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Form **990**

Department of the Treasury
Internal Revenue Service

# Return of Organization Exempt From Income Tax

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

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

OMB No 1545-0047

**2011**

**Open to Public Inspection**

**A For the 2011 calendar year, or tax year beginning 01-01-2011 and ending 12-31-2011**

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

**C** Name of organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

Doing Business As
TUBEROUS SCLEROSIS ALLIANCE

Number and street (or P O box if mail is not delivered to street address) | Room/suite
801 ROEDER ROAD NO 750

City or town, state or country, and ZIP + 4
SILVER SPRING, MD 20910

**D Employer identification number**
95-3018799

**E Telephone number**
(301) 562-9890

**G** Gross receipts $ 4,162,007

**F** Name and address of principal officer
KARI L ROSBECK
801 ROEDER ROAD NO 750
SILVER SPRING, MD 20910

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

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

**H(c)** Group exemption number ▶

**I** Tax-exempt status ☑ 501(c)(3) ☐ 501(c) ( ) ◀ (insert no ) ☐ 4947(a)(1) or ☐ 527

**J Website:** ▶ WWW TSALLIANCE ORG

**K** Form of organization ☑ Corporation ☐ Trust ☐ Association ☐ Other ▶ | **L** Year of formation 1975 | **M** State of legal domicile CA

## Part I Summary

**1** Briefly describe the organization's mission or most significant activities
THE NATIONAL TUBEROUS SCLEROSIS ASSOCIATION DBA TUBEROUS SCLEROSIS ALLIANCE IS DEDICATED TO FINDING A CURE FOR TUBEROUS SCLEROSIS WHILE IMPROVING THE LIVES OF THOSE AFFECTED

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

| | | | |
|---|---|---|---|
| **Activities & Governance** | **3** Number of voting members of the governing body (Part VI, line 1a) | **3** | 27 |
| | **4** Number of independent voting members of the governing body (Part VI, line 1b) | **4** | 27 |
| | **5** Total number of individuals employed in calendar year 2011 (Part V, line 2a) | **5** | 13 |
| | **6** Total number of volunteers (estimate if necessary) | **6** | 2,000 |
| | **7a** Total unrelated business revenue from Part VIII, column (C), line 12 | **7a** | 0 |
| | **b** Net unrelated business taxable income from Form 990-T, line 34 | **7b** | 0 |

| | | Prior Year | Current Year |
|---|---|---|---|
| **Revenue** | **8** Contributions and grants (Part VIII, line 1h) | 1,449,542 | 3,875,096 |
| | **9** Program service revenue (Part VIII, line 2g) | 4,250 | 212,084 |
| | **10** Investment income (Part VIII, column (A), lines 3, 4, and 7d ) | 7,821 | 9,439 |
| | **11** Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) | -19,424 | -131,202 |
| | **12** Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12) | 1,442,189 | 3,965,417 |
| **Expenses** | **13** Grants and similar amounts paid (Part IX, column (A), lines 1–3 ) | 663,012 | 1,174,276 |
| | **14** Benefits paid to or for members (Part IX, column (A), line 4) | 0 | 0 |
| | **15** Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10) | 562,165 | 1,122,866 |
| | **16a** Professional fundraising fees (Part IX, column (A), line 11e) | 0 | 16,500 |
| | **b** Total fundraising expenses (Part IX, column (D), line 25) ▶542,944 | | |
| | **17** Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e) | 531,212 | 1,320,882 |
| | **18** Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25) | 1,756,389 | 3,634,524 |
| | **19** Revenue less expenses Subtract line 18 from line 12 | -314,200 | 330,893 |

| | | Beginning of Current Year | End of Year |
|---|---|---|---|
| **Net Assets or Fund Balances** | **20** Total assets (Part X, line 16) | 7,808,197 | 7,974,678 |
| | **21** Total liabilities (Part X, line 26) | 145,908 | 222,313 |
| | **22** Net assets or fund balances Subtract line 21 from line 20 | 7,662,289 | 7,752,365 |

## Part II Signature Block

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

**Sign Here**

****** | 2012-04-13
Signature of officer | Date

KARI L ROSBECK PRESIDENT AND CEO
Type or print name and title

**Paid Preparer's Use Only**

| | | | |
|---|---|---|---|
| Preparer's signature: SUBRINA L WOOD | Date | Check if self-employed ☐ | Preparer's taxpayer identification number (see instructions) P00365899 |
| Firm's name (or yours if self-employed), address, and ZIP + 4: TATE & TRYON, 2021 L STREET NW, WASHINGTON, DC 20036 | | | EIN ▶ 52-1855942 |
| | | | Phone no ▶ (202) 293-2200 |

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

## 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 and section 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported

**4a** (Code ) (Expenses $ 1,970,929 including grants of $ 1,174,276 ) (Revenue $ 212,084 )

RESEARCH PROGRAM THE TS ALLIANCE HAS FUNDED MORE THAN $15 3 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 THE 2011 INTERNATIONAL TSC RESEARCH CONFERENCE 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, (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 THE 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 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 2011 MORE THAN 1,120 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 THE TS ALLIANCE RECEIVED A TWO-YEAR $200,000 GRANT AWARD FROM THE PEDIATRIC EPILEPSY RESEARCH FOUNDATION, WHICH WILL HELP UNDERWRITE ABOUT HALF THE CONTINUED OPERATION OF THE TSC DATABASE THROUGH 2013 THE TS ALLIANCE HOSTED THE 2011 INTERNATIONAL TSC RESEARCH CONFERENCE, "SUMMIT ON DRUG DISCOVERY IN TSC AND RELATED DISORDERS", WHICH PROVIDED THE OPPORTUNITY FOR RESEARCH AND HEALTHCARE COMMUNITIES TO COME TOGETHER TO DISCUSS THE LATEST PROGRESS IN CLINICAL, TRANSLATIONAL, AND BASIC RESEARCH EXCITING NEW CLINICAL DATA PRESENTATIONS DESCRIBED THE EFFICACY OF EVEROLIMUS AND SIROLIMUS AT REDUCING GROWTH OF TUMORS IN THE BRAIN AND KIDNEY, RESPECTIVELY ADDITIONALLY, A SMALL CLINICAL STUDY DEMONSTRATED ENCOURAGING EFFECTS OF SIROLIMUS ON REDUCING THE SEVERITY OF FACIAL ANGIOFIBROMAS SCIENTISTS ALSO DESCRIBED IMPORTANT PROGRESS ON PRE-CLINICAL STUDIES EVALUATING THE EFFECT OF DRUGS THAT AFFECT OTHER PARTS OF THE MTOR PATHWAY OR OTHER CELLULAR MECHANISMS THAT IMPACT CELL GROWTH FROM BASIC RESEARCH WE ARE LEARNING NEW BIOLOGICAL ACTIVITIES - SUCH AS NEURON GROWTH, PROTEIN DEGRADATION IN THE CELL, AND EFFECTS OF GLIAL CELLS ON NEURONAL EXCITABILITY - THAT COULD BE IMPORTANT TARGETS FOR NEW THERAPEUTIC APPROACHES A TOTAL OF 24 RESEARCH AWARDS WERE FUNDED IN 2011 FOR $1,174,277 THE TS ALLIANCE ROTHBERG COURAGE AWARD FOR RESEARCH CONTINUED SUPPORTING TWO ONGOING PROJECTS, THE DEVELOPMENT OF SEIZURE TRACKER AS AN EPILEPSY CLINICAL TRIAL TOOL AND THE TSC NEUROCOGNITIVE TRIAL, A CLINICAL STUDY OF EVEROLIMUS EFFECTS ON NEUROCOGNITION INITIATED THIS YEAR AT CHILDREN'S HOSPITAL BOSTON AND CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER THREE NEW COURAGE AWARDS WERE GRANTED IN 2011 FROM NET ASSETS TO DR HOPE NORTHRUP(UNIVERSITY OF TEXAS AT HOUSTON) TO SUPPORT THE IDENTIFICATION OF ADDITIONAL TSC GENES, TO DR JOHN BISSLER (CINCINNATI CHILDRENS HOSPITAL AND MEDICAL CENTER) FOR THE DEVELOPMENT OF MRI-GUIDED HIGH-INTENSITY FOCUSED ULTRASOUND TO TREAT KIDNEY OR LUNG LESIONS, AND TO DR ELIZABETH HENSKE(BRIGHAM & WOMENS HOSPITAL) TO SUPPORT A STUDY TO DETERMINE WHETHER INHIBITION OF AUTOPHAGY MIGHT KILL ABNORMALLY GROWING CELLS IN TSC THE TS ALLIANCE CONTINUED TO SUPPORT 13 RESEARCH GRANTS AWARDED IN PREVIOUS YEARS ADDITIONALLY, TWO NEW POSTDOCTORAL RESEARCH GRANTS WERE INITIATED THIS YEAR TO SUPPORT YOUNG SCIENTISTS WORKING ON TSC RESEARCH DR MAGDALENA TYBURCZY (BRIGHAM & WOMEN'S HOSPITAL) WAS AWARDED A GRANT FOR DETERMINING THE MOLECULAR PATHOGENESIS OF TSC IN INDIVIDUALS IN WHOM NO TSC1 OR TSC2 MUTATION HAS BEEN IDENTIFIED, AND DR BRIAN SIROKY (CINCINNATI CHILDREN'S HOSPITAL AND MEDICAL CENTER) WAS FUNDED TO STUDY THE ROLE OF ENDOPLASMIC RETICULUM STRESS IN THE PATHOGENESIS AND TREATMENT OF TSC RENAL CELL CYSTIC DISEASE 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 THIS YEAR THE TS ALLIANCE AWARDED DRUG SCREENING PROGRAM GRANTS TO SUPPORT PROJECTS THAT WILL TEST DRUGS FOR THEIR POTENTIAL TO INFLUENCE NEUROLOGIC MANIFESTATIONS OF TSC AN AWARD TO DR MUSTAFA SAHIN (CHILDREN'S HOSPITAL BOSTON) WAS GRANTED 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 A GRANT TO DR SEOK-HYUNG KIM (VANDERBILT UNIVERSITY) WAS AWARDED TO SUPPORT THE SCREENING OF COMPOUNDS TO REVERSE ABNORMAL NEURONAL PHENOTYPES IN TSC2 MUTANT ZEBRAFISH BOTH DRS SAHIN AND KIM WILL TEST A FEW THOUSAND DRUGS, INCLUDING HUNDREDS OF DRUGS APPROVED BY THE FDA FOR OTHER INDICATIONS, IN AN EFFORT TO IDENTIFY DRUGS THAT IMPROVE NEURONAL FUNCTION AND COULD BE MOVED RELATIVELY RAPIDLY INTO CLINICAL TESTING AS TRANSLATIONAL RESEARCH IN TSC PRODUCES ADDITIONAL IDEAS FOR CLINICAL STUDIES, THE EFFICIENT INITIATION AND CONDUCT OF FUTURE CLINICAL TRIALS WILL REQUIRE INFRASTRUCTURE IN PLACE TO ENABLE INVESTIGATORS TO QUICKLY AND AFFORDABLY EXECUTE STUDIES TO BEGIN BUILDING SUCH AN INFRASTRUCTURE, CLINICIANS FROM FIVE TSC CLINICS CAME TOGETHER TO ESTABLISH A TSC CLINICAL RESEARCH CONSORTIUM THAT CAN EXPAND AS NEEDED TO ACCOMMODATE FUTURE CLINICAL STUDIES THE TS ALLIANCE CHIEF SCIENTIFIC OFFICER IS ON THE LEADERSHIP TEAM OF THE CONSORTIUM

