



See a Social Security Number? Say Something!
Report Privacy Problems to <https://public.resource.org/privacy>
Or call the IRS Identity Theft Hotline at 1-800-908-4490



Part III

Statement of Program Service Accomplishments

Check if Schedule O contains a response to any question 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 \$ 1,046,940 including grants of \$ 839,957) (Revenue \$ 202,286)
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 \$16.5 MILLION IN RESEARCH ON TSC SINCE 1984 DIRECTED BY STEVEN L. ROBERDS, PH.D., CHIEF SCIENTIFIC OFFICER, THE TS ALLIANCE RESEARCH GRANTS PROGRAM FUNDS RESEARCH FOCUSED ON TSC 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 GRANT REVIEW 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 IDENTIFIES SPECIFIC CORRELATIONS BETWEEN TSC GENE MUTATIONS AND THE IMPACT OF THE DISEASE ON A PERSON'S HEALTH OVER THEIR LIFETIME AS OF DECEMBER 2012, 1,175 PEOPLE WITH TUBEROUS SCLEROSIS COMPLEX WERE ENROLLED IN THE PROJECT FROM AMONG 15 U.S.-BASED SITES AND ONE INTERNATIONAL SITE 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 2012, THE TS ALLIANCE INVESTED \$179,725 IN THE TSC DATABASE THE TS ALLIANCE RECEIVED THE SECOND HALF OF A TWO-YEAR \$200,000 GRANT AWARD FROM THE PEDIATRIC EPILEPSY RESEARCH FOUNDATION IN FALL 2012, WHICH WILL UNDERWRITE A PORTION OF THE OPERATIONAL EXPENSES OF THE TSC DATABASE THROUGH 2013 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 2012 TSC CLINICAL CONSENSUS CONFERENCE TO UPDATE CONSENSUS RECOMMENDATIONS FOR THE DIAGNOSIS, SURVEILLANCE, AND MANAGEMENT OF TSC THE PRIOR GUIDELINES WERE BASED ON A 1998 CONSENSUS CONFERENCE, AND THE TSC FIELD HAS MADE TREMENDOUS ADVANCEMENTS IN THE MEANTIME APPROXIMATELY 80 EXPERTS FROM 14 COUNTRIES PARTICIPATED IN THIS EFFORT TO UPDATE RECOMMENDATIONS AROUND ALL ASPECTS OF TSC BRAIN TUMORS, DERMATOLOGY AND DENTAL, EPILEPSY, GENETICS, NEUROPSYCHIATRY, PULMONARY, RENAL, AND A COLLECTION OF ADDITIONAL MANIFESTATIONS INCLUDING CARDIAC, ENDOCRINE, GASTROINTESTINAL, AND RETINAL INDEED, CONSENSUS WAS REACHED DURING THE INTENSE DAY-AND-A-HALF MEETING BASED ON EVALUATION OF DATA IN THE SCIENTIFIC LITERATURE AND EXPERT OPINION THE TS ALLIANCE WILL FINANCIALLY SUPPORT OPEN-ACCESS PUBLICATION OF PEER-REVIEWED ARTICLES IN MEDICAL JOURNALS TO DESCRIBE THESE GUIDELINES SO THAT THEY ARE FREELY AVAILABLE TO ANYONE AROUND THE WORLD A TOTAL OF 18 RESEARCH AWARDS WERE FUNDED IN 2012 FOR \$839,957 THE TS ALLIANCE ROTHBERG COURAGE AWARD FOR RESEARCH CONTINUED SUPPORTING FIVE 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) WORK BY DR. HOPE NORTHRUP (UNIVERSITY OF TEXAS AT HOUSTON) TO IDENTIFY ADDITIONAL TSC GENES, (4) WORK BY DR. JOHN BISSLER (CINCINNATI CHILDREN'S HOSPITAL AND MEDICAL CENTER) TO DEVELOP MRI-GUIDED HIGH-INTENSITY FOCUSED ULTRASOUND TO TREAT KIDNEY OR LUNG LESIONS, AND (5) A STUDY BY DR. ELIZABETH HENSKES (BRIGHAM & WOMEN'S HOSPITAL) TO DETERMINE WHETHER INHIBITION OF AUTOPHAGY MIGHT KILL ABNORMALLY GROWING CELLS IN TSC THE TS ALLIANCE CONTINUED TO SUPPORT 11 RESEARCH GRANTS AWARDED IN PREVIOUS YEARS ADDITIONALLY, A NEW POSTDOCTORAL RESEARCH GRANT WAS INITIATED THIS YEAR TO SUPPORT A YOUNG SCIENTIST WORKING ON TSC RESEARCH DR. JEANNIE LI (HARVARD UNIVERSITY) WAS AWARDED A POSTDOCTORAL FELLOWSHIP IN LATE 2012 THAT INVOLVES DRUG SCREENING, WHICH WILL BE INITIATED IN EARLY 2013 HER GOAL IS 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 TSC DRUG SCREENING PROGRAM CONTINUED SPONSORING RESEARCH IN DR. ARISTOTELIS ASTRINIDIS' LABORATORY (DREXEL UNIVERSITY) TOWARD FINDING FDA-APPROVED ONCOLOGY DRUGS THAT WILL STOP TUMOR CELL GROWTH IN TSC THE PROGRAM ALSO CONTINUED FUNDING THE WORK OF DR. JOHN FRANGIONI (BETH ISRAEL DEACONESS HOSPITAL), WHO HAS DEVELOPED A NEW SYSTEM FOR IMAGING OF TUMORS IN LIVE MICE AND HAS SET UP A HIGH-THROUGHPUT SCREEN USING CELLS IN CULTURE IN ORDER TO PRE-SCREEN POTENTIAL DRUGS AND COMPOUNDS PRIOR TO TESTING IN MICE 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 TS ALLIANCE INVESTED \$112,500 TO SUPPORT A NEW TSC CLINICAL RESEARCH CONSORTIUM THE FIVE CLINICS COMPRISING THIS CONSORTIUM RECEIVED NIH GRANTS TO CONDUCT TWO CLINICAL STUDIES OVER THE NEXT FIVE YEARS 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 \$ 493,457 including grants of \$) (Revenue \$)
FAMILY SERVICES DEVELOPS PROGRAMS AND SERVICES THAT PROVIDE INDIVIDUALS WITH TSC DIRECT ACCESS TO THE INFORMATION, RESOURCES, AND SPECIALISTS EXPERIENCED IN THE DIAGNOSIS, TREATMENT AND MANAGEMENT OF TSC THROUGH THE NETWORK OF 32 VOLUNTEER BRANCHES OF THE ORGANIZATION, CALLED COMMUNITY ALLIANCES, LOCAL EDUCATIONAL AND SUPPORT GROUP MEETINGS ARE HELD THROUGHOUT THE COUNTRY THE TS ALLIANCE HOSTED 12 EDUCATIONAL MEETINGS AND 20 GATHERINGS HELD AT COMMUNITY ALLIANCE LOCATIONS DURING THE FISCAL YEAR 2012 THESE MEETINGS FACILITATED STRONGER CONNECTIONS WITH PEERS, RESEARCHERS, AND CLINICIANS IN THE COMMUNITY AND EDUCATED THE TSC COMMUNITY ABOUT CLINICAL TRIALS, RESEARCH AND TREATMENT OPTIONS FOR THOSE LIVING WITH TSC THE DEPARTMENT OF ADVOCACY AND EDUCATION SUPPORTS FAMILIES AND INDIVIDUALS FROM ALL OVER THE UNITED STATES BY PROVIDING SUPPORT AND INFORMATION INCLUDING DIRECT DURING ONE-ON-ONE MEETINGS IN ADDITION, VOLUNTEER CLINIC AMBASSADORS SUPPORTED OVER 153 INDIVIDUALS AT TSC CLINICS IN MIAMI, FL, CINCINNATI, OH, COLUMBUS, OH, ATLANTA, GA, NASHVILLE, TN, BIRMINGHAM, AL, AND DENVER, CO THE DIRECTOR OF ADVOCACY AND EDUCATION ATTENDS INDIVIDUAL EDUCATION PROGRAM (IEP) MEETINGS IN PERSON, THROUGH SKYPE, AND VIA CONFERENCE CALLS TO SUPPORT FAMILIES IN GETTING EDUCATIONAL SERVICES FOR THEIR CHILDREN THERE ARE 18 ADVOCATE LIAISON VOLUNTEERS, WORKING IN 18 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 1,300 FREE PARENT TRAININGS AND WEBINARS ON EDUCATIONAL ADVOCACY OFFERED TO FAMILIES DEALING WITH EDUCATIONAL ISSUES FOR THEIR CHILDREN THERE WERE ALSO 4 EDUCATIONAL SITUATION VIDEOS DEVELOPED AND PLACED ON THE TS ALLIANCE WEBSITE TO SUPPORT PARENTS IN GETTING AN APPROPRIATE EDUCATION FOR THEIR CHILDREN THERE WERE 30 ONLINE CHATS HELD FOR SIBLINGS AGES 8-13, 14-18, AND ADULTS TO SUPPORT ISSUES SIBLINGS FACE ON A DAILY BASIS HAVING A BROTHER OR SISTER WITH TSC A NEW SIBLING FACEBOOK PAGE WAS DEVELOPED TO BETTER SERVE THIS POPULATION THE DIRECTOR OF EDUCATION AND ADVOCACY ALSO FACILITATES THE ADULT TASK FORCE, AND HELD 9 MONTHLY TOPIC CALLS ON IDENTIFIED ISSUES OF IMPORTANCE TO BETTER SUPPORT ADULTS LIVING WITH TSC THE ADULT REGIONAL COORDINATOR PROGRAM WAS DEVELOPED WITH 10 ADULT VOLUNTEERS NOW SUPPORTING ADULTS 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 OVER 1,500 MEMBERS FROM 69 COUNTRIES AS OF DECEMBER 31, 2012	

