### \*\* PUBLIC INSPECTION COPY \*\*

Form **990** 

# **Return of Organization Exempt From Income Tax**

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service

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

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

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

Open to Public Inspection

<u>A</u>	For th	e 2020 calendar year, or tax year beginning and	ending			
В	Check if applicab	C Name of organization		D Employer identifi	cation number	
	Addre	ss NATIONAL TUBEROUS SCLEROSIS ASSOCIATIO	M			
	Name chan	Doing business as TSC ALLIANCE	/14	95-30187	99	
	Initial returr	Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	E Telephone numbe	r ,	
	Final return	8737 COLESVILLE ROAD	400	301-562-	9890	
	termi ated			G Gross receipts \$	5,266,	631.
	Amer returr			H(a) Is this a group re	eturn	
	Appli tion	[Finame and address of principal officer: NAKI LI. ROSDECK		for subordinates	? Yes [	X No
	pendi	<sup>ng</sup> SAME AS C ABOVE		H(b) Are all subordinates in	cluded? Yes	No
1	Tax-ex	empt status: $X = 501(c)(3) = 501(c)(3)$ (insert no.) 4947(a)(1) of the status (1) of the status (2) of the status (3)	or 527	If "No," attach a	list. See instruction	ns
J	Websi	te: ► WWW.TSALLIANCE.ORG		H(c) Group exemptio	n number 🕨	
K	Form o	forganization: X Corporation Trust Association Other	L Year	of formation: 1975 n	A State of legal domi	icile: CA
P	art I	Summary				
	1	Briefly describe the organization's mission or most significant activities: FIND:	ING A	CURE FOR TUI	BEROUS	
Governance		SCLEROSIS COMPLEX WHILE IMPROVING THE LIV	ES OF	THOSE AFFEC	TED.	
E E	2	Check this box if the organization discontinued its operations or dispos	sed of more	than 25% of its net ass	ets.	
Š	3	Number of voting members of the governing body (Part VI, line 1a)	,	3		27
		Number of independent voting members of the governing body (Part VI, line 1b)		4		27
90	5	Total number of individuals employed in calendar year 2020 (Part V, line 2a)		5		22
/itie	6	Total number of volunteers (estimate if necessary)		6		<u> 2284</u>
Activities &	7 a	Total unrelated business revenue from Part VIII, column (C), line 12		7a		0.
	b	Net unrelated business taxable income from Form 990-T, Part I, line 11				0.
		•		Prior Year	Current Ye	
d)	8	Contributions and grants (Part VIII, line 1h)		5,527,543.	4,345,	
Revenue	9	Program service revenue (Part VIII, line 2g)		461,658.	792,	
eve	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)		27,826.		770.
α	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		699,207.	-21,	
	12	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)		6,716,234.	5,128,	
	13	Grants and similar amounts paid (Part IX, column (A), lines 1-3)		617,106.	685,	
	14	Benefits paid to or for members (Part IX, column (A), line 4)		0.		0.
ý	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		2,223,956.	2,382,	
Expenses	16a	Professional fundraising fees (Part IX, column (A), line 11e)		0.		0.
ğ	. b	Total fundraising expenses (Part IX, column (D), line 25)  941,58	87 <b>.</b>			
Ú	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		2,798,273.	2,353,	
	18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)		5,639,335.	5,422,	
		Revenue less expenses. Subtract line 18 from line 12		1,076,899.	-294,	026.
0 C				ginning of Current Year	End of Yea	
Assets	20	Total assets (Part X, line 16)		10,351,316.	11,657,	
t As		Total liabilities (Part X, line 26)		594,729.	2,195,	
Ž		Net assets or fund balances. Subtract line 21 from line 20		9,756,587.	9,462,	561.
1200000000	art II	Signature Block				
		lities of perjury, I declare that I have examined this return, including accompanying schedules			knowledge and belie	ef, it is
true	, correc	et, and complete. Declaration of properer (other than officer) is based on all information of wh	iich preparer	has any knowledge.	10 140	
		Signature of officer		Date	12,002	
Sig				Daily	·	
Her	e	KARI L. ROSBECK, PRESIDENT & CEO Type or print name and title				
		/ · · · · · · · · · · · · · · · · · ·		Date Check	PTIN	
D. 1		Print/Type preparer's name  ELIZABETH W. HELLER  Preparer's signature  LUZABETH W. HELLER	00	4 (4 0 ( 0 4 )	L0000000	20
Paid			~~ ·  U		42-071432	
	parer	Firm's name RSM US LLP Firm's address 2021 L STREET NW, SUITE 400		FIRM'S EIN	<del></del>	<u></u>
use	Only	WASHINGTON, DC 20036		Dhone no 20	2-293-220	n
N4=	, +h = 11	RS discuss this return with the preparer shown above? See instructions		FIIOHE 110. 2 U	X Yes	No
ivid	y uite li				[ 103	110