**4b** (Code ) (Expenses $ 380,633 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 3 TOWN HALL MEETINGS HELD AT COMMUNITY ALLIANCE LOCATIONS DURING THE FISCAL YEAR 2011 AS WELL AS 22 OTHER EDUCATIONAL MEETINGS AND SUPPORT MEETINGS THESE MEETINGS FACILITATED STRONGER CONNECTIONS WITH PEERS, RESEARCHERS, AND CLINICIANS IN THE COMMUNITY AND EDUCATED THE TSC COMMUNITY ABOUT CLINICAL TRIALS THE TS ALLIANCE ALSO CONTINUED ITS SERIES OF FREE EDUCATIONAL TELECONFERENCES AIMED AT REACHING CONSTITUENTS ACROSS THE COUNTRY WITH CLINICAL CARE SPECIALISTS AND SCIENTISTS FROM THE CONVENIENCE OF THEIR HOMES IN ADDITION, THE DEPARTMENT OF ADVOCACY AND EDUCATION SUPPORTS FAMILIES AND INDIVIDUALS FROM ALL OVER THE UNITED STATES BY PROVIDING SUPPORT AND INFORMATION INCLUDING DIRECT SUPPORT TWO DAYS PER MONTH AT TSC CLINICS IN MIAMI, CINCINNATI, COLUMBUS OR ATLANTA DURING ONE-ON-ONE MEETINGS IN ADDITION, VOLUNTEER CLINIC AMBASSADORS SUPPORTED INDIVIDUALS IN COLUMBUS, CINCINNATI, ATLANTA, MIAMI AND BIRMINGHAM THE DIRECTOR OF ADVOCACY AND EDUCATION ATTENDS INDIVIDUAL EDUCATION PROGRAM (IEP) MEETINGS IN PERSON, THROUGH SKYPE, AND CONFERENCE CALLS AND ALSO MAINTAINS AN ONGOING BLOG TO ENCOURAGE FREQUENT AND INTERACTIVE CONVERSATION WITH CONSTITUENTS AS THEY ENCOUNTER CHALLENGES ON A DAILY BASIS THERE ARE 10 ADVOCATE LIAISON VOLUNTEERS, WORKING IN 10 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 309 FREE PARENT TRAININGS AND WEBINARS ON EDUCATIONAL ADVOCACY OFFERED TO FAMILIES DEALING WITH EDUCATIONAL ISSUES FOR THEIR CHILDREN THERE WERE 33 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 THE DIRECTOR OF EDUCATION AND ADVOCACY ALSO FACILITATES THE ADULT TASK FORCE, WHICH HOLDS MONTHLY TOPIC CALLS IN IDENTIFIED ISSUES OF IMPORTANCE TO BETTER SUPPORT ADULTS LIVING WITH TSC FINALLY, THE TS ALLIANCE CREATED A NEW ONLINE SOCIAL NETWORK THROUGH "INSPIRE" THIS SOCIAL NETWORK WAS DEVELOPED TO BETTER FIT THE NEEDS OF OUR TSC POPULATION AND INCLUDED 1,012 MEMBERS FROM 53 COUNTRIES AS OF DECEMBER 31, 2011

**4c** (Code ) (Expenses $ 194,475 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 2011, THE TS ALLIANCE PRODUCED THREE ISSUES OF ITS NATIONAL MAGAZINE, PERSPECTIVE, WHICH IS MAILED TO MORE THAN 12,000 CONSTITUENTS AS WELL AS POSTED ON THE WEBSITE THE TS ALLIANCE'S WEBSITE INCREASES AWARENESS AND PROVIDES EXTENSIVE EDUCATION THOUGH ITS WEBSITE VIA 850,000 TO 1 MILLION HITS MONTHLY FROM AN AVERAGE OF MORE THAN 18,750 UNIQUE VISITORS THE SITE'S ONLINE MAIL LIST FORM CONTINUES TO CAPTURE 50 OR MORE NEW CONSTITUENTS EVERY MONTH THE TS ALLIANCE WEBSITE WAS REDESIGNED IN SUMMER 2011 TO REFLECT SIMPLER NAVIGATION, INCORPORATE MORE VIDEO AND ALLOW FOR INSTANT ACCESS TO A WEALTH OF INFORMATION THE TS ALLIANCE RELIES HEAVILY ON SOCIAL MEDIA TO EDUCATE CONSTITUENTS AND PROMOTE NEW RESOURCES AND EVENTS ITS FACEBOOK GROUP BOASTS MORE THAN 4,700 MEMBERS, WHILE ITS TWITTER ACCOUNT HAS ALMOST 400 FOLLOWERS THE TS ALLIANCE ALSO PROVIDES PUBLIC EDUCATION THROUGH A SERIES OF FREE RESEARCH TELECONFERENCES, FEATURING PRESENTATIONS FROM THE NATION'S TOP RESEARCHERS, CLINICIANS AND OTHER HEALTHCARE PROVIDERS, WHICH ARE ALSO RECORDED AND MADE AVAILABLE ON THE WEBSITE FOR ALL CONSTITUENTS

(Code ) (Expenses $ 26,188 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 THE 2011 BIO INTERNATIONAL CONVENTION, CHILD NEUROLOGY FOUNDATION'S ADVISORY BOARD MEETING, COALITION FOR IMAGING AND BIOENGINEERING RESEARCH (CIBR), INSTITUTE OF MEDICINE COMMITTEE MEETINGS ON THE PUBLIC HEALTH DIMENSIONS OF THE EPILEPSIES, LAM FOUNDATION CONFERENCE, RESEARCH AMERICA'S NATIONAL HEALTH RESEARCH FORUM, NATIONAL INSTITUTES OF HEALTH OFFICE OF RARE DISEASES CONFERENCE, NIAMS COALITION 2011 OUTREACH & EDUCATION MEETING, PARTNERING TO ADVANCE THERAPEUTICS FOR NEUROLOGICAL DISORDERS THE NINDS NONPROFIT FORUM, NORD/DIA ANNUAL CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS, SOCIETY FOR NEUROSCIENCE ANNUAL MEETING AND NIH-SPONSORED EPILEPSY SOCIAL, AND TUBEROUS SCLEROSIS ASSOCIATION INTERNATIONAL TSC RESEARCH CONFERENCE IN IRELAND IN ADDITION, THE TS ALLIANCE ATTENDED THE AMERICAN EPILEPSY SOCIETY (AES) MEETING IN BALTIMORE, INCLUDING A TSC RECEPTION FOR MORE THAN 50 RESEARCHERS, A MEET-THE-EXPERT PANEL WITH 10 TSC FAMILIES AND 9 TSC CLINICIAN EXPERTS, AND THE TSC SPECIAL INTEREST GROUP SCIENTIFIC SESSION FINALLY, THE TS ALLIANCE CO-SPONSORED WITH THE CENTER FOR BIOMEDICAL CONTINUING EDUCATION, A CME SPEAKER PROGRAM SERIES EMERGING THERAPEUTIC OPTIONS FOR TUBEROUS SCLEROSIS COMPLEX FOURTEEN TSC CLINIC DIRECTORS SERVED AS FACULTY THIS PROGRAM PRESENTED 3 GRAND ROUNDS AND 5 DINNER SESSIONS IN DALLAS, NEW YORK, LOS ANGELES, ATLANTA AND ST PAUL 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 THROUGH THIS COLLABORATION THE TS ALLIANCE HAS PROVIDED INFORMATION ON MORE THAN 300 FREE TRAINING ON EDUCATIONAL ADVOCACY FOR FAMILIES DEALING WITH EDUCATIONAL ISSUES FOR THEIR CHILDREN THROUGHOUT THE COUNTRY 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 PROVIDING CHILDREN WITH APPROPRIATE EDUCATION IS THE KEY TO INDIVIDUALS HAVING A GOOD QUALITY OF LIFE

(Code ) (Expenses $ 163,120 including grants of $ ) (Revenue $ )

GOVERNMENT RELATIONS FOCUSES ON EDUCATING MEMBERS OF CONGRESS ABOUT TSC TO FURTHER TSC RESEARCH, AWARENESS AND CLINICAL CARE IN 2011, THE TS ALLIANCE GRASSROOTS VOLUNTEERS CONDUCTED A MARCH ON CAPITOL HILL RESULTING IN 40 MEMBERS OF THE HOUSE OF REPRESENTATIVES SIGNING A LETTER OF SUPPORT CIRCULATED BY REPRESENTATIVE LORETTA SANCHEZ (D-CA) AND 9 SENATORS SIGNING A BIPARTISAN LETTER OF SUPPORT CIRCULATED BY SENATOR SHERROD BROWN (D-OH) FOR FY12 APPROPRIATIONS THE US CONGRESS APPROPRIATED $6 4 MILLION FOR FY11 IN APRIL 2011 AND $5 1 MILLION FOR FY12 IN DECEMBER 2011 TO TSC RESEARCH THROUGH THE DEPARTMENT OF DEFENSE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM IN 2011 THE TSC RESEARCH PROGRAM (TSCRP) ADMINISTERED FROM THE APPROPRIATION IS A COMPETITIVE PEER REVIEW GRANT PROGRAM ACCORDING TO THE U S ARMY MEDICAL RESEARCH AND MATERIAL COMMAND, CDMRP, TUBEROUS SCLEROSIS COMPLEX RESEARCH PROGRAM REPORT "TODAY, THE TSCRP IS ONE OF THE LEADING SOURCES OF EXTRAMURAL TSC RESEARCH FUNDING IN THE UNITED STATES THE TSCRP FILLS IMPORTANT GAPS IN TSC RESEARCH NOT ADDRESSED BY OTHER FUNDING AGENCIES " A HALLMARK ACHIEVEMENT IS THE RESEARCH SUPPORTED BY THE TSCRP 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, WHICH IS IMPORTANT IN NORMAL CELL GROWTH AND HAS BEEN SHOWN TO BE DISRUPTED IN MANY TYPES OF CANCER THIS RESEARCH HAS RAPIDLY LED TO THE DEVELOPMENT OF ANIMAL MODELS OF TSC AND CLINICAL TRIALS, RESULTING IN THE FIRST DRUG SPECIFICALLY TO TREAT TSC BEING APPROVED BY THE FDA IN OCTOBER 2010 NONE OF THIS PROGRESS WOULD HAVE BEEN POSSIBLE WITHOUT THE CRITICAL SUPPORT PROVIDED THROUGH THE TSCRP