4c	(Code) (Expenses \$ 335,697 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 2012, THE TS ALLIANCE PRODUCED THREE ISSUES OF ITS NATIONAL MAGAZINE, PERSPECTIVE, WHICH IS MAILED TO MORE THAN 13,000 CONSTITUENTS AS WELL AS POSTED ON THE WEBSITE THE TS ALLIANCE'S WEBSITE INCREASES AWARENESS AND PROVIDES EXTENSIVE EDUCATION WITH 799,000 TO 1.2 MILLION HITS MONTHLY FROM AN AVERAGE OF MORE THAN 9,250 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 5,000 MEMBERS, WHILE ITS TWITTER ACCOUNT HAS 600-PLUS FOLLOWERS THE TS ALLIANCE ALSO PROVIDES PUBLIC EDUCATION THROUGH A SERIES OF REGIONAL TSC CONFERENCES, FOUR WERE HELD IN 2012 INCLUDING WASHINGTON, DC, HOUSTON, TX, LOS ANGELES, CA, AND BOSTON, MA TO INCREASE PUBLIC AWARENESS, THE TS ALLIANCE HEAVILY PROMOTED MAY AS NATIONAL TSC AWARENESS MONTH VIA ITS VARIOUS SOCIAL MEDIA AND WEB PROPERTIES, AND IT TOOK THE LEAD IN PROMOTING THE VERY FIRST TSC GLOBAL AWARENESS DAY ON MAY 15 THIS INCLUDED A RADIO MEDIA TOUR AND AUDIO RELEASE ON TSC GLOBAL AWARENESS DAY WITH TOTAL OUTREACH TO 8,065,000 LISTENERS ON 2,007 NETWORKS AND 2,015 AIRINGS AND A WINDOW DISPLAY IN ROCKEFELLER CENTER, NEW YORK CITY THROUGHOUT MAY WITH THE FDA-APPROVAL OF THE SECOND TSC INDICATION, THE TS ALLIANCE BROADENED PUBLIC AWARENESS THROUGH OUTREACH TO PRESS AND PARTICIPATION IN A SECOND RADIO MEDIA TOUR REACHING A TOTAL LISTENERSHIP OF 3,913,000 WITH PLACEMENT ON 19 NETWORKS IN 2012, THE TS ALLIANCE CO-SPONSORED A REPORT ON EPILEPSY BY THE INSTITUTE OF MEDICINE THROUGH OUR PARTNERSHIP WITH VISION 2020, A COALITION THAT FOCUSES ON EPILEPSY RESEARCH, CARE, SERVICES, EDUCATION, AND ADVOCACY EFFORTS THIS LANDMARK STUDY PROVIDES THE BLUEPRINT FOR IMPROVING THE OUTCOMES FOR THOSE LIVING WITH EPILEPSY A FULL REPORT AND RECOMMENDATIONS CAN BE FOUND AT HTTP://WWW.IOM.EDU/REPORTS/2012/EPILEPSY-ACROSS-THE-SPECTRUM.ASPX	

