amount of cash grant	(d)Amount of non-cash assistance	(e)Method of valuation (book, FMV, appraisal, other)	(f)Description of non-cash assistance

Part IV

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

Return Reference	Explanation
PART I, LINE 2	THE TS ALLIANCE HAS FUNDED MORE THAN \$17.4 MILLION IN RESEARCH ON TSC SINCE 1984. DIRECTED BY STEVEN L. ROBERTS, PH.D., CHIEF SCIENTIFIC OFFICER, THE TS ALLIANCE RESEARCH GRANTS PROGRAM FUNDS RESEARCH FOCUSED ON TSC WITH PRIORITIES SET BY THE RESEARCHERS TOGETHER WITH THE TS ALLIANCE. COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS ARE ENCOURAGED AND FOSTERED, AND THE TS ALLIANCE IS WORKING TO INCREASE FUNDING FOR RESEARCH ON TSC THROUGH THE TS ALLIANCE RESEARCH GRANTS PROGRAM. APPLICATIONS CAN BE SUBMITTED FOR: - PREDOCTORAL AWARDS - POSTDOCTORAL & CLINICAL FELLOWSHIPS - TSC INNOVATOR AWARDS (PREVIOUSLY CALLED JR. AND SR. INVESTIGATOR AWARDS) - TSC WORKSHOP/CONFERENCE GRANT AWARDS - TSC SUPPLEMENTAL FUNDING AWARDS - ROTHBERG COURAGE AWARD - DRUG SCREENING AWARD - CLINICAL RESEARCH NETWORK.
FORM 990, SCHEDULE I, LINE 2	GRANTS ARE REVIEWED IN A THREE-STEP PROCESS: - A GRANT REVIEW COMMITTEE COMPOSED OF INDIVIDUALS KNOWLEDGEABLE ABOUT THE CLINICAL AND BASIC COMPONENTS OF TSC, REVIEW ALL GRANT APPLICATIONS FOR SCIENTIFIC MERIT, RELEVANCY TO THE FUNDING PRIORITIES OF THE ORGANIZATION AND WITH A FOCUS ON UNDERSTANDING THE MECHANISMS OF TSC AND/OR THE DEVELOPMENT OF TREATMENTS AND THERAPIES FOR THE MANIFESTATIONS OF THE DISEASE. - THE SCIENCE AND MEDICAL COMMITTEE OF THE BOARD OF DIRECTORS THEN REVIEW THE RECOMMENDATIONS TO THE BOARD OF DIRECTORS. - THE BOARD OF DIRECTORS THEN REVIEWS THE RECOMMENDATIONS OF THE SCIENCE AND MEDICAL COMMITTEE AND MAKES FINAL APPROVAL FOR THE FUNDING OF GRANT APPLICATIONS.

Schedule J
(Form 990)

Department of the Treasury
Internal Revenue Service

Compensation Information

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

▶ Complete if the organization answered "Yes" to Form 990, Part IV, line 23.
▶ Attach to Form 990. ▶ See separate instructions.

▶ Information about Schedule J (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public Inspection

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 ☐ Travel for companions ☐ Tax idemnification and gross-up payments ☐ Discretionary spending account ☐ Housing allowance or residence for personal use ☐ Payments for business use of personal residence ☐ Health or social club dues or initiation fees ☐ Personal services (e g , maid, chauffeur, chef)		
b If any of the boxes in line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain	1b	
2 Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, officers, including the CEO/Executive Director, regarding the items checked in line 1a?	2	
3 Indicate which, if any, of the following the filing organization used to establish the compensation of the organization's CEO/Executive Director Check all that apply Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III ☒ Compensation committee ☐ Independent compensation consultant ☒ Form 990 of other organizations ☒ Written employment contract ☒ Compensation survey or study ☒ Approval by the board or compensation committee		
4 During the year, did any person listed 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? If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III	4c	No
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	Yes
b Any related organization? If "Yes," to line 5a or 5b, describe in Part III	5b	No
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? If "Yes," to line 6a or 6b, describe in Part III	6b	No
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 Regulations 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	