**4d** Other program services (Describe in Schedule O )
(Expenses $ 189,308 including grants of $ ) (Revenue $ )

**4e** **Total program service expenses** ▶ $ 2,735,345

## Part IV Checklist of Required Schedules

| | | | Yes | No |
|---|---|---|---|---|
| 1 | Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? *If "Yes," complete Schedule A* | 1 | Yes | |
| 2 | Is the organization required to complete *Schedule B, Schedule of Contributors* (see instructions)? | 2 | Yes | |
| 3 | Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? *If "Yes," complete Schedule C, Part I* | 3 | | No |
| 4 | **Section 501(c)(3) organizations.** Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? *If "Yes," complete Schedule C, Part II* | 4 | Yes | |
| 5 | Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? *If "Yes," complete Schedule C, Part III* | 5 | | |
| 6 | Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? *If "Yes," complete Schedule D, Part I* | 6 | | No |
| 7 | Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas or historic structures? *If "Yes," complete Schedule D, Part II* | 7 | | No |
| 8 | Did the organization maintain collections of works of art, historical treasures, or other similar assets? *If "Yes," complete Schedule D, Part III* | 8 | | No |
| 9 | Did the organization report an amount in Part X, line 21, serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? *If "Yes," complete Schedule D, Part IV* | 9 | | No |
| 10 | Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? *If "Yes," complete Schedule D, Part V* | 10 | Yes | |
| 11 | If the organization's answer to any of the following questions is 'Yes,' then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable | | | |
| a | Did the organization report an amount for land, buildings, and equipment in Part X, line10? *If "Yes," complete Schedule D, Part VI.* | 11a | Yes | |
| b | Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? *If "Yes," complete Schedule D, Part VII.* | 11b | | No |
| c | Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? *If "Yes," complete Schedule D, Part VIII.* | 11c | | No |
| d | Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? *If "Yes," complete Schedule D, Part IX.* | 11d | Yes | |
| e | Did the organization report an amount for other liabilities in Part X, line 25? *If "Yes," complete Schedule D, Part X.* | 11e | Yes | |
| f | Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? *If "Yes," complete Schedule D, Part X.* | 11f | Yes | |
| 12a | Did the organization obtain separate, independent audited financial statements for the tax year? *If "Yes," complete Schedule D, Parts XI, XII, and XIII* | 12a | | No |
| b | Was the organization included in consolidated, independent audited financial statements for the tax year? *If "Yes," and if the organization answered 'No' to line 12a, then completing Schedule D, Parts XI, XII, and XIII is optional* | 12b | Yes | |
| 13 | Is the organization a school described in section 170(b)(1)(A)(ii)? *If "Yes," complete Schedule E* | 13 | | No |
| 14a | Did the organization maintain an office, employees, or agents outside of the United States? | 14a | | No |
| b | Did the organization have aggregate revenues or expenses of more than $10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at $100,000 or more? *If "Yes," complete Schedule F, Part I* | 14b | Yes | |
| 15 | Did the organization report on Part IX, column (A), line 3, more than $5,000 of grants or assistance to any organization or entity located outside the U S ? *If "Yes," complete Schedule F, Part II and IV* | 15 | Yes | |
| 16 | Did the organization report on Part IX, column (A), line 3, more than $5,000 of aggregate grants or assistance to individuals located outside the U S ? *If "Yes," complete Schedule F, Part III and IV* | 16 | | No |
| 17 | Did the organization report a total of more than $15,000, of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? *If "Yes," complete Schedule G, Part I* | 17 | Yes | |
| 18 | Did the organization report more than $15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? *If "Yes," complete Schedule G, Part II* | 18 | Yes | |
| 19 | Did the organization report more than $15,000 of gross income from gaming activities on Part VIII, line 9a? *If "Yes," complete Schedule G, Part III* | 19 | | No |
| 20a | Did the organization operate one or more hospitals? *If "Yes," complete Schedule H* | 20a | | No |
| b | If "Yes" to line 20a, did the organization attach its audited financial statement to this return? **Note.** All Form 990 filers that operated one or more hospitals must attach audited financial statements | 20b | | |

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

| | | | | |
|---|---|---|---|---|
| **21** | Did the organization report more than $5,000 of grants and other assistance to governments and organizations in the United States on Part IX, column (A), line 1? *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, questions 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 questions 24b–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, highly 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 a grant selection committee member, or to a person related to such an individual? *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** | | No |
| **c** | An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or 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, Parts II, III, IV, and V, line 1* | **34** | Yes | |
| **35a** | Is any related organization a controlled entity of the filing organization within the meaning of section 512(b)(13)? | **35a** | | No |
| **b** | 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** | | No |
| **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 11 and 19? **Note.** All Form 990 filers are required to complete Schedule O | **38** | Yes | |

## Part V Statements Regarding Other IRS Filings and Tax Compliance

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 . . . . . | **1a** | 24 | | |
| **b** | Enter the number of Forms W-2G included in line 1a *Enter -0-* if not applicable | **1b** | 0 | | |
| **c** | Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? . . . . . | | | **1c** | Yes | |
| **2a** | Enter the number of employees reported on Form W-3, *Transmittal of Wage and Tax Statements* filed for the calendar year ending with or within the year covered by this return . . . . . | **2a** | 13 | | | |
| **b** | If at least one is reported on line 2a, did the organization file all required federal employment tax returns? | | | **2b** | Yes | |
| | **Note.** If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions) | | | | | |
| **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 or securities 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? . . . . . | | | **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** | 6 | | | |
| **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.** All 501(c)(29) organizations must list in Schedule O each state in which they are licensed to issue qualified health plans, the amount of reserves required by each state, and the amount of reserves the organization allocated to each state | | | **13a** | | |
| **b** | Enter the aggregate 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 aggregate 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 . . . . . | 1a | 27 | | |
| b | Enter the number of voting members included in line 1a, above, who are independent . . . . . | 1b | 27 | | |
| 2 | Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee? . . . . . | | 2 | | No |
| 3 | Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person? . | | 3 | | No |
| 4 | Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? | | 4 | | No |
| 5 | Did the organization become aware during the year of a significant diversion of the organization's assets? . | | 5 | | No |
| 6 | Did the organization have members or stockholders? . . . . . | | 6 | Yes | |
| 7a | Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? . . . . . | | 7a | Yes | |
| 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 the 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

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 See Additional Data Table

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

THE ORGANIZATION
801 ROEDER ROAD NO 750
SILVER SPRING, MD 20910
(301) 562-9890

## 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, and **current** key employees 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 organizations compensated any current or former officer, director, or trustee

| (A) Name and Title | (B) Average hours per week (describe hours for related organizations in Schedule O) | (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) CELIA MASTBAUM IMMEDIATE PAST CHAIR | 5 00 | X | | X | | | | 0 | 0 | 0 |
| (2) DAVID PARKES CHAIR | 5 00 | X | | X | | | | 0 | 0 | 0 |
| (3) HENRY SHAPIRO VICE CHAIR | 5 00 | X | | X | | | | 0 | 0 | 0 |
| (4) MATT BOLGER SECRETARY | 5 00 | X | | X | | | | 0 | 0 | 0 |
| (5) RITA DIDOMENICO TREASURER | 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) WILL COOPER SR BOARD MEMBER | 4 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) JANIE FROST RN BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (13) JENNIFER GLASSMAN BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (14) STEVEN GOLDSTEIN BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (15) KEITH HALL BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (16) RON HEFFRON BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (17) ELIZABETH HENSKE MD BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |

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

| (A) Name and Title | (B) Average hours per week (describe hours for related organizations in Schedule O) | (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 | | | |
| (18) LINDA JACKSON BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (19) CATHY KRINSKY BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (20) THEODORE MASTROIANNI BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (21) ALAN MARSHALL BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (22) KATHY MAYRSOHN BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (23) JOHN NICHOLSON MD MBA BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (24) COURTNEY O'MALLEY BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (25) DAVID SCHENKEIN MD BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (26) JUDITH SHOULAK BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (27) ELIZABETH THIELE MD PHD BOARD MEMBER | 2 00 | X | | | | | | 0 | 0 | 0 |
| (28) KARI L ROSBECK PRESIDENT & CEO | 50 00 | | | X | | | | 141,328 | 2,884 | 30,797 |
| | | | | | | | | | | |
| | | | | | | | | | | |

| | | | | |
|---|---|---|---|---|
| **1b** | **Sub-Total** . . . . . ▶ | | | |
| **c** | **Total from continuation sheets to Part VII, Section A** . . . . ▶ | | | |
| **d** | **Total (add lines 1b and 1c)** . . . . . ▶ | 141,328 | 2,884 | 30,797 |

**2** Total number of individuals (including but not limited to those listed above) who received more than $100,000 of reportable compensation from the organization ▶ 1

| | | | Yes | No |
|---|---|---|---|---|
| **3** | Did the organization list any **former** officer, director or trustee, key employee, or highest compensated employee on line 1a? *If "Yes," complete Schedule J for such individual* . . . . . | **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? *If "Yes," complete Schedule J for such individual* . . . . . | **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? *If "Yes," complete Schedule J for such person* . . . . . | **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) Name and business address | (B) Description of services | (C) Compensation |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |

**2** Total number of independent contractors (including but not limited to those listed above) who received more than $100,000 of compensation from the organization ▶ 0