	(Code) (Expenses \$ 725,124 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 PARTICIPATED IN AND PRESENTED AT SEVERAL PROFESSIONAL MEETINGS INCLUDING LAM FOUNDATION CONFERENCE, 4TH INTERNATIONAL BIRT-HOGG-DUBE SYMPOSIUM, WORLD ORPHAN DRUG CONGRESS, ASSOCIATION OF CLINICAL RESEARCH PROFESSIONALS CONFERENCE, NINDS AUTISM AND EPILEPSY WORKSHOP, INTERAGENCY COLLABORATIVE TO ADVANCE RESEARCH IN EPILEPSY (ICARE), PARTNERING TO ADVANCE THERAPEUTICS FOR NEUROLOGICAL DISORDERS THE NINDS NONPROFIT FORUM, NORD/DIA ANNUAL CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS, CHILD NEUROLOGY SOCIETY ANNUAL MEETING, AND THE INTERNATIONAL TSC RESEARCH CONFERENCE IN ITALY 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 THE TSC SPECIAL INTEREST GROUP SCIENTIFIC SESSION 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 GOVERNMENT RELATIONS FOCUSES ON EDUCATING MEMBERS OF CONGRESS ABOUT TSC TO FURTHER TSC RESEARCH, AWARENESS AND CLINICAL CARE IN 2012, THE TS ALLIANCE GRASSROOTS VOLUNTEERS CONDUCTED A MARCH ON CAPITOL HILL RESULTING IN 66 MEMBERS OF THE HOUSE OF REPRESENTATIVES SIGNING A LETTER OF SUPPORT CIRCULATED BY REPRESENTATIVE LORETTA SANCHEZ (D-CA) AND 13 SENATORS SIGNING A BIPARTISAN LETTER OF SUPPORT CIRCULATED BY SENATOR RON WYDEN (D-OR) FOR FY13 APPROPRIATIONS THE US CONGRESS APPROPRIATED \$6 MILLION FOR FY13 TO TSC RESEARCH THROUGH THE DEPARTMENT OF DEFENSE'S CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM THE TSC RESEARCH PROGRAM (TSCRIP) 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 TSCRIP IS ONE OF THE LEADING SOURCES OF EXTRAMURAL TSC RESEARCH FUNDING IN THE UNITED STATES THE TSCRIP FILLS IMPORTANT GAPS IN TSC RESEARCH NOT ADDRESSED BY OTHER FUNDING AGENCIES " A HALLMARK ACHIEVEMENT IS TSCRIP-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 THROUGH 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 AND A THROUGH TSCRIP FUNDED RESEARCH ON THE DEVELOPMENT OF ANIMAL MODELS OF TSC THAT HAVE SEIZURES AND A BETTER UNDERSTAND THE ETIOLOGY OF TSC, A CLINICAL TRIAL IS PLANNED 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 TSCRIP ADDITIONAL GOVERNMENT RELATIONS EFFORTS INCLUDED A CONGRESSIONAL BRIEFING ON CAPITOL HILL TO COMMEMORATE THE INAUGURAL TSC GLOBAL AWARENESS DAY ON MAY 15, 2012 THIS EVENT WAS ATTENDED BY CONGRESSIONAL STAFF AND KEY MEMBERS OF THE TSC RESEARCH AND GRASSROOTS COMMUNITY	

4d	Other program services (Describe in Schedule O)
	(Expenses \$ 725,124 including grants of \$) (Revenue \$)
4e	Total program service expenses ▶ 2,601,218

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)? <i>If "Yes," complete Schedule A</i> 	Yes	
2 Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> (see instructions)? 	Yes	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i> 		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? <i>If "Yes," complete Schedule C, Part II</i> 	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? <i>If "Yes," complete Schedule C, Part III</i> 		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? <i>If "Yes," complete Schedule D, Part I</i> 		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? <i>If "Yes," complete Schedule D, Part II</i> 		No
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i> 		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? <i>If "Yes," complete Schedule D, Part IV</i> 		No
10 Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i> 	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? <i>If "Yes," complete Schedule D, Part VI</i> 	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? <i>If "Yes," complete Schedule D, Part VII</i> 		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? <i>If "Yes," complete Schedule D, Part VIII</i> 		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? <i>If "Yes," complete Schedule D, Part IX</i> 	Yes	
e Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i> 	Yes	
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i> 	Yes	
12a Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i> 		No
b Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i> 	Yes	
13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		No
14a Did the organization maintain an office, employees, or agents outside of the United States?		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? <i>If "Yes," complete Schedule F, Parts I and IV</i> 	Yes	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or assistance to any organization or entity located outside the United States? <i>If "Yes," complete Schedule F, Parts II and IV</i> 	Yes	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or assistance to individuals located outside the United States? <i>If "Yes," complete Schedule F, Parts III and IV</i> 		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? <i>If "Yes," complete Schedule G, Part I (see instructions)</i> 	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? <i>If "Yes," complete Schedule G, Part II</i> 	Yes	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i> 		No
20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		No
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		

Part IV

Checklist of Required Schedules (continued)

21	Did the organization report more than \$5,000 of grants and other assistance to any government or organization in the United States on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	21	Yes	
22	Did the organization report more than \$5,000 of grants and other assistance to individuals in the United States on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22		No
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete Schedule J	23	Yes	
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25	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? If "Yes," complete Schedule L, Part I	25a		No
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I	25b		No
26	Was a loan to or by a current or former officer, director, trustee, key employee, highest compensated employee, or disqualified person outstanding as of the end of the organization's tax year? If "Yes," complete Schedule L, Part II	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? If "Yes," complete Schedule L, Part III	27		No
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)			
a	A current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28a		No
b	A family member of a current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28b	Yes	
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? If "Yes," complete Schedule L, Part IV	28c		No
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29	Yes	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M	30		No
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	31		No
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II	32		No
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I	33		No
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1	34	Yes	
35a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		No
b	If 'Yes' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If "Yes," complete Schedule R, Part V, line 2	36		No
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI	37		No
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O	38	Yes	

Part V

Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response to any question in this Part V