Form 8879-EO

## IRS e-file Signature Authorization for an Exempt Organization

0047	1545-	Ma	OMD	
- 111147	1545-	NO.	OWH	

For calendar year 2020, or fiscal year beginning , 20 Do not send to the IRS. Keep for your records. Department of the Treasury ► Go to www.irs.gov/Form8879EO for the latest information. Internal Revenue Service Name of exempt organization or person subject to tax Taxpayer identification number NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, 95-3018799 Name and title of officer or person subject to tax KARI L ROSBECK PRESIDENT & CEO Type of Return and Return Information (Whole Dollars Only) Part I Check the box for the return for which you are using this Form 8879-EO and enter the applicable amount, if any, from the return. If you check the box on line 1a, 2a, 3a, 4a, 5a, 6a, or 7a below, and the amount on that line for the return being filed with this form was blank, then leave line 1b, 2b, 3b, 4b, 5b, 6b, or 7b, whichever is applicable, blank (do not enter -0-). But, if you entered -0- on the return, then enter -0- on the applicable line below. Do not complete more than one line in Part I. 5,128,164. 1a Form 990 check here X b Total revenue, if any (Form 990, Part VIII, column (A), line 12) 1b 1b b Total revenue, if any (Form 990-EZ, line 9) \_\_\_\_\_\_ 2b \_\_\_ 2a Form 990-EZ check here b Total tax (Form 1120-POL, line 22) 3b 3a Form 1120-POL check here b Tax based on investment income (Form 990-PF, Part VI, line 5) 4b 4a Form 990-PF check here 5a Form 8868 check here b Balance due (Form 8868, line 3c) 5b **b** Total tax (Form 990-T, Part III, line 4) \_\_\_\_\_\_\_6b 6a Form 990-T check here b Total tax (Form 4720, Part III, line 1) 7a Form 4720 check here Declaration and Signature Authorization of Officer or Person Subject to Tax Under penalties of perjury, I declare that X I am an officer of the above organization or I am a person subject to tax with respect to and that I have examined a copy \_, (EIN)\_ (name of organization) of the 2020 electronic return and accompanying schedules and statements, and, to the best of my knowledge and belief, they are true, correct, and complete. I further declare that the amount in Part I above is the amount shown on the copy of the electronic return. I consent to allow my intermediate service provider, transmitter, or electronic return originator (ERO) to send the return to the IRS and receive from the IRS (a) an acknowledgement of receipt or reason for rejection of the transmission, (b) the reason for any delay in processing the return or refund, and (c) the date of any refund. If applicable, I authorize the U.S. Treasury and its designated Financial Agent to initiate an electronic funds withdrawal (direct debit) entry to the financial institution account indicated in the tax preparation software for payment of the federal taxes owed on this return, and the financial institution to debit the entry to this account. To revoke a payment, I must contact the U.S. Treasury Financial Agent at 1-888-353-4537 no later than 2 business days prior to the payment (settlement) date. I also authorize the financial institutions involved in the processing of the electronic payment of taxes to receive confidential information necessary to answer inquiries and resolve issues related to the payment. I have selected a personal identification number (PIN) as my signature for the electronic return and, if applicable, the consent to electronic funds withdrawal. PIN: check one box only 20910 X lauthorize RSM US LLP to enter my PIN Enter five numbers, but ERO firm name do not enter all zeros as my signature on the tax year 2020 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I also authorize the aforementioned ERO to enter my PIN on the return's disclosure consent screen. As an officer or person subject to tax with respect to the organization, I will enter my PIN as my signature on the tax year 2020 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I will enter my PIN on the return's disclosure consent screen. nature of officer or person subject to tax Part III Certification and Authentication ERO's EFIN/PIN. Enter your six-digit electronic filing identification 78104653719 number (EFIN) followed by your five-digit self-selected PIN. Do not enter all zeros I certify that the above numeric entry is my PIN, which is my signature on the 2020 electronically filed return indicated above. I confirm that I am submitting this return in accordance with the requirements of Pub. 4163, Modernized e-File (MeF) Information for Authorized IRS e-file Providers for Business Returns. ERO's signature ► RSM US LLP Date > 03/30/21