## Part VIII Statement of Revenue

| | | | (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 76,544 | | | | |
| | b | Membership dues 1b | | | | |
| | c | Fundraising events 1c 1,720,223 | | | | |
| | d | Related organizations 1d 175,000 | | | | |
| | e | Government grants (contributions) 1e 16,000 | | | | |
| | f | All other contributions, gifts, grants, and similar amounts not included above 1f 1,887,329 | | | | |
| | g | Noncash contributions included in lines 1a-1f $ 60,533 | | | | |
| | h | **Total.** Add lines 1a-1f | 3,875,096 | | | |
| Program Service Revenue | | Business Code | | | | |
| | 2a | RESEARCH PROGRAM REVEN 900099 | 212,084 | 212,084 | | |
| | b | | | | | |
| | c | | | | | |
| | d | | | | | |
| | e | | | | | |
| | f | All other program service revenue | | | | |
| | g | **Total.** Add lines 2a–2f | 212,084 | | | |
| | 3 | Investment income (including dividends, interest and other similar amounts) | 9,722 | | | 9,722 |
| | 4 | Income from investment of tax-exempt bond proceeds | | | | |
| | 5 | Royalties | | | | |
| | | (i) Real / (ii) Personal | | | | |
| | 6a | Gross rents | | | | |
| | b | Less rental expenses | | | | |
| | c | Rental income or (loss) | | | | |
| | d | Net rental income or (loss) | | | | |
| | | (i) Securities / (ii) Other | | | | |
| | 7a | Gross amount from sales of assets other than inventory | | | | |
| | b | Less cost or other basis and sales expenses 283 | | | | |
| | c | Gain or (loss) -283 | | | | |
| | d | Net gain or (loss) | -283 | | | -283 |
| Other Revenue | 8a | Gross income from fundraising events (not including $ 1,720,223 of contributions reported on line 1c) See Part IV, line 18 a 52,068 | | | | |
| | b | Less direct expenses b 196,307 | | | | |
| | c | Net income or (loss) from fundraising events | -144,239 | | | -144,239 |
| | 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 | 13,037 | | | 13,037 |
| | b | | | | | |
| | c | | | | | |
| | d | All other revenue | | | | |
| | e | **Total.** Add lines 11a–11d | 13,037 | | | |
| | 12 | **Total revenue.** See Instructions | 3,965,417 | 212,084 | 0 | -121,763 |

## Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns

All other organizations must complete column (A) but are not required to complete columns (B), (C), and (D)

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 | 1,141,026 | 1,141,026 | | |
| 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 | 33,250 | 33,250 | | |
| 4 | Benefits paid to or for members | | | | |
| 5 | Compensation of current officers, directors, trustees, and key employees . . . . | 175,009 | 97,448 | 25,463 | 52,098 |
| 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 | 768,460 | 428,840 | 110,396 | 229,224 |
| 8 | Pension plan contributions (include section 401(k) and section 403(b) employer contributions) . . . . | 21,778 | 12,000 | 3,356 | 6,422 |
| 9 | Other employee benefits . . . . . | 78,872 | 43,461 | 12,154 | 23,257 |
| 10 | Payroll taxes . . . . . | 78,747 | 43,392 | 12,135 | 23,220 |
| 11 | Fees for services (non-employees) | | | | |
| a | Management . . . . . | | | | |
| b | Legal . . . . . | 23,962 | 14,581 | 9,381 | |
| c | Accounting . . . . . | 29,967 | | 29,967 | |
| d | Lobbying . . . . . | 98,880 | 98,880 | | |
| e | Professional fundraising *See Part IV, line 17* . . | 16,500 | | | 16,500 |
| f | Investment management fees . . . . . | | | | |
| g | Other . . . . . | 119,658 | 93,029 | 5,669 | 20,960 |
| 12 | Advertising and promotion . . . . | | | | |
| 13 | Office expenses . . . . . | 222,476 | 114,387 | 43,801 | 64,288 |
| 14 | Information technology . . . . . | 67,756 | 16,325 | 51,261 | 170 |
| 15 | Royalties . . | | | | |
| 16 | Occupancy . . . . . | 147,924 | 148 | 147,454 | 322 |
| 17 | Travel . . . . . | 151,852 | 125,893 | 3,474 | 22,485 |
| 18 | Payments of travel or entertainment expenses for any federal, state, or local public officials . . . . . | | | | |
| 19 | Conferences, conventions, and meetings . . . . | 159,976 | 147,414 | 12,562 | |
| 20 | Interest . . . . . | | | | |
| 21 | Payments to affiliates . . . . . | | | | |
| 22 | Depreciation, depletion, and amortization . . . . . | 36,133 | 32,370 | 3,763 | |
| 23 | Insurance . . . . . | 8,428 | | 8,428 | |
| 24 | Other expenses Itemize expenses not covered above (List miscellaneous expenses in line 24f If line 24f amount exceeds 10% of line 25, column (A) amount, list line 24f expenses on Schedule O ) | | | | |
| a | NATURAL HISTORY DATABAS | 112,768 | 112,768 | | |
| b | BANK AND CREDIT CARD FE | 56,902 | 148 | 56,682 | 72 |
| c | MISCELLANEOUS EXPENSES | 55,714 | 8,771 | 40,112 | 6,831 |
| d | CLINIC EXPENSE | 28,486 | 28,486 | | |
| e | | | | | |
| f | All other expenses | | 142,728 | -219,823 | 77,095 |
| 25 | **Total functional expenses.** Add lines 1 through 24f | 3,634,524 | 2,735,345 | 356,235 | 542,944 |
| 26 | **Joint costs.** Check here ▶ ☑ if following SOP 98-2 (ASC 958-720) Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation | 87,842 | 43,921 | 0 | 43,921 |

## Part X Balance Sheet

| | | | | (A) Beginning of year | | (B) End of year |
|---|---|---|---|---|---|---|
| Assets | 1 | Cash—non-interest-bearing | | 290,797 | 1 | 2,222,455 |
| | 2 | Savings and temporary cash investments | | 2,430,404 | 2 | 864,087 |
| | 3 | Pledges and grants receivable, net | | 375,150 | 3 | 379,000 |
| | 4 | Accounts receivable, net | | 5,378 | 4 | 319 |
| | 5 | Receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L | | | 5 | |
| | 6 | Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) Complete Part II of Schedule L | | | 6 | |
| | 7 | Notes and loans receivable, net | | | 7 | |
| | 8 | Inventories for sale or use | | 15,410 | 8 | 8,002 |
| | 9 | Prepaid expenses and deferred charges | | 105,444 | 9 | 138,019 |
| | 10a | Land, buildings, and equipment cost or other basis *Complete Part VI of Schedule D* | 10a 399,132 | | | |
| | b | Less accumulated depreciation | 10b 257,415 | 145,096 | 10c | 141,717 |
| | 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 | | 4,440,518 | 15 | 4,221,079 |
| | 16 | **Total assets.** Add lines 1 through 15 (must equal line 34) | | 7,808,197 | 16 | 7,974,678 |
| Liabilities | 17 | Accounts payable and accrued expenses | | 78,297 | 17 | 143,549 |
| | 18 | Grants payable | | | 18 | |
| | 19 | Deferred revenue | | 11,171 | 19 | 1,628 |
| | 20 | Tax-exempt bond liabilities | | | 20 | |
| | 21 | Escrow or custodial account liability *Complete Part IV of Schedule D* | | | 21 | |
| | 22 | Payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons *Complete Part II of Schedule L* | | | 22 | |
| | 23 | Secured mortgages and notes payable to unrelated third parties | | | 23 | |
| | 24 | Unsecured notes and loans payable to unrelated third parties | | | 24 | |
| | 25 | Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24) Complete Part X of Schedule D | | 56,440 | 25 | 77,136 |
| | 26 | **Total liabilities.** Add lines 17 through 25 | | 145,908 | 26 | 222,313 |
| Net Assets or Fund Balances | | **Organizations that follow SFAS 117, check here ▶ ☑ and complete lines 27 through 29, and lines 33 and 34.** | | | | |
| | 27 | Unrestricted net assets | | 5,037,196 | 27 | 4,804,940 |
| | 28 | Temporarily restricted net assets | | 1,745,649 | 28 | 2,067,981 |
| | 29 | Permanently restricted net assets | | 879,444 | 29 | 879,444 |
| | | **Organizations that do not follow SFAS 117, check here ▶ ☐ and complete lines 30 through 34.** | | | | |
| | 30 | Capital stock or trust principal, or current funds | | | 30 | |
| | 31 | Paid-in or capital surplus, or land, building or equipment fund | | | 31 | |
| | 32 | Retained earnings, endowment, accumulated income, or other funds | | | 32 | |
| | 33 | Total net assets or fund balances | | 7,662,289 | 33 | 7,752,365 |
| | 34 | Total liabilities and net assets/fund balances | | 7,808,197 | 34 | 7,974,678 |

## Part XI Reconcilliation 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 | 3,965,417 |
| 2 | Total expenses (must equal Part IX, column (A), line 25) | 2 | 3,634,524 |
| 3 | Revenue less expenses Subtract line 2 from line 1 | 3 | 330,893 |
| 4 | Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A)) | 4 | 7,662,289 |
| 5 | Other changes in net assets or fund balances (explain in Schedule O) | 5 | -240,817 |
| 6 | Net assets or fund balances at end of year Combine lines 3, 4, and 5 (must equal Part X, line 33, column (B)) | 6 | 7,752,365 |

## 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? | 2a | | No |
| b | Were the organization's financial statements audited by an independent accountant? | 2b | Yes | |
| c | If "Yes," to 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O | 2c | Yes | |
| d | If "Yes" to line 2a or 2b, check a box below to indicate whether the financial statements for the year were issued on a separate basis, consolidated basis, or both ☐ Separate basis ☑ Consolidated basis ☐ Both consolidated and separated basis | | | |
| 3a | As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? | 3a | | No |
| b | If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits | 3b | | |

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# 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

**2011**

**Open to Public Inspection**

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

**Employer identification number**
95-3018799

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

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

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

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

3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**

4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state

_____

5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II )

6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**

7 ☑ An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)** (Complete Part II )

8 ☐ A community trust described in **section 170(b)(1)(A)(vi)** (Complete Part II )

9 ☐ An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See **section 509(a)(2).** (Complete Part III )

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

11 ☐ An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2) See **section 509(a)(3).** Check the box that describes the type of supporting organization and complete lines 11e through 11h

**a** ☐ Type I **b** ☐ Type II **c** ☐ Type III - Functionally integrated **d** ☐ Type III - Other

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

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

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

| | Yes | No |
|---|---|---|
| **(i)** a person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the the supported organization? **11g(i)** | | |
| **(ii)** a family member of a person described in (i) above? **11g(ii)** | | |
| **(iii)** a 35% controlled entity of a person described in (i) or (ii) above? **11g(iii)** | | |