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable.	23	
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable.	0	
c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	Yes
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return.	2a	16
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions).	2b	Yes
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a	No
b	If "Yes," has it filed a Form 990-T for this year? If "No," provide an explanation in Schedule O.	3b	
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a	No
b	If "Yes," enter the name of the foreign country: _____ See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a	No
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b	No
c	If "Yes," to line 5a or 5b, did the organization file Form 8886-T?	5c	
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?	6a	No
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b	
7	Organizations that may receive deductible contributions under section 170(c).		
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	Yes
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	Yes
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c	Yes
d	If "Yes," indicate the number of Forms 8282 filed during the year.	7d	1
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e	
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f	
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g	
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h	
8	Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?	8	
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the organization make any taxable distributions under section 4966?	9a	
b	Did the organization make a distribution to a donor, donor advisor, or related person?	9b	
10	Section 501(c)(7) organizations. Enter		
a	Initiation fees and capital contributions included on Part VIII, line 12.	10a	
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities.	10b	
11	Section 501(c)(12) organizations. Enter		
a	Gross income from members or shareholders.	11a	
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them).	11b	
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a	
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year.	12b	
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
a	Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O.	13a	
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans.	13b	
c	Enter the amount of reserves on hand.	13c	
14a	Did the organization receive any payments for indoor tanning services during the tax year?	14a	No
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O.	14b	

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 to any question 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		
	If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O		
b	Enter the number of voting members included in line 1a, above, who are independent		
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	Yes
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
b	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		
a	The governing body?	8a	Yes
b	Each committee with authority to act on behalf of the governing body?	8b	Yes
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O	9	No

Section B. Policies

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

		Yes	No
10a	Did the organization have local chapters, branches, or affiliates?	10a	Yes
b	If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	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
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990		
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13	12a	Yes
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b	Yes
c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	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?		
a	The organization's CEO, Executive Director, or top management official	15a	Yes
b	Other officers or key employees of the organization	15b	Yes
	If "Yes" to line 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
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?	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 (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 to any question 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) HENRY SHAPIRO CHAIR	5 00	X		X				0	0	0
(2) MATT BOLGER VICE CHAIR	5 00	X		X				0	0	0
(3) DAVID PARKES IMMEDIATE PAST CHAIR	5 00	X		X				0	0	0
(4) CELIA MASTBAUM TREASURER	5 00	X		X				0	0	0
(5) KEITH HALL SECRETARY	5 00	X		X				0	0	0
(6) JULIE BLUM BOARD MEMBER	3 00	X						0	0	0
(7) MARK CARROLL BOARD MEMBER	2 00	X						0	0	0
(8) RITA DIDOMENICO BOARD MEMBER	2 00	X						0	0	0
(9) PETER CRINO MD PHD BOARD MEMBER	2 00	X						0	0	0
(10) REIKO DONATO BOARD MEMBER	4 00	X						0	0	0
(11) WILLIAM FORD BOARD MEMBER	2 00	X						0	0	0
(12) JENNIFER GLASSMAN BOARD MEMBER	2 00	X						0	0	0
(13) STEVEN GOLDSTEIN BOARD MEMBER	2 00	X						0	0	0
(14) ROB MOSS BOARD MEMBER	2 00	X						0	0	0
(15) RON HEFFRON BOARD MEMBER	2 00	X						0	0	0
(16) ELIZABETH HENSKE MD 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)	▼	392,256	25,796	73,423

2 Total number of individuals (including but not limited to those listed in Item 1) who received or accrued more than \$100,000 of reportable compensation from the organization. **3**

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

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A)	(B)	(C)
Name and business address	Description of services	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 to any question 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, 513, or 514	
Contributions, Gifts, Grants and Other Similar Amounts	1a	Federated campaigns . . .	1a	82,623	3,199,643			
	b	Membership dues	1b					
	c	Fundraising events	1c	1,610,679				
	d	Related organizations	1d	202,000				
	e	Government grants (contributions)	1e					
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	1,304,341				
	g	Noncash contributions included in lines 1a-1f \$		28,975				
	h	Total. Add lines 1a-1f						
Program Service Revenue			Business Code					
	2a	RESEARCH PROGRAM REVENUE	900099	116,786	116,786			
	b	NOVARTIS CONTRACT	900099	86,000	86,000			
	c							
	d							
	e							
	f	All other program service revenue						
	g	Total. Add lines 2a-2f			202,786			
Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)		9,794			9,794	
	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	125				
		c	Gain or (loss)	-125				
	d	Net gain or (loss)			-125			-125
	8a	Gross income from fundraising events (not including \$ 1,610,679 of contributions reported on line 1c) See Part IV, line 18				-90,348		-90,348
		a	19,470					
		b	Less direct expenses	b	109,818			
	c	Net income or (loss) from fundraising events . .						
	9a	Gross income from gaming activities See Part IV, line 19						
		a						
		b	Less direct expenses	b				
c	Net income or (loss) from gaming activities . .							
10a	Gross sales of inventory, less returns and allowances							
	a							
	b	Less cost of goods sold	b					
c	Net income or (loss) from sales of inventory . .							
Miscellaneous Revenue		Business Code						
11a	OTHER	900099	22,550				22,550	
b								
c								
d	All other revenue							
e	Total. Add lines 11a-11d			22,550				
12	Total revenue. See Instructions			3,344,300	202,786	0	-58,129	

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 to any question 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.	762,957	762,957		
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.	77,000	77,000		
4	Benefits paid to or for members.				
5	Compensation of current officers, directors, trustees, and key employees.	491,475	289,424	79,422	122,629
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.	595,250	350,687	96,291	148,272
8	Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions).	16,717	9,820	2,686	4,211
9	Other employee benefits.	65,473	38,462	10,519	16,492
10	Payroll taxes.	84,156	49,438	13,520	21,198
11	Fees for services (non-employees):				
a	Management.				
b	Legal.	30,133	14,246	12,232	3,655
c	Accounting.	29,788	16,775	5,563	7,450
d	Lobbying.	98,880	98,880		
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).	59,342	24,319	3,202	31,821
12	Advertising and promotion.				
13	Office expenses.	245,670	105,992	64,256	75,422
14	Information technology.	62,333	15,600	46,310	423
15	Royalties.				
16	Occupancy.	144,950		144,950	
17	Travel.	205,354	177,292	1,690	26,372
18	Payments of travel or entertainment expenses for any federal, state, or local public officials.				
19	Conferences, conventions, and meetings.	88,911	76,693	12,113	105
20	Interest.				
21	Payments to affiliates.				
22	Depreciation, depletion, and amortization.	47,306	44,840	2,466	
23	Insurance.	8,249		8,249	
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	179,725	179,725		
b	CLINICAL RESEARCH NETWO	112,501	112,501		
c	BANK AND CREDIT CARD FE	39,446		39,446	
d	EQUIPMENT & MAINTENANCE	14,391	1,498	10,757	2,136
e	All other expenses	12,197	155,069	-209,736	66,864
25	Total functional expenses. Add lines 1 through 24e.	3,488,704	2,601,218	343,936	543,550
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).	87,606	43,803	0	43,803