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

For each individual whose compensation must be reported 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) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation reported as deferred in prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
(1) KARI L ROSBECK PRESIDENT & CEO	(i)	137,053	0	0	4,112	28,045	169,210	0
	(ii)	13,705	0	0	411	2,804	16,920	0
(2) STEVEN L ROBERDS CHIEF SCIENTIFIC OFFICER	(i)	163,642	0	0	4,909	23,958	192,509	0
	(ii)	0	0	0	0	0	0	0

Part III Supplemental Information

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II

Also complete this part for any additional information

Return Reference	Explanation
PART I, LINE 5	KARI LUTHER ROSBECK, PRESIDENT AND CEO, MARY JANE PERRAUT, CFO, AND STEVE ROBERDS, CSO, ALL HAVE INCENTIVE COMPENSATION EQUAL TO A PERCENTAGE OF THEIR SALARY BASED ON KEY PERFORMANCE OBJECTIVES AS ESTABLISHED BY THE COMPENSATION COMMITTEE
FORM 990, SCHEDULE J	KARI LUTHER ROSBECK, PRESIDENT & CEO AND MARY JANE PERRAUT, CFO, ARE EMPLOYEES OF TUBEROUS SCLEROSIS ALLIANCE AND ARE COMPENSATED THROUGH TS ALLIANCE MS ROSBECK AND MS PERRAUT SERVE THE ENDOWMENT WITHOUT COMPENSATION

SCHEDULE M
(Form 990)

Department of the Treasury
Internal Revenue Service

Noncash Contributions

►Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.
► Attach to Form 990.

►Information about Schedule M (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

Employer identification number
95-3018799

Part I Types of Property

	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1 Art—Works of art				
2 Art—Historical treasures				
3 Art—Fractional interests				
4 Books and publications				
5 Clothing and household goods				
6 Cars and other vehicles				
7 Boats and planes				
8 Intellectual property				
9 Securities—Publicly traded				
10 Securities—Closely held stock				
11 Securities—Partnership, LLC, or trust interests				
12 Securities—Miscellaneous				
13 Qualified conservation contribution—Historic structures				
14 Qualified conservation contribution—Other				
15 Real estate—Residential				
16 Real estate—Commercial				
17 Real estate—Other				
18 Collectibles				
19 Food inventory				
20 Drugs and medical supplies				
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ► (SPECIAL EVENT)	X	9	47,984	FMV
26 Other ► ()				
27 Other ► ()				
28 Other ► ()				

29

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

30a

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

30a

Yes

No

b

If "Yes," describe the arrangement in Part II

31

Does the organization have a gift acceptance policy that requires the review of any non-standard contributions?

31

Yes

No

32a

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

32a

Yes

No

b

If "Yes," describe in Part II

33

If the organization did not report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II

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

Cat No 51227J

Schedule M (Form 990) (2013)

Part III

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

Return Reference	Explanation
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SCHEDULE O

(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on
Form 990 or to provide any additional information.
▶ Attach to Form 990 or 990-EZ.
▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is at
www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public
Inspection

Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC	Employer identification number 95-3018799
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Return Reference	Explanation
FORM 990, PART VI, SECTION A, LINE 6	MEMBERSHIP IS AVAILABLE TO ANY PERSON WHO SUBSCRIBES TO THE PURPOSES AND OBJECTIVES OF THE CORPORATION, WITHOUT REGARD TO RACE, RELIGION, GENDER, SEXUAL ORIENTATION, AGE, COLOR, NATIONAL ORIGIN OR MENTAL OR PHYSICAL HANDICAP OR DISABILITY THERE SHALL BE NO LIMIT TO THE NUMBER OF MEMBERS IN THE CORPORATION 1) THERE MAY BE ONE OR MORE CLASSES OF MEMBERSHIP AS DETERMINED BY THE BOARD 2) MEMBERSHIP IS NOT TRANSFERABLE OR ASSIGNABLE

Return Reference	Explanation
FORM 990, PART VI, SECTION A, LINE 7A	THE TS ALLIANCE IS A MEMBERSHIP-BASED ORGANIZATION, WHICH MEANS MEMBERS HELP ELECT THE BOARD OF DIRECTORS 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 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

Return Reference	Explanation
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