**h** Provide the following information about the supported organization(s)

| (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? Yes | (iv) No | (v) Did you notify the organization in col (i) of your support? Yes | (v) No | (vi) Is the organization in col (i) organized in the U S ? Yes | (vi) No | (vii) Amount of support? |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| **Total** | | | | | | | | | |

**Part II** **Support Schedule for Organizations Described in IRC 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)**
(Complete only if you checked the box on line 5, 7, or 8 of Part I 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) 2007 | (b) 2008 | (c) 2009 | (d) 2010 | (e) 2011 | (f) Total |
|---|---|---|---|---|---|---|
| 1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants ") | 3,524,716 | 3,324,865 | 3,221,297 | 1,449,542 | 3,812,563 | 15,332,983 |
| 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 | 3,524,716 | 3,324,865 | 3,221,297 | 1,449,542 | 3,812,563 | 15,332,983 |
| 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) | | | | | | 793,585 |
| 6 **Public Support.** Subtract line 5 from line 4 | | | | | | 14,539,398 |

## Section B. Total Support

| Calendar year (or fiscal year beginning in) | (a) 2007 | (b) 2008 | (c) 2009 | (d) 2010 | (e) 2011 | (f) Total |
|---|---|---|---|---|---|---|
| 7 Amounts from line 4 | 3,524,716 | 3,324,865 | 3,221,297 | 1,449,542 | 3,812,563 | 15,332,983 |
| 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources | 128,476 | 35,978 | 4,704 | 7,821 | 9,722 | 186,701 |
| 9 Net income from unrelated business activities, whether or not the business is regularly carried on | | | | | | |
| 10 Other income (Explain in Part IV ) Do not include gain or loss from the sale of capital assets | 2,467 | 13,767 | 3,967 | 5,728 | 13,037 | 38,966 |
| 11 **Total support** (Add lines 7 through 10) | | | | | | 15,558,650 |

| | | |
|---|---|---|
| 12 Gross receipts from related activities, etc (See instructions ) | 12 | 4,133,242 |

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 2011 (line 6 column (f) divided by line 11 column (f)) | 14 | 93 450 % |
| 15 Public Support Percentage for 2010 Schedule A, Part II, line 14 | 15 | 95 560 % |

16a **33 1/3% support test—2011.** 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—2010.** If the organization did not check the box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization ▶☐

17a **10%-facts-and-circumstances test—2011.** 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—2010.** 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 III** **Support Schedule for Organizations Described in IRC 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) 2007 | (b) 2008 | (c) 2009 | (d) 2010 | (e) 2011 | (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) 2007 | (b) 2008 | (c) 2009 | (d) 2010 | (e) 2011 | (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 2011 (line 8 column (f) divided by line 13 column (f)) | 15 | |
| 16 Public support percentage from 2010 Schedule A, Part III, line 15 | 16 | |

## Section D. Computation of Investment Income Percentage

| | | |
|---|---|---|
| 17 Investment income percentage for **2011** (line 10c column (f) divided by line 13 column (f)) | 17 | |
| 18 Investment income percentage from **2010** Schedule A, Part III, line 17 | 18 | |

19a **33 1/3% support tests—2011.** 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—2010.** 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.** Supplemental Information. Complete this part to provide the explanation required by Part II, line 10; Part II, line 17a or 17b; or Part III, line 12. Also complete this part for any additional information. (See instructions).

| Facts And Circumstances Test |
| --- |
| |

**Explanation**

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# 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

**2011**

**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, line 35c (Proxy Tax), then**

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

| Name of the organization | Employer identification number |
|---|---|
| NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC | 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 on behalf of or in opposition to candidates for public office in Part IV

2 Political expenditures ▶ $

3 Volunteer hours

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

1 Enter the amount of any excise tax incurred by the organization under section 4955 ▶ $

2 Enter the amount of any excise tax incurred by organization managers under section 4955 ▶ $

3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? ☐ Yes ☐ No

4a Was a correction made? ☐ Yes ☐ No

b If "Yes," describe in Part IV

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

1 Enter the amount directly expended by the filing organization for section 527 exempt function activities ▶ $

2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt funtion activities ▶ $

3 Total exempt function expenditures Add lines 1 and 2 Enter here and on Form 1120-POL, line 17b ▶ $

4 Did the filing organization file **Form 1120-POL** for this year? ☐ Yes ☐ No

5 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- |
|---|---|---|---|---|
| | | | | |
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**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) | 7,688 | |
| b Total lobbying expenditures to influence a legislative body (direct lobbying) | 155,432 | |
| c Total lobbying expenditures (add lines 1a and 1b) | 163,120 | |
| d Other exempt purpose expenditures | 3,519,642 | |
| e Total exempt purpose expenditures (add lines 1c and 1d) | 3,682,762 | |
| f Lobbying nontaxable amount Enter the amount from the following table in both columns | 334,138 | |
| g Grassroots nontaxable amount (enter 25% of line 1f) | 83,535 | |
| 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 | |

| 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 |

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) 2008 | (b) 2009 | (c) 2010 | (d) 2011 | (e) Total |
|---|---|---|---|---|---|
| 2a Lobbying non-taxable amount | 296,364 | 326,843 | 226,416 | 334,138 | 1,183,761 |
| b Lobbying ceiling amount (150% of line 2a, column(e)) | | | | | 1,775,642 |
| c Total lobbying expenditures | 142,286 | 152,958 | 74,182 | 163,120 | 532,546 |
| d Grassroots non-taxable amount | 74,091 | 81,711 | 56,604 | 83,535 | 295,941 |
| e Grassroots ceiling amount (150% of line 2d, column (e)) | | | | | 443,912 |
| f Grassroots lobbying expenditures | 16,771 | 34,107 | 7,007 | 7,688 | 65,573 |

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

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

## Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

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

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

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

## Part IV Supplemental Information

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

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

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**SCHEDULE D** (Form 990)

Department of the Treasury
Internal Revenue Service

# Supplemental Financial Statements

▶ Complete if the organization answered "Yes," to Form 990, Part IV, line 6, 7, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b
▶ Attach to Form 990. ▶ See separate instructions.

OMB No 1545-0047

**2011**

**Open to Public Inspection**

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

**Employer identification number**
95-3018799

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

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

5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? ☐ Yes ☐ No

6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds may be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit ☐ Yes ☐ No

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

1 Purpose(s) of conservation easements held by the organization (check all that apply)
☐ Preservation of land for public use (e g , recreation or pleasure)
☐ Preservation of an historically importantly land area
☐ Protection of natural habitat
☐ Preservation of a certified historic structure
☐ Preservation of open space

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

| | | Held at the End of the Year |
|---|---|---|
| a | Total number of conservation easements | 2a |
| b | Total acreage restricted by conservation easements | 2b |
| c | Number of conservation easements on a certified historic structure included in (a) | 2c |
| d | Number of conservation easements included in (c) acquired after 8/17/06 | 2d |

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

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

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? ☐ Yes ☐ No

6 Staff and volunteer hours devoted to monitoring, inspecting and enforcing conservation easements during the year ▶ _____

7 Amount of expenses incurred in monitoring, inspecting, and enforcing conservation easements during the year ▶ $ _____

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and 170(h)(4)(B)(ii)? ☐ Yes ☐ No

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

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

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

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

(i) Revenues included in Form 990, Part VIII, line 1 ▶ $ _____

(ii) Assets included in Form 990, Part X ▶ $ _____

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

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

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

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

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

- a ☐ Public exhibition
- b ☐ Scholarly research
- c ☐ Preservation for future generations
- d ☐ Loan or exchange programs
- e ☐ Other

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

5 During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? ☐ Yes ☐ No

## Part IV Escrow and Custodial Arrangements. Complete if the organization answered "Yes" to Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? ☐ Yes ☐ No

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

| | | Amount |
|---|---|---|
| c | Beginning balance | 1c |
| d | Additions during the year | 1d |
| e | Distributions during the year | 1e |
| f | Ending balance | 1f |

2a Did the organization include an amount on Form 990, Part X, line 21? ☐ Yes ☐ No

b If "Yes," explain the arrangement in Part XIV

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

| | | (a) Current Year | (b) Prior Year | (c) Two Years Back | (d) Three Years Back | (e) Four Years Back |
|---|---|---|---|---|---|---|
| 1a | Beginning of year balance | 4,443,045 | 3,866,081 | 3,750,509 | 4,856,856 | |
| b | Contributions | 29,825 | 13,835 | 13,523 | 6,722 | |
| c | Investment earnings or losses | -47,583 | 584,775 | 312,223 | -832,060 | |
| d | Grants or scholarships | | | | | |
| e | Other expenditures for facilities and programs | 175,000 | | 210,174 | 281,009 | |
| f | Administrative expenses | 29,137 | 21,646 | | | |
| g | End of year balance | 4,221,150 | 4,443,045 | 3,866,081 | 3,750,509 | |

2 Provide the estimated percentage of the year end balance held as

- a Board designated or quasi-endowment ▶
- b Permanent endowment ▶ 20 830 %
- c Term endowment ▶ 79 170 %

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by

| | | Yes | No |
|---|---|---|---|
| (i) unrelated organizations | 3a(i) | | 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 XIV 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 | | 336,611 | 199,524 | 137,087 |
| e Other | | 35,521 | 30,891 | 4,630 |
| **Total.** Add lines 1a-1e *(Column (d) should equal Form 990, Part X, column (B), line 10(c).)* ▶ | | | | 141,717 |

**Part VII Investments—Other Securities.** See Form 990, Part X, line 12.

| (a) Description of security or category (including name of security) | (b) Book value | (c) Method of valuation Cost or end-of-year market value |
|---|---|---|
| (1) Financial derivatives | | |
| (2) Closely-held equity interests | | |
| Other | | |
| | | |
| | | |
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| | | |
| | | |
| **Total.** *(Column (b) should equal Form 990, Part X, col (B) line 12 )* ▶ | | |

**Part VIII Investments—Program Related.** See Form 990, Part X, line 13.

| (a) Description of investment type | (b) Book value | (c) Method of valuation Cost or end-of-year market value |
|---|---|---|
| | | |
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| **Total.** *(Column (b) should equal Form 990, Part X, col (B) line 13 )* ▶ | | |