Part X

Balance Sheet

Check if Schedule O contains a response to any question in this Part X

☒

					(A)		(B)
					Beginning of year		End of year
Assets	1	Cash—non-interest-bearing			2,222,455	1	2,334,967
	2	Savings and temporary cash investments			864,087	2	492,140
	3	Pledges and grants receivable, net			379,000	3	336,000
	4	Accounts receivable, net			319	4	86,517
	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			8,002	8	4,395
	9	Prepaid expenses and deferred charges			138,019	9	155,998
	10a	Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	10a	377,609	141,717	10c	100,412
	b	Less accumulated depreciation	10b	277,197			
	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			4,221,079	15	4,452,762
16	Total assets. Add lines 1 through 15 (must equal line 34)			7,974,678	16	7,963,191	
Liabilities	17	Accounts payable and accrued expenses			143,549	17	32,281
	18	Grants payable				18	
	19	Deferred revenue			1,628	19	1,628
	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			77,136	25	85,127
	26	Total liabilities. Add lines 17 through 25			222,313	26	119,036
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			4,804,940	27	5,255,154
	28	Temporarily restricted net assets			2,067,981	28	1,709,557
	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			7,752,365	33	7,844,155
	34	Total liabilities and net assets/fund balances			7,974,678	34	7,963,191

Part XI Reconciliation of Net Assets

Check if Schedule O contains a response to any question in this Part XI

1	Total revenue (must equal Part VIII, column (A), line 12)	1	3,344,300
2	Total expenses (must equal Part IX, column (A), line 25)	2	3,488,704
3	Revenue less expenses Subtract line 2 from line 1	3	-144,404
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	7,752,365
5	Net unrealized gains (losses) on investments	5	-19
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	236,215
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	7,844,155

Part XII Financial Statements and Reporting

Check if Schedule O contains a response to any question 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.

OMB No 1545-0047

2012

Open to Public Inspection

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

Part I

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

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

- 1

☐

A church, convention of churches, or association of churches 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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants ")	3,324,865	3,221,297	1,449,542	3,812,563	3,199,643	15,007,910
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	3,324,865	3,221,297	1,449,542	3,812,563	3,199,643	15,007,910
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)						252,551
6 Public support. Subtract line 5 from line 4						14,755,359

Section B. Total Support							
Calendar year (or fiscal year beginning in) ▶		(a) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(f) Total
7	Amounts from line 4	3,324,865	3,221,297	1,449,542	3,812,563	3,199,643	15,007,910
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	35,978	4,704	7,821	9,722	9,794	68,019
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)	13,767	3,967	5,728	13,037	23,048	59,547
11	Total support (Add lines 7 through 10)						15,135,476
12	Gross receipts from related activities, etc (see instructions)					12	2,228,284
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 2012 (line 6, column (f) divided by line 11, column (f))	14	97 490 %
15	Public support percentage for 2011 Schedule A, Part II, line 14	15	93 450 %
16a	33 1/3% support test—2012. 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—2011. 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—2012. 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—2011. 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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(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) 2008	(b) 2009	(c) 2010	(d) 2011	(e) 2012	(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 2012 (line 8, column (f) divided by line 13, column (f))	15	
16 Public support percentage from 2011 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage		
17 Investment income percentage for 2012 (line 10c, column (f) divided by line 13, column (f))	17	
18 Investment income percentage from 2011 Schedule A, Part III, line 17	18	
19a 33 1/3% support tests—2012. 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—2011. 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.** Complete this part to 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

Explanation

SCHEDULE C

(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities

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

▶ Complete if the organization is described below. ▶ Attach to Form 990 or Form 990-EZ.
▶ See separate instructions.

OMB No 1545-0047

2012

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
---	--

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)	16,179													
b	Total lobbying expenditures to influence a legislative body (direct lobbying)	125,231													
c	Total lobbying expenditures (add lines 1a and 1b)	141,410													
d	Other exempt purpose expenditures	3,330,791													
e	Total exempt purpose expenditures (add lines 1c and 1d)	3,472,201													
f	Lobbying nontaxable amount Enter the amount from the following table in both columns	323,610													
<table><tr><td>If the amount on line 1e, column (a) or (b) is:</td><td>The lobbying nontaxable amount is:</td></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)	80,903													
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) 2009	(b) 2010	(c) 2011	(d) 2012	(e) Total
2a Lobbying nontaxable amount	326,843	226,416	334,138	323,610	1,211,007
b Lobbying ceiling amount (150% of line 2a, column(e))					1,816,511
c Total lobbying expenditures	152,958	74,182	163,120	141,410	531,670
d Grassroots nontaxable amount	81,711	56,604	83,535	80,903	302,753
e Grassroots ceiling amount (150% of line 2d, column (e))					454,130
f Grassroots lobbying expenditures	34,107	7,007	7,688	16,179	64,981

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).

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

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

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

Part IV Supplemental Information

Complete this part to 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.

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

SCHEDULE D
(Form 990)

Supplemental Financial Statements

OMB No 1545-0047

2012

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

▶ 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.

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

Part I

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

	(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year	
2	Aggregate contributions to (during year)	
3	Aggregate grants from (during year)	
4	Aggregate value at end of year	
5	Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? ☐ Yes ☐ No	
6	Did the organization inform all grantees, donors, and donor advisors in writing that grant funds 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

	Amount
1c	
1d	
1e	
1f	

c

Beginning balance

d

Additions during the year

e

Distributions during the year

f

Ending balance

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	4,221,150	4,443,045	3,866,081	3,750,509	4,856,856
b Contributions	43,996	29,825	13,835	13,523	6,722
c Net investment earnings, gains, and losses	420,983	-47,583	584,775	312,223	-832,060
d Grants or scholarships					
e Other expenditures for facilities and programs	202,000	175,000		210,174	281,009
f Administrative expenses	26,764	29,137	21,646		
g End of year balance	4,457,365	4,221,150	4,443,045	3,866,081	3,750,509

2

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

a

Board designated or quasi-endowment

78 840 %

b

Permanent endowment

19 730 %

c

Temporarily restricted endowment

1 430 %

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. 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		27,000	27,000	0
d Equipment		21,819	13,930	7,889
e Other		328,790	236,267	92,523
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				100,412