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 12C	ANNUALLY EACH MEMBER OF THE BOARD OF DIRECTORS WILL RECEIVE NOTICE OF THE ORGANIZATION'S CONFLICT OF INTEREST STATEMENT EACH MEMBER WILL BE PROVIDED WITH A STATEMENT TO MAKE DISCLOSURE OF ANY POTENTIAL CONFLICT OF INTEREST IF DURING THE COURSE OF THE YEAR A POTENTIAL CONFLICT OF INTEREST ARISES THAT HAS NOT PREVIOUSLY BEEN DISCLOSED, THE BOARD MEMBERS WILL MAKE WRITTEN NOTICE OF A POTENTIAL CONFLICT OF INTEREST AND RECUSE HIMSELF OR HERSELF FROM ANY DISCUSSIONS AND VOTES IN CONNECTION WITH THE ISSUE IDENTIFIED ANY TIME A MEMBERS IS RECUSED FROM DISCUSSION ON AN ISSUE, THE MINUTES OF COMMITTEE MEETING AND BOARD MEETING WILL DULY RECORD SUCH ACTIONS FOR FISCAL YEAR 2013 THE FOLLOWING CONFLICTS OF INTEREST WERE DISCLOSED BOARD MEMBER ELIZABETH THIELE, MD, PHD, IS EMPLOYED AT MASSACHUSETTS GENERAL HOSPITAL, WHICH RECEIVED A \$38,624 GRANT FOR THE TSC NATURAL HISTORY DATABASE

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

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

Return Reference	Explanation
FORM 990, PART XI, LINE 9	CHANGE IN INTEREST IN AFFILIATE 537,401

Return Reference	Explanation
FORM 990, PART XI, LINE 2C	THE AUDIT REVIEW PROCESS HAS REMAIN UNCHANGED FROM THE PRIOR YEAR

SCHEDULE R
(Form 990)

Department of the Treasury
Internal Revenue Service

Related Organizations and Unrelated Partnerships

▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 33, 34, 35b, 36, or 37.
▶ Attach to Form 990. ▶ See separate instructions.
▶ Information about Schedule R (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

2013

Open to Public Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

Employer identification number
95-3018799

Part I Identification of Disregarded Entities

Complete if the organization answered "Yes" on Form 990, Part IV, line 33.

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

Part II Identification of Related Tax-Exempt Organizations

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

(a) Name, address, and EIN of related organization	(b) Primary activity	(c) Legal domicile (state or foreign country)	(d) Exempt Code section	(e) Public charity status (if section 501(c)(3))	(f) Direct controlling entity	(g) Section 512(b)(13) controlled entity?	
						Yes	No
(1) TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT 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)	NATIONAL TUBEROUS SCLEROSIS ASSOCIATION (TSA)		No

Part III

Identification of Related Organizations Taxable as a Partnership

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

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

Part IV

Identification of Related Organizations Taxable as a Corporation or Trust

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

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

Part V

Transactions With Related Organizations

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

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

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

a Receipt of (i) interest (ii) annuities (iii) royalties or (iv) rent from a controlled entity

b Gift, grant, or capital contribution to related organization(s)

c Gift, grant, or capital contribution from related organization(s)

d Loans or loan guarantees to or for related organization(s)

e Loans or loan guarantees by related organization(s)

f Dividends from related organization(s)

g Sale of assets to related organization(s)

h Purchase of assets from related organization(s)

i Exchange of assets with related organization(s)

j Lease of facilities, equipment, or other assets to related organization(s)

k Lease of facilities, equipment, or other assets from related organization(s)

l Performance of services or membership or fundraising solicitations for related organization(s)

m Performance of services or membership or fundraising solicitations by related organization(s)

n Sharing of facilities, equipment, mailing lists, or other assets with related organization(s)

o Sharing of paid employees with related organization(s)

p Reimbursement paid to related organization(s) for expenses

q Reimbursement paid by related organization(s) for expenses

r Other transfer of cash or property to related organization(s)

s Other transfer of cash or property from related organization(s)

Yes

No

1a

No

1b

No

1c

Yes

1d

No

1e

No

1f

No

1g

No

1h

No

1i

No

1j

No

1k

No

1l

No

1m

No

1n

Yes

1o

Yes

1p

No

1q

No

1r

No

1s

No

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

(a) Name of related organization	(b) Transaction type (a-s)	(c) Amount involved	(d) Method of determining amount involved
(1) TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FUND	C	197,200	CASH

Schedule R (Form 990) 2013

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

[illegible]

Part VII

Supplemental Information

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

Return Reference	Explanation
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