**Part IX Other Assets.** See Form 990, Part X, line 15.

| (a) Description | (b) Book value |
|---|---|
| (1) INTEREST IN NET ASSETS OF AFFILIATE | 4,221,150 |
| (2) DUE FROM AFFILIATE | -71 |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| **Total.** *(Column (b) should equal Form 990, Part X, col.(B) line 15.)* . . . . . ▶ | 4,221,079 |

**Part X Other Liabilities.** See Form 990, Part X, line 25.

| 1 (a) Description of Liability | (b) Amount |
|---|---|
| Federal Income Taxes | |
| ACCRUED COMPENSATION | 77,136 |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| **Total.** *(Column (b) should equal Form 990, Part X, col (B) line 25 )* ▶ | 77,136 |

**2.** Fin 48 (ASC 740) Footnote In Part XIV, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC740)

## Part XI Reconciliation of Change in Net Assets from Form 990 to Financial Statements

| | | | |
|---|---|---|---|
| 1 | Total revenue (Form 990, Part VIII, column (A), line 12) | 1 | 3,965,417 |
| 2 | Total expenses (Form 990, Part IX, column (A), line 25) | 2 | 3,634,524 |
| 3 | Excess or (deficit) for the year Subtract line 2 from line 1 | 3 | 330,893 |
| 4 | Net unrealized gains (losses) on investments | 4 | 78 |
| 5 | Donated services and use of facilities | 5 | |
| 6 | Investment expenses | 6 | |
| 7 | Prior period adjustments | 7 | |
| 8 | Other (Describe in Part XIV) | 8 | -240,895 |
| 9 | Total adjustments (net) Add lines 4 - 8 | 9 | -240,817 |
| 10 | Excess or (deficit) for the year per financial statements Combine lines 3 and 9 | 10 | 90,076 |

## Part XII Reconciliation of Revenue per Audited Financial Statements With Revenue per Return

| | | | | | |
|---|---|---|---|---|---|
| 1 | Total revenue, gains, and other support per audited financial statements | | | 1 | 3,740,848 |
| 2 | Amounts included on line 1 but not on Form 990, Part VIII, line 12 | | | | |
| a | Net unrealized gains on investments | 2a | 78 | | |
| b | Donated services and use of facilities | 2b | 16,248 | | |
| c | Recoveries of prior year grants | 2c | | | |
| d | Other (Describe in Part XIV) | 2d | -240,895 | | |
| e | Add lines **2a** through **2d** | | | 2e | -224,569 |
| 3 | Subtract line **2e** from line **1** | | | 3 | 3,965,417 |
| 4 | Amounts included on Form 990, Part VIII, line 12, but not on line **1** | | | | |
| a | Investment expenses not included on Form 990, Part VIII, line 7b | 4a | | | |
| b | Other (Describe in Part XIV) | 4b | | | |
| c | Add lines **4a** and **4b** | | | 4c | 0 |
| 5 | Total Revenue Add lines **3** and **4c.** (This should equal Form 990, Part I, line 12 ) | | | 5 | 3,965,417 |

## Part XIII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return

| | | | | | |
|---|---|---|---|---|---|
| 1 | Total expenses and losses per audited financial statements | | | 1 | 3,650,772 |
| 2 | Amounts included on line 1 but not on Form 990, Part IX, line 25 | | | | |
| a | Donated services and use of facilities | 2a | 16,248 | | |
| b | Prior year adjustments | 2b | | | |
| c | Other losses | 2c | | | |
| d | Other (Describe in Part XIV) | 2d | | | |
| e | Add lines **2a** through **2d** | | | 2e | 16,248 |
| 3 | Subtract line **2e** from line **1** | | | 3 | 3,634,524 |
| 4 | Amounts included on Form 990, Part IX, line 25, but not on line **1:** | | | | |
| a | Investment expenses not included on Form 990, Part VIII, line 7b | 4a | | | |
| b | Other (Describe in Part XIV) | 4b | | | |
| c | Add lines **4a** and **4b** | | | 4c | 0 |
| 5 | Total expenses Add lines **3** and **4c.** (This should equal Form 990, Part I, line 18 ) | | | 5 | 3,634,524 |

## Part XIV Supplemental Information

Complete this part to provide the descriptions required for Part II, lines 3, 5, and 9, Part III, lines 1a and 4, Part IV, lines 1b and 2b, Part V, line 4, Part X, Part XI, line 8, Part XII, lines 2d and 4b, and Part XIII, lines 2d and 4b Also complete this part to provide any additional information

| Identifier | Return Reference | Explanation |
|---|---|---|
| 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 | 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, 2008 THROUGH DECEMBER 31, 2011 TAX PERIODS ARE OPEN FOR EXAMINATION BY TAXING AUTHORITIES |
| PART XI, LINE 8 - OTHER ADJUSTMENTS | | CHANGE IN INTEREST IN AFFILIATE AND UNREALIZED LOSS -221,895 LOSS ON SUBLEASE -19,000 TOTAL TO SCHEDULE D, PART XI, LINE 8 -240,895 |
| PART XII, LINE 2D - OTHER ADJUSTMENTS | | CHANGE IN INTEREST IN ENDOWMENT FUND -221,895 LOSS ON SUBLEASE -19,000 |

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SCHEDULE F (Form 990)

Department of the Treasury
Internal Revenue Service

# Statement of Activities Outside the United States

▶ Complete if the organization answered "Yes" to Form 990, Part IV, line 14b, 15, or 16.
▶ Attach to Form 990. ▶ See separate instructions.

OMB No 1545-0047

2011

Open to Public Inspection

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

Employer identification number
95-3018799

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

1 **For grantmakers.** Does the organization maintain records to substantiate the amount of 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 **For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of grant funds outside the United States

3 Activites per Region (Use Part V if additional space is needed )

| (a) Region | (b) Number of offices in the region | (c) Number of employees or agents in region or independent contractors | (d) Activities conducted in region (by type) (e g , fundraising, program services, investments, grants to recipients located in the region) | (e) If activity listed in (d) is a program service, describe specific type of service(s) in region | (f) Total expenditures for region/investments in region |
|---|---|---|---|---|---|
| EUROPE | 0 | 0 | GRANTS TO RECIPIENTS | RESEARCH AWARDS | 33,250 |
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| 3a Sub-total | 0 | 0 | | | 33,250 |
| b Total from continuation sheets to Part I | 0 | 0 | | | 0 |
| c **Totals** (add lines 3a and 3b) | 0 | 0 | | | 33,250 |

**Part II** **Grants and Other Assistance to Organizations or Entities Outside the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 15, for any recipient who received more than $5,000. Check this box if no one recipient received more than $5,000 . . . . . ▶ ☑
Use Part V 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 of non-cash assistance | (h) Description of non-cash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
|---|---|---|---|---|---|---|---|---|
| | | EUROPE | RESEARCH GRANT | 33,250 | CHECK | | | CASH |
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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** **Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 16. Use Part V if additional space is needed.

| (a) Type of grant or assistance | (b) Region | (c) Number of recipients | (d) Amount of cash grant | (e) Manner of cash disbursement | (f) Amount of non-cash assistance | (g) Description of non-cash assistance | (h) Method of valuation (book, FMV, appraisal, other) |
|---|---|---|---|---|---|---|---|
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## 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 (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 and/or Form 3520-A. (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 |

**Part V Supplemental Information**

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

| Identifier | ReturnReference | Explanation |
|---|---|---|
| PROCEDURE FOR MONITORING GRANTS OUTSIDE THE U S | | SCHEDULE F, PART I, LINE 2 GRANTEE ORGANIZATIONS ARE EXPECTED TO FILE ANNUAL PROGRESS REPORTS TO OUTLINED GRANT GOALS AND MILESTONES THESE REPORTS ARE REVIEWED BY A COMMITTEE OF PEERS THIS COMMITTEE MAKES DETERMINATIONS BASED ON QUALITY OF WORK TO GOALS IF THE GRANTEE ORGANIZATION WILL CONTINUE TO RECEIVE FUNDING A FINAL WRITTEN AND FINANCIAL REPORT IS REQUIRED OF ALL GRANTEES |
| METHOD USED TO ACCCOUNT FOR EXPENDITURES | | SCHEDULE F, PART I, LINE 3 CASH |
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SCHEDULE G (Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

# Supplemental Information Regarding Fundraising or Gaming Activities

**Complete if the organization answered "Yes" to Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than $15,000 on Form 990-EZ, line 6a.**
**Attach to Form 990 or Form 990-EZ. See separate instructions.**

OMB No 1545-0047

**2011**

**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
- **b** ☐ Internet and e-mail solicitations
- **c** ☐ Phone solicitations
- **d** ☐ In-person solicitations
- **e** ☐ Solicitation of non-government grants
- **f** ☐ Solicitation of government grants
- **g** ☑ Special fundraising events

**2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising 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 Form 990-EZ filers are not required to complete this table

| **(i)** Name and address of individual or entity (fundraiser) | **(ii)** Activity | **(iii)** Did fundraiser have custody or control of contributions? Yes | **(iii)** No | **(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 |
|---|---|---|---|---|---|---|
| BLUE ROOM EVENTS INC<br>5777 WEST CENTURY BLVD<br>STE 880<br><br>LOS ANGELES, CA 90045 | COMEDY FOR A CURE EVENT | | No | 212,675 | 16,500 | 212,675 |
| | | | | | | |
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| **Total** . . . . . ▶ | | | | 212,675 | 16,500 | 212,675 |

**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 on Form 990-EZ, line 6a. List events with gross receipts greater than $5,000.

| Revenue / Direct Expenses | | (a) Event #1 WALKS (event type) | (b) Event #2 LA COMEDY FOR CURE (event type) | (c) Other Events 9 (total number) | (d) Total Events (Add col (a) through col (c)) |
|---|---|---|---|---|---|
| Revenue | 1 Gross receipts | 1,234,855 | 212,675 | 324,761 | 1,772,291 |
| | 2 Less Charitable contributions | 1,225,105 | 191,921 | 303,197 | 1,720,223 |
| | 3 Gross income (line 1 minus line 2) | 9,750 | 20,754 | 21,564 | 52,068 |
| Direct Expenses | 4 Cash prizes | | | | |
| | 5 Non-cash prizes | | | | |
| | 6 Rent/facility costs | | | | |
| | 7 Food and beverages | | | | |
| | 8 Entertainment | | | | |
| | 9 Other direct expenses | 53,500 | 29,728 | 113,079 | 196,307 |
| | 10 Direct expense summary Add lines 4 through 9 in column (d) ▶ | | | | ( 196,307 ) |
| | 11 Net income summary Combine lines 3 and 10 in column (d) ▶ | | | | -144,239 |