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

1	Total revenue, gains, and other support per audited financial statements	1	3,679,620
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12	2e	335,320
a	Net unrealized gains on investments	2a	-19
b	Donated services and use of facilities	2b	99,124
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII)	2d	236,215
e	Add lines 2a through 2d	2e	335,320
3	Subtract line 2e from line 1	3	3,344,300
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1	4c	0
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	
5	Total revenue Add lines 3 and 4c . (This must equal Form 990, Part I, line 12)	5	3,344,300

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

1	Total expenses and losses per audited financial statements	1	3,587,830
2	Amounts included on line 1 but not on Form 990, Part IX, line 25	2e	99,124
a	Donated services and use of facilities	2a	99,124
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII)	2d	
e	Add lines 2a through 2d	2e	99,124
3	Subtract line 2e from line 1	3	3,488,706
4	Amounts included on Form 990, Part IX, line 25, but not on line 1 :	4c	0
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	
5	Total expenses Add lines 3 and 4c . (This must equal Form 990, Part I, line 18)	5	3,488,706

Part XIII Supplemental Information

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

Identifier	Return Reference	Explanation
DESCRIPTION OF INTENDED USE OF ENDOWMENT FUNDS	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.
DESCRIPTION OF UNCERTAIN TAX POSITIONS UNDER FIN 48	PART X, LINE 2	THE ALLIANCE BELIEVES THAT IT HAS APPROPRIATE SUPPORT FOR ANY INCOME TAX POSITIONS TAKEN. THEREFORE, MANAGEMENT HAS NOT IDENTIFIED ANY UNCERTAIN INCOME TAX POSITIONS. AT A MINIMUM, THE JUNE 30, 2009 THROUGH DECEMBER 31, 2012 TAX PERIODS ARE OPEN FOR EXAMINATION BY TAXING AUTHORITIES.
PART XI, LINE 2D - OTHER ADJUSTMENTS		CHANGE IN INTEREST IN ENDOWMENT FUND 236,215

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	77,000	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

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

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, 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
Complete this part to 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 II, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information (see instructions).

Schedule F (Form 990) 2012

SCHEDULE G
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding
Fundraising or Gaming Activities

Complete if the organization answered "Yes" to Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a. Form 990-EZ filers are not required to complete this part.
▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No 1545-0047

2012

Open to Public
Inspection

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

Part I Fundraising Activities. Complete if the organization answered "Yes" to Form 990, Part IV, line 17.

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

a	☐ Mail solicitations	e	☐ Solicitation of non-government grants
b	☐ Internet and email solicitations	f	☐ Solicitation of government grants
c	☐ Phone solicitations	g	☒ Special fundraising events
d	☐ In-person solicitations		
- 2a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? ☐ Yes ☒ No

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

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
BLUE ROOM EVENTS INC 5777 WEST CENTURY BLVD STE 880 LOS ANGELES, CA 90045	COMEDY FOR A CURE EVENT		No	182,521	16,500	182,521
Total ▶				182,521	16,500	182,521

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

.....

.....

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)	0 (total number)	(add col (a) through col (c))
Revenue	1	Gross receipts	1,212,247	198,021	219,881
	2	Less Contributions . . .	1,212,247	183,451	214,981
	3	Gross income (line 1 minus line 2)		14,570	4,900
Direct Expenses	4	Cash prizes			
	5	Noncash prizes			
	6	Rent/facility costs . . .			
	7	Food and beverages . .			
	8	Entertainment			
	9	Other direct expenses .	51,638	31,850	26,330
	10	Direct expense summary Add lines 4 through 9 in column (d) ▶			
	11	Net income summary Combine line 3, column (d), and line 10 ▶			

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

		(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col (a) through col (c))
Revenue	1	Gross revenue			
Direct Expenses	2	Cash prizes			
	3	Non-cash prizes			
	4	Rent/facility costs			
	5	Other direct expenses . . .			
	6	Volunteer labor	Yes No	Yes No	Yes No
	7	Direct expense summary Add lines 2 through 5 in column (d) ▶			
	8	Net gaming income summary Combine lines 1 and 7 in 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. Complete this part to 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).

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

efile GRAPHIC print - DO NOT PROCESS | As Filed Data - |

Schedule I
(Form 990)

Department of the Treasury
Internal Revenue Service

Grants and Other Assistance to Organizations,
Governments and Individuals in the United States

Complete if the organization answered "Yes," to Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990

DLN: 93493112002053

OMB No 1545-0047

2012

Open to Public
Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

Employer identification number
95-3018799

Part I

General Information on Grants and Assistance

- 1

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

Yes

No

2

Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States
- Part II

Grants and Other Assistance to Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21, for any recipient that received more than \$5,000. 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) | 103,102 | | | | CLINICAL TRIALS AND RESEARCH GRANTS |
| (2) VANDERBILT UNIVERSITY MEDICAL CENTER
DEPT OF FINANCE DEPT AT 40303
ATLANTA,GA 31192 | 62-0476822 | 501(C)(3) | 141,000 | | | | RESEARCH GRANT |
| (3) UNIVERSITY OF TEXAS
PO BOX 4786-750
HOUSTON,TX 77210 | 74-6000949 | 501(C)(3) | 12,066 | | | | RESEARCH GRANT |
| (4) CHILDREN'S HOSPITAL
PO BOX 414413
BOSTON,MA 02241 | 04-2774441 | 501(C)(3) | 271,865 | | | | RESEARCH GRANT |
| (5) SEIZURE TRACKER
4008 RONSON DRIVE
ALEXANDRIA,VA 22310 | 26-2311059 | | 6,000 | | | | RESEARCH GRANT |
| (6) NEW YORK UNIVERSITY MEDICAL CENTER
550 1ST AVE
NEW YORK,NY 10016 | 13-5562308 | 501(C)(3) | 11,499 | | | | RESEARCH GRANT |
| (7) MASSACHUSETTS GENERAL HOSPITAL
PO BOX 414876
BOSTON,MA 02241 | 04-2697983 | 501(C)(3) | 76,835 | | | | RESEARCH GRANT |
| (8) CINCINNATI CHILDREN'S HOSPITAL
3333 BURNET AVE ML 7030
CINCINNATI,OH 452293039 | 31-0833936 | 501(C)(3) | 180,960 | | | | RESEARCH GRANT |
| (9) UNIVERSITY OF TEXAS MD ANDERSON CANCER CENTER
PO BOX 4786-750
HOUSTON,TX 77210 | 74-6000949 | 501(C)(3) | -40,370 | | | | RESEARCH GRANT |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
- 2

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

8

3

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

7
- For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Cat No 50055P

Schedule I (Form 990) 2012

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.

Complete this part to provide the information required in Part I, line 2, Part III, column (b), and any other additional information

Identifier	Return Reference	Explanation
PROCEDURE FOR MONITORING GRANTS IN THE U S	PART I, LINE 2	SCHEDULE I, PART I, LINE 2 THE TS ALLIANCE HAS FUNDED MORE THAN \$16 5 MILLION IN RESEARCH ON TSC SINCE 1984 DIRECTED BY STEVEN L ROBERDS, PH D, CHIEF SCIENTIFIC OFFICER, THE TS ALLIANCE RESEARCH GRANTS PROGRAM FUNDS RESEARCH FOCUSED ON TSC WITH PRIORITIES SET BY THE RESEARCHERS TOGETHER WITH THE TS ALLIANCE COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS ARE ENCOURAGED AND FOSTERED, AND THE TS ALLIANCE IS WORKING TO INCREASE FUNDING FOR RESEARCH ON TSC THROUGH THE TS ALLIANCE RESEARCH GRANTS PROGRAM, APPLICATIONS CAN BE SUBMITTED FOR - 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
		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

Software ID:

Software Version:

EIN: 95-3018799

Name: NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

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

(a) Name and address of organization or government	(b) EIN	(c) IRC Code section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
BRIGHAM & WOMEN'S HOSPITAL75 FRANCIS STREET BOSTON,MA 02115	04-2312909	501(C)(3)	103,102				CLINICAL TRIALS AND RESEARCH GRANTS
VANDERBILT UNIVERSITY MEDICAL CENTERDEPT OF FINANCE DEPT AT 40303 ATLANTA,GA 31192	62-0476822	501(C)(3)	141,000				RESEARCH GRANT
UNIVERSITY OF TEXASPO BOX 4786-750 HOUSTON,TX 77210	74-6000949	501(C)(3)	12,066				RESEARCH GRANT
CHILDREN'S HOSPITALPO BOX 414413 BOSTON,MA 02241	04-2774441	501(C)(3)	271,865				RESEARCH GRANT
SEIZURE TRACKER4008 RONSON DRIVE ALEXANDRIA,VA 22310	26-2311059		6,000				RESEARCH GRANT
NEW YORK UNIVERSITY MEDICAL CENTER550 1ST AVE NEW YORK,NY 10016	13-5562308	501(C)(3)	11,499				RESEARCH GRANT
MASSACHUSETTS GENERAL HOSPITALPO BOX 414876 BOSTON,MA 02241	04-2697983	501(C)(3)	76,835				RESEARCH GRANT
CINCINNATI CHILDREN'S HOSPITAL3333 BURNET AVE ML 7030 CINCINNATI,OH 452293039	31-0833936	501(C)(3)	180,960				RESEARCH GRANT
UNIVERSITY OF TEXAS MD ANDERSON CANCER CENTERPO BOX 4786-750 HOUSTON,TX 77210	74-6000949	501(C)(3)	-40,370				RESEARCH GRANT

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, question 23.

▶ Attach to Form 990. ▶ See separate instructions.

OMB No 1545-0047

2012

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 ☐ Housing allowance or residence for personal use ☐ Travel for companions ☐ Payments for business use of personal residence ☐ Tax idemnification and gross-up payments ☐ Health or social club dues or initiation fees ☐ Discretionary spending account ☐ Personal services (e g , maid, chauffeur, chef)			
b	If any of the boxes in line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all 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 officers, directors, trustees, and the CEO/Executive Director, regarding the items checked in line 1a?	2		
3	Indicate which, if any, of the following the 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 ☒ Written employment contract ☐ Independent compensation consultant ☒ Compensation survey or study ☒ Form 990 of other organizations ☒ Approval by the board or compensation committee			
4	During the year, did any person listed in Form 990, Part VII, Section A, line 1a with respect to the filing organization or a related organization:			
a	Receive a severance payment or change-of-control payment?	4a		No
b	Participate in, or receive payment from, a supplemental nonqualified retirement plan?	4b		No
c	Participate in, or receive payment from, an equity-based compensation arrangement? 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)	138,889	0	0	4,167	26,924	169,980	0
	(ii)	13,889	0	0	417	2,692	16,998	0
(2) STEVEN L ROBERDS CHIEF SCIENTIFIC OFFICER	(i)	158,107	0	0	4,743	23,158	186,008	0
	(ii)	0	0	0	0	0	0	0

Part III Supplemental Information

Complete this part to 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.

Identifier	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
SUPPLEMENTAL INFORMATION	PART III	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 L
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Transactions with Interested Persons

▶ Complete if the organization answered
"Yes" on Form 990, Part IV, lines 25a, 25b, 26, 27, 28a, 28b, or 28c,
or Form 990-EZ, Part V, line 38a or 40b.
▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.

OMB No 1545-0047

2012

Open to Public Inspection

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

Part I Excess Benefit Transactions (section 501(c)(3) and section 501(c)(4) organizations only).

Complete if the organization answered "Yes" on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b

1	(a) Name of disqualified person	(b) Relationship between disqualified person and organization	(c) Description of transaction	(d) Corrected?	
				Yes	No

2 Enter the amount of tax incurred by organization managers or disqualified persons during the year under section 4958 ▶ \$

3 Enter the amount of tax, if any, on line 2, above, reimbursed by the organization ▶ \$

Part II Loans to and/or From Interested Persons.

Complete if the organization answered "Yes" on Form 990-EZ, Part V, line 38a, or Form 990, Part IV, line 26, or if the organization reported an amount on Form 990, Part X, line 5, 6, or 22

(a) Name of interested person	(b) Relationship with organization	(c) Purpose of loan	(d) Loan to or from the organization?		(e) Original principal amount	(f) Balance due	(g) In default?		(h) Approved by board or committee?	(i) Written agreement?	
			To	From			Yes	No		Yes	No
Total ▶ \$											

Part III Grants or Assistance Benefitting Interested Persons.

Complete if the organization answered "Yes" on Form 990, Part IV, line 27.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of assistance	(d) Type of assistance	(e) Purpose of assistance

Part IV Business Transactions Involving Interested Persons.