**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.

| Revenue / Direct Expenses | | (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 _____

**11** 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** Provide 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

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 Complete this part to provide additional information for responses to question on Schedule G (see instructions.)

| Identifier | ReturnReference | Explanation |
|---|---|---|

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**Schedule I (Form 990)**

Department of the Treasury
Internal Revenue Service

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

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

OMB No 1545-0047

**2011**

**Open to Public Inspection**

Name of the organization
NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC

**Employer identification number**
95-3018799

## Part I General Information on Grants and Assistance

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

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

## Part II Grants and Other Assistance to Governments and Organizations in the United States.

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

| (a) Name and address of organization or government | (b) EIN | (c) IRC Code section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|---|---|---|---|---|---|---|---|
| See Additional Data Table | | | | | | | |
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2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table . . . ▶ 13

3 Enter total number of other organizations listed in the line 1 table . . . ▶ 14

**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. Use Schedule I-1 (Form 990) 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 |
|---|---|---|---|---|---|
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**Part IV** **Supplemental Information.** Complete this part to provide the information required in Part I, line 2, 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 $15 3 MILLION IN RESEARCH ON TSC SINCE 1984 DIRECTED BY STEVEN L ROBERDS, PH D, VICE PRESIDENT AND 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 |
| | | 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 |

**Additional Data** Return to Form

**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) | 136,000 | | | | CLINCAL TRIALS AND RESEARCH GRANTS |
| BETH ISRAEL DEACONESS MEDICAL CENTER330 BROOKLINE AVENUE E/BR 264 BOSTON,MA 022155491 | 04-2103881 | 501(C)(3) | 50,000 | | | | RESEARCH GRANT |
| DREXEL UNIVERSITY SCHOOL OF MEDICINE 3201 ARCH STREET SUITE 100 PHILADELPHIA,PA 19104 | 23-1352630 | 501(C)(3) | 12,500 | | | | RESEARCH GRANT |
| VANDERBILT UNIVERSITY MEDICAL CENTERDEPT OF FINANCE DEPT AT 40303 ATLANTA,GA 31192 | 62-0476822 | 501(C)(3) | 103,500 | | | | RESEARCH GRANT |
| UNIVERSITY OF TEXASPO BOX 4786-750 HOUSTON,TX 77210 | 74-6000949 | 501(C)(3) | 50,000 | | | | RESEARCH GRANT |
| UNIVERSITY OF WASHINGTON4326 UNIVERSITY WAY NE SEATTLE,WA 98105 | 91-6001537 | 501(C)(3) | 40,698 | | | | RESEARCH GRANT |
| CHILDREN'S HOSPITALPO BOX 414413 BOSTON,MA 02241 | 04-2774441 | 501(C)(3) | 188,064 | | | | RESEARCH GRANT |
| SEIZURE TRACKER4008 RONSON DRIVE ALEXANDRIA,VA 22310 | 26-2311059 | | 6,000 | | | | RESEARCH GRANT |
| HARVARD MEDICAL SCHOOL25 SHATTUCK ST SUITE 509 BOSTON,MA 02115 | 04-2103580 | 501(C)(3) | 49,500 | | | | RESEARCH GRANT |
| COLUMBIA UNIVERSITY MEDICAL CENTERPO BOX 29789 NEW YORK,NY 10087 | 13-5598093 | 501(C)(3) | 66,000 | | | | RESEARCH GRANT |
| NEW YORK UNIVERSITY MEDICAL CENTER550 1ST AVE NEW YORK,NY 10016 | 13-5562308 | 501(C)(3) | 45,959 | | | | RESEARCH GRANT |
| MASSACHUSETTS GENERAL HOSPITALPO BOX 414876 BOSTON,MA 02241 | 04-2697983 | 501(C)(3) | 97,430 | | | | RESEARCH GRANT |
| CINCINNATI CHILDREN'S HOSPITAL3333 BURNET AVE ML 7030 CINCINNATI,OH 452293039 | 31-0833936 | 501(C)(3) | 152,260 | | | | RESEARCH GRANT |
| UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER PO BOX 203382 HOUSTON,TX 772163382 | 74-1761309 | 501(C)(3) | 143,115 | | | | RESEARCH GRANT |

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**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

**2011**

**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 appropiate 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<br>☐ First-class or charter travel ☐ Housing allowance or residence for personal use<br>☐ Travel for companions ☐ Payments for business use of personal residence<br>☐ Tax idemnification and gross-up payments ☐ Health or social club dues or initiation fees<br>☐ 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 orprovision of all the expenses described above? If "No," complete Part III to explain | **1b** | | |
| **2** | Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all officers, directors, trustees, and the CEO/Executive Director, regarding the items checked in line 1a? | **2** | | |
| **3** | Indicate which, if any, of the following the organization uses to establish the compensation of the organization's CEO/Executive Director Check all that apply<br>☑ Compensation committee ☑ Written employment contract<br>☐ Independent compensation consultant ☑ Compensation survey or study<br>☑ Form 990 of other organizations ☑ Approval by the board or compensation committee | | | |
| **4** | During the year, did any person listed in Form 990, Part VII, Section A, line 1a with respect to the filing organization or a related organization | | | |
| **a** | Receive a severance payment or change-of-control payment? | **4a** | | No |
| **b** | Participate in, or receive payment from, a supplemental nonqualified retirement plan? | **4b** | | No |
| **c** | Participate in, or receive payment from, an equity-based compensation arrangement? | **4c** | | No |
| | If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III | | | |
| | **Only 501(c)(3) and 501(c)(4) organizations only must complete lines 5-9.** | | | |
| **5** | For persons listed in form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of | | | |
| **a** | The organization? | **5a** | Yes | |
| **b** | Any related organization? | **5b** | | No |
| | If "Yes," to line 5a or 5b, describe in Part III | | | |
| **6** | For persons listed in form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of | | | |
| **a** | The organization? | **6a** | Yes | |
| **b** | Any related organization? | **6b** | | No |
| | If "Yes," to line 6a or 6b, describe in Part III | | | |
| **7** | For persons listed in Form 990, Part VII, Section A, line 1a, did the organization provide any non-fixed payments not described in lines 5 and 6? If "Yes," describe in Part III | **7** | | No |
| **8** | Were any amounts reported in Form 990, Part VII, paid or accured pursuant to a contract that was subject to the initial contract exception described in Regs section 53 4958-4(a)(3)? If "Yes," describe in Part III | **8** | | No |
| **9** | If "Yes" to line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53 4958-6(c)? | **9** | | |

**Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees.** Use Schedule J-1 if additional space 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, columns (D) and (E) for that individual

| (A) Name | | (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 in prior Form 990 or Form 990-EZ |
|---|---|---|---|---|---|---|---|---|
| | | (i) Base compensation | (ii) Bonus & incentive compensation | (iii) Other reportable compensation | | | | |
| (1) KARI L ROSBECK | (i) | 136,526 | 4,802 | 0 | 4,427 | 25,754 | 171,509 | 0 |
| | (ii) | 2,786 | 98 | 0 | 90 | 526 | 3,500 | 0 |
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## Part III Supplemental Information

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

| Identifier | Return Reference | Explanation |
|---|---|---|
| | PART I, LINE 5 | KARI LUTHER ROSBECK, PRESIDENT AND CEO, HAS INCENTIVE COMPENSATION EQUAL TO A PERCENTAGE OF HER SALARY BASED ON KEY PERFORMANCE OBJECTIVES AS ESTABLISHED BY THE COMPENSATION COMMITTEE |
| | PART I, LINE 6 | KARI LUTHER ROSBECK, PRESIDENT AND CEO, HAS INCENTIVE COMPENSATION EQUAL TO A PERCENTAGE OF HER SALARY BASED ON KEY PERFORMANCE OBJECTIVES AS ESTABLISHED BY THE COMPENSATION COMMITT |
| SUPPLEMENTAL INFORMATION | PART III | KARI LUTHER ROSBECK IS THE CEO OF TUBEROUS SCLEROSIS ALLIANCE AND IS COMPENSATED THROUGH TS ALLIANCE MS ROSBECK SERVES THE ENDOWMENT WITHOUT COMPENSATION |

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SCHEDULE M (Form 990)

Department of the Treasury
Internal Revenue Service

# NonCash Contributions

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

OMB No 1545-0047

2011

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) Contribution amounts reported on Form 990, Part VIII, line 1g | (d) Method of determining 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 ▸ ( VARIOUS ) | X | 98 | 60,533 | FMV |
| 26 | Other ▸ ( SPECIAL EVENT ) | | | | |
| 27 | Other ▸ ( GIFTS & ITEMS ) | | | | |
| 28 | Other ▸ ( ) | | | | |

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, Donee Acknowledgement . . . **29** 0

| | | | Yes | No |
|---|---|---|---|---|
| 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 | | 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 | | No |
| 32a | Does the organization hire or use third parties or related organizations to solicit, process, or sell non-cash contributions? | 32a | | No |
| b | If "Yes," describe in Part II | | | |
| 33 | If the organization did not report revenues in column (c) for a type of property for which column (a) is checked, describe in Part II | | | |

## Part II

**Supplemental Information.** Complete this part to provide the information required by Part I, lines 30b, 32b, and 33. Also complete this part for any additional information.

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

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**SCHEDULE O**
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

# Supplemental Information to Form 990 or 990-EZ

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

OMB No 1545-0047

**2011**

**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 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 2011 THE FOLLOWING CONFLICTS OF INTEREST WERE DISCLOSED BOARD MEMBER JANIE FROST'S HUSBAND IS A PARTNER IN THE MINNESOTA EPILEPSY GROUP, WHICH RECEIVED $6,768 FOR DATABASE PAYMENTS FROM TS ALLIANCE BOARD MEMBER ELIZABETH THIELE, MD, PHD IS EMPLOYED AT MASSACHUSETTS GENERAL HOSPITAL WHICH RECEIVED AN $11,500 GRANT FOR HER WORK ON GLUCOSE RESTRICTION ON TSC AND RECEIVED $15,000 FOR DATABASE PAYMENTS BOARD MEMBER PETER CRINO, MD, PHD IS EMPLOYED AT UNIVERSITY OF PENNSYLVANIA SCHOOL OF MEDICINE WHICH RECEIVED $14,040 FOR DATABASE PAYMENTS |

| 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 AND THE CHIEF FINANCIAL OFFICER, 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 5 | NET UNREALIZED GAINS ON INVESTMENTS 78 CHANGE IN INTEREST IN AFFILIATE AND UNREALIZED LOSS -221,895 LOSS ON SUBLEASE -19,000 TOTAL TO FORM 990, PART XI, LINE 5 -240,817 |

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

efile GRAPHIC print - DO NOT PROCESS | As Filed Data - | DLN: 93493104003352

# 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

**2011**

**Open to Public Inspection**

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

**Employer identification number**
95-3018799

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

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

| (a) Name, address, and EIN of related organization | (b) Primary activity | (c) Legal domicile (state or foreign country) | (d) Exempt Code section | (e) Public charity status (if section 501(c)(3)) | (f) Direct controlling entity | (g) Section 512(b)(13) controlled organization | |
|---|---|---|---|---|---|---|---|
| | | | | | | Yes | No |
| **(1)** TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FUND<br>801 ROEDER ROAD 750<br>SILVER SPRING, MD 20910<br>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 |
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**Part III** **Identification of Related Organizations Taxable as a Partnership** (Complete if the organization answered "Yes" on Form 990, Part IV, line 34 because it had one or more related organizations treated as a partnership during the tax year.)

| (a) Name, address, and EIN of related organization | (b) Primary activity | (c) Legal domicile (state or foreign country) | (d) Direct controlling entity | (e) Predominant income (related, unrelated, excluded from tax under sections 512-514) | (f) Share of total income | (g) Share of end-of-year assets | (h) Disproprtionate allocations? Yes | (h) No | (i) Code V—UBI amount in box 20 of Schedule K-1 (Form 1065) | (j) General or managing partner? Yes | (j) No | (k) Percentage ownership |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
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**Part IV** **Identification of Related Organizations Taxable as a Corporation or Trust** (Complete if the organization answered "Yes" on Form 990, Part IV, line 34 because it had one or more related organizations treated as a corporation or trust during the tax year.)

| (a) Name, address, and EIN of related organization | (b) Primary activity | (c) Legal domicile (state or foreign country) | (d) Direct controlling entity | (e) Type of entity (C corp, S corp, or trust) | (f) Share of total income | (g) Share of end-of-year assets | (h) Percentage ownership |
|---|---|---|---|---|---|---|---|
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## Part V Transactions With Related Organizations (Complete if the organization answered "Yes" on Form 990, Part IV, line 34, 35, 35A, or 36.)

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

| | | Yes | No |
|---|---|---|---|
| **1** During the tax year, did the orgranization engage in any of the following transactions with one or more related organizations listed in Parts II-IV? | | | |
| **a** Receipt of **(i)** interest **(ii)** annuities **(iii)** royalties **(iv)** rent from a controlled entity | 1a | | No |
| **b** Gift, grant, or capital contribution to related organization(s) | 1b | | No |
| **c** Gift, grant, or capital contribution from related organization(s) | 1c | Yes | |
| **d** Loans or loan guarantees to or for related organization(s) | 1d | | No |
| **e** Loans or loan guarantees by related organization(s) | 1e | | No |
| **f** Sale of assets to related organization(s) | 1f | | No |
| **g** Purchase of assets from related organization(s) | 1g | | No |
| **h** Exchange of assets with related organization(s) | 1h | | No |
| **i** Lease of facilities, equipment, or other assets to related organization(s) | 1i | | No |
| **j** Lease of facilities, equipment, or other assets from related organization(s) | 1j | | No |
| **k** Performance of services or membership or fundraising solicitations for related organization(s) | 1k | | No |
| **l** Performance of services or membership or fundraising solicitations by related organization(s) | 1l | | No |
| **m** Sharing of facilities, equipment, mailing lists, or other assets with related organization(s) | 1m | Yes | |
| **n** Sharing of paid employees with related organization(s) | 1n | Yes | |
| **o** Reimbursement paid to related organization(s) for expenses | 1o | | No |
| **p** Reimbursement paid by related organization(s) for expenses | 1p | | No |
| **q** Other transfer of cash or property to related organization(s) | 1q | | No |
| **r** Other transfer of cash or property from related organization(s) | 1r | | No |

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

| (a) Name of other organization | (b) Transaction type(a-r) | (c) Amount involved | (d) Method of determining amount involved |
|---|---|---|---|
| **(1)** TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FUND | C | 175,000 | CASH |
| **(1)** See Additional Data Table | | | |
| **(2)** | | | |
| **(3)** | | | |
| **(4)** | | | |
| **(5)** | | | |
| **(6)** | | | |

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

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

| (a) Name, address, and EIN of entity | (b) Primary activity | (c) Legal domicile (state or foreign country) | (d) Predominant income(related, unrelated, excluded from tax under sections 512-514) | (e) Are all partners section 501(c)(3) organizations? | | (f) Share of total income | (g) Share of end-of-year assets | (h) Disproprtionate allocations? | | (i) Code V—UBI amount in box 20 of Schedule K-1 (Form 1065) | (j) General or managing partner? | | (k) Percentage ownership |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | Yes | No | | | Yes | No | | Yes | No | |
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**Software ID:**
**Software Version:**
**EIN:** 95-3018799
**Name:** NATIONAL TUBEROUS SCLEROSIS ASSOCIATION INC



## 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, Special Condition Description:**

| Special Condition Description |
|---|

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

**4d. Other program services**

(Code ) (Expenses $ 26,188 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 THE 2011 BIO INTERNATIONAL CONVENTION, CHILD NEUROLOGY FOUNDATION'S ADVISORY BOARD MEETING, COALITION FOR IMAGING AND BIOENGINEERING RESEARCH (CIBR), INSTITUTE OF MEDICINE COMMITTEE MEETINGS ON THE PUBLIC HEALTH DIMENSIONS OF THE EPILEPSIES, LAM FOUNDATION CONFERENCE, RESEARCH AMERICA'S NATIONAL HEALTH RESEARCH FORUM, NATIONAL INSTITUTES OF HEALTH OFFICE OF RARE DISEASES CONFERENCE, NIAMS COALITION 2011 OUTREACH & EDUCATION MEETING, PARTNERING TO ADVANCE THERAPEUTICS FOR NEUROLOGICAL DISORDERS THE NINDS NONPROFIT FORUM, NORD/DIA ANNUAL CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS, SOCIETY FOR NEUROSCIENCE ANNUAL MEETING AND NIH-SPONSORED EPILEPSY SOCIAL, AND TUBEROUS SCLEROSIS ASSOCIATION INTERNATIONAL TSC RESEARCH CONFERENCE IN IRELAND IN ADDITION, THE TS ALLIANCE ATTENDED THE AMERICAN EPILEPSY SOCIETY (AES) MEETING IN BALTIMORE, INCLUDING A TSC RECEPTION FOR MORE THAN 50 RESEARCHERS, A MEET-THE-EXPERT PANEL WITH 10 TSC FAMILIES AND 9 TSC CLINICIAN EXPERTS, AND THE TSC SPECIAL INTEREST GROUP SCIENTIFIC SESSION FINALLY, THE TS ALLIANCE CO-SPONSORED WITH THE CENTER FOR BIOMEDICAL CONTINUING EDUCATION, A CME SPEAKER PROGRAM SERIES EMERGING THERAPEUTIC OPTIONS FOR TUBEROUS SCLEROSIS COMPLEX FOURTEEN TSC CLINIC DIRECTORS SERVED AS FACULTY THIS PROGRAM PRESENTED 3 GRAND ROUNDS AND 5 DINNER SESSIONS IN DALLAS, NEW YORK, LOS ANGELES, ATLANTA AND ST PAUL 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 THROUGH THIS COLLABORATION THE TS ALLIANCE HAS PROVIDED INFORMATION ON MORE THAN 300 FREE TRAINING ON EDUCATIONAL ADVOCACY FOR FAMILIES DEALING WITH EDUCATIONAL ISSUES FOR THEIR CHILDREN THROUGHOUT THE COUNTRY 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 PROVIDING CHILDREN WITH APPROPRIATE EDUCATION IS THE KEY TO INDIVIDUALS HAVING A GOOD QUALITY OF LIFE

(Code ) (Expenses $ 163,120 including grants of $ ) (Revenue $ )

GOVERNMENT RELATIONS FOCUSES ON EDUCATING MEMBERS OF CONGRESS ABOUT TSC TO FURTHER TSC RESEARCH, AWARENESS AND CLINICAL CARE IN 2011, THE TS ALLIANCE GRASSROOTS VOLUNTEERS CONDUCTED A MARCH ON CAPITOL HILL RESULTING IN 40 MEMBERS OF THE HOUSE OF REPRESENTATIVES SIGNING A LETTER OF SUPPORT CIRCULATED BY REPRESENTATIVE LORETTA SANCHEZ (D-CA) AND 9 SENATORS SIGNING A BIPARTISAN LETTER OF SUPPORT CIRCULATED BY SENATOR SHERROD BROWN (D-OH) FOR FY12 APPROPRIATIONS THE US CONGRESS APPROPRIATED $6 4 MILLION FOR FY11 IN APRIL 2011 AND $5 1 MILLION FOR FY12 IN DECEMBER 2011 TO TSC RESEARCH THROUGH THE DEPARTMENT OF DEFENSE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM IN 2011 THE TSC RESEARCH PROGRAM (TSCRP) ADMINISTERED FROM THE APPROPRIATION IS A COMPETITIVE PEER REVIEW GRANT PROGRAM ACCORDING TO THE U S ARMY MEDICAL RESEARCH AND MATERIAL COMMAND, CDMRP, TUBEROUS SCLEROSIS COMPLEX RESEARCH PROGRAM REPORT "TODAY, THE TSCRP IS ONE OF THE LEADING SOURCES OF EXTRAMURAL TSC RESEARCH FUNDING IN THE UNITED STATES THE TSCRP FILLS IMPORTANT GAPS IN TSC RESEARCH NOT ADDRESSED BY OTHER FUNDING AGENCIES " A HALLMARK ACHIEVEMENT IS THE RESEARCH SUPPORTED BY THE TSCRP 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, WHICH IS IMPORTANT IN NORMAL CELL GROWTH AND HAS BEEN SHOWN TO BE DISRUPTED IN MANY TYPES OF CANCER THIS RESEARCH HAS RAPIDLY LED TO THE DEVELOPMENT OF ANIMAL MODELS OF TSC AND CLINICAL TRIALS, RESULTING IN THE FIRST DRUG SPECIFICALLY TO TREAT TSC BEING APPROVED BY THE FDA IN OCTOBER 2010 NONE OF THIS PROGRESS WOULD HAVE BEEN POSSIBLE WITHOUT THE CRITICAL SUPPORT PROVIDED THROUGH THE TSCRP