Complete if the organization answered "Yes" on Form 990, Part IV, line 28a, 28b, or 28c.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of transaction	(d) Description of transaction	(e) Sharing of organization's revenues?	
				Yes	No
(1) LISA MOSS	SPOUSE-BOARD MEMBER	50,200	SEE BELOW		No

Part V Supplemental Information

Complete this part to provide additional information for responses to questions on Schedule L (see instructions)

Identifier	Return Reference	Explanation
		LISA MOSS IS MARRIED TO BOARD MEMBER ROBERT MOSS MS MOSS WORKED FOR A PORTION OF THE YEAR AS A PART-TIME, INDEPENDENT CONSULTANT ON TWO EVENTS, ART FOR A CURE AND THE NATIONAL WALK ON THE MALL HER CONSULTING AGREEMENT ENDED IN JUNE 16, 2012 MS MOSS THEN SUBMITTED AN APPLICATION FOR EMPLOYMENT FOR THE DIRECTOR OF DONOR RELATION POSITION, COMPETING AGAINST OTHER QUALIFIED CANDIDATES SHE WAS RIGOROUSLY INTERVIEWED BY A SEARCH COMMITTEE, BY THE CEO AND BY A STAFF TEAM SHE BEGAN FULL-TIME EMPLOYMENT JULY 30, 2012 ROBERT MOSS RESIGNED FROM THE BOARD IN NOVEMBER 2012

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.

OMB No 1545-0047

2012

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		28,975	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 1-28 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) (2012)

Part II

Supplemental Information. Complete this part to 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.

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

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.

OMB No 1545-0047

2012

**Open to Public
Inspection**

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

Identifier	Return Reference	Explanation
	FORM 990, PART VI, SECTION A, LINE 4	THE TS ALLIANCE MADE SEVERAL REVISIONS TO ITS ORGANIZATIONAL BYLAWS TO REFLECT MINOR CHANGES IN OPERATIONAL PROCEDURES THE BYLAWS WERE APPROVED BY THE BOARD OF DIRECTORS ON JUNE 13, 2012

Identifier	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

Identifier	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.

Identifier	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.

Identifier	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 2012 THE FOLLOWING CONFLICTS OF INTEREST WERE DISCLOSED BOARD MEMBER ROBERT MOSS'S COMPANY SEIZURE TRACKER WAS PAID \$6,000 FOR SOFTWARE TO TRACK SEIZURE ACTIVITY BOARD MEMBER ELIZABETH THIELE, MD, PHD IS EMPLOYED AT MASSACHUSETTS GENERAL HOSPITAL WHICH RECEIVED A \$20,000 GRANT FOR THE TSC NATURAL HISTORY DATABASE BOARD MEMBER ELIZABETH HENSKEL, MD IS EMPLOYED AT BRIGHAM AND WOMEN'S HOSPITAL WHICH RECEIVED A RESEARCH GRANT OF \$53,602 FOR THE TARGETING AUTOPHAGY & CELLULAR METABOLISM FOR TREATMENT OF TSC PROJECT

Identifier	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

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

Identifier	Return Reference	Explanation
CHANGES IN NET ASSETS OR FUND BALANCES	FORM 990, PART XI, LINE 9	CHANGE IN INTEREST IN AFFILIATE AND UNREALIZED LOSS 236,215

Identifier	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" to Form 990, Part IV, line 33, 34, 35, 36, or 37.
▶ Attach to Form 990. ▶ See separate instructions.

OMB No 1545-0047

2012

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" to 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" to 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" to 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" to 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" to 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 other organization	(b) Transaction type (a-s)	(c) Amount involved	(d) Method of determining amount involved
(1) TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FUND	C	202,000	CASH

Schedule R (Form 990) 2012

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**

Complete this part to provide additional information for responses to questions on Schedule R (see instructions)

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

Additional Data

Software ID:

Software Version:

EIN: 95-3018799

Name: NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional Trustee	Officer	Key employee	Highest compensated employee	Former			
HENRY SHAPIRO CHAIR	5 00	X		X				0	0	0
MATT BOLGER VICE CHAIR	5 00	X		X				0	0	0
DAVID PARKES IMMEDIATE PAST CHAIR	5 00	X		X				0	0	0
CELIA MASTBAUM TREASURER	5 00	X		X				0	0	0
KEITH HALL SECRETARY	5 00	X		X				0	0	0
JULIE BLUM BOARD MEMBER	3 00	X						0	0	0
MARK CARROLL BOARD MEMBER	2 00	X						0	0	0
RITA DIDOMENICO BOARD MEMBER	2 00	X						0	0	0
PETER CRINO MD PHD BOARD MEMBER	2 00	X						0	0	0
REIKO DONATO BOARD MEMBER	4 00	X						0	0	0
WILLIAM FORD BOARD MEMBER	2 00	X						0	0	0
JENNIFER GLASSMAN BOARD MEMBER	2 00	X						0	0	0
STEVEN GOLDSTEIN BOARD MEMBER	2 00	X						0	0	0
ROB MOSS BOARD MEMBER	2 00	X						0	0	0
RON HEFFRON BOARD MEMBER	2 00	X						0	0	0
ELIZABETH HENSKE MD BOARD MEMBER	2 00	X						0	0	0
LINDA JACKSON BOARD MEMBER	2 00	X						0	0	0
DEBORA MORITZ BOARD MEMBER	4 00	X						0	0	0
THEODORE MASTROIANNI BOARD MEMBER	2 00	X						0	0	0
ALAN MARSHALL BOARD MEMBER	2 00	X						0	0	0
DAVID MICHAELS BOARD MEMBER	2 00	X						0	0	0
COURTNEY O'MALLEY BOARD MEMBER	2 00	X						0	0	0
JOHN NICHOLSON BOARD MEMBER	2 00	X						0	0	0
REBECCA ANHANG PRICE BOARD MEMBER	2 00	X						0	0	0
JUDITH SHOULAK BOARD MEMBER	2 00	X						0	0	0

Form 990, Part VII - Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors										
(A) Name and Title	(B) Average hours per week (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			
ELIZABETH THIELE MD PHD BOARD MEMBER	2 00	X						0	0	0
KARI L ROSBECK PRESIDENT & CEO	50 00 5 00			X				138,889	13,889	34,200
MARY JANE PERRAUT CHIEF FINANCIAL OFFICER	45 00 5 00			X				95,260	11,907	11,322
STEVEN L ROBERDS CHIEF SCIENTIFIC OFFICER	45 00				X			158,107	0	27,901

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