**ERO Must Retain This Form - See Instructions** 

Do Not Submit This Form to the IRS Unless Requested To Do So

	990 (2020) NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 Page	2
Par		_
	Check if Schedule O contains a response or note to any line in this Part III	
1	Briefly describe the organization's mission:	
	THE NATIONAL TUBEROUS SCLEROSIS ASSOCIATION, D/B/A TSC ALLIANCE, IS	_
	DEDICATED TO FINDING A CURE FOR TUBEROUS SCLEROSIS COMPLEX WHILE IMPROVING THE LIVES OF THOSE AFFECTED.	_
	IMPROVING THE DIVES OF THOSE AFFECTED.	_
2	Did the organization undertake any significant program services during the year which were not listed on the	_
_	prior Form 990 or 990-EZ?	,
	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?	)
	If "Yes," describe these changes on Schedule O.	
4	Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses.	
	Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and	
	revenue, if any, for each program service reported.	
4a	(Code:) (Expenses \$2,543,079. including grants of \$680,788. ) (Revenue \$901,832.	)
	RESEARCH PROGRAM STIMULATES AND SUPPORTS BASIC, TRANSLATIONAL, AND	
	CLINICAL RESEARCH ON THE VARIOUS MANIFESTATIONS OF TUBEROUS SCLEROSIS	_
	COMPLEX (TSC) TO FURTHER THE DEVELOPMENT OF CLINICAL THERAPIES AND,	_
	ULTIMATELY, A CURE FOR TSC. DIRECTED BY STEVEN L. ROBERDS, PHD, CHIEF	_
	SCIENTIFIC OFFICER, THE TSC ALLIANCE RESEARCH PROGRAM BUILDS AND FOSTERS COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS BY	_
	COLLECTING AND DISTRIBUTING TSC NATURAL HISTORY DATA AND BIOSAMPLES,	_
	THROUGH COLLABORATIVE PRECLINICAL AND CLINICAL RESEARCH PROGRAMS, AND	_
	BY HOSTING BIENNIAL INTERNATIONAL TSC RESEARCH CONFERENCES.	_
		_
	SINCE 1984, THE TSC ALLIANCE HAS INVESTED \$27.7 MILLION INTO TSC	_
	RESEARCH PROJECTS THROUGH GRANTS AND CONTRACTS: \$18.5 MILLION IN	
4b	(Code:) (Expenses \$698,125. including grants of \$5,000. ) (Revenue \$	)
	SUPPORT SERVICES DEVELOPS PROGRAMS AND SERVICES THAT PROVIDE	
	INDIVIDUALS WITH TSC DIRECT ACCESS TO INFORMATION, RESOURCES, AND	_
	SPECIALISTS EXPERIENCED IN THE DIAGNOSIS, TREATMENT AND MANAGEMENT OF	_
	TSC.	_
	IN 2020 THE TSC ALLIANCE FACILITATED 28,447 PEER-TO-PEER SUPPORTS FROM	_
	ADULT REGIONAL COORDINATORS (12 VOLUNTEERS IN 8 REGIONS NATIONWIDE),	_
	CLINIC AMBASSADORS (22 VOLUNTEERS IN 26 TSC CLINICS AND TSC CENTERS OF	_
	EXCELLENCE NATIONWIDE), DEPENDENT ADULT TRANSITION RESOURCE	_
	COORDINATORS (32 VOLUNTEERS IN 26 STATES AND PUERTO RICO), EDUCATION	_
	PARENT MENTORS (31 VOLUNTEERS IN 22 STATES), AND COMMUNITY ALLIANCE	_
	LEADERS (93 VOLUNTEERS IN 33 REGIONS ACROSS THE UNITED STATES) WITH	
4c	(Code:) (Expenses \$ 502,083. 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 2020, THE TSC ALLIANCE	
	PRODUCED TWO ISSUES OF ITS NATIONAL MAGAZINE, PERSPECTIVE, WHICH IS	
	MAILED TO APPROXIMATELY 14,500 CONSTITUENTS AS WELL AS POSTED ON THE	
	WEBSITE. THE TSC ALLIANCE'S WEBSITE INCREASES AWARENESS AND PROVIDES	
	EXTENSIVE EDUCATION THROUGH AN AVERAGE OF MORE THAN 22,300 UNIQUE	_
	VISITORS EACH MONTH.	_
	MILE MOO ALLTANGE ALCO DELTEC HEAVILLY ON GOOTAL MEDIA MO EDUCAME	_
	THE TSC ALLIANCE ALSO RELIES HEAVILY ON SOCIAL MEDIA TO EDUCATE	

THE TSC ALLIANCE ALSO RELIES HEAVILY ON SOCIAL MEDIA TO EDUCATE CONSTITUENTS AND PROMOTE NEW RESOURCES AND EVENTS. ITS FACEBOOK GROUP BOASTS MORE THAN 10,000 MEMBERS, WHILE ITS TWITTER AND INSTAGRAM

4d Other program services (Describe on Schedule O.)

(Expenses \$ 240,862 including grants of \$

) (Revenue \$

e Total program service expenses ► 3,984,149.

			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	X	
2	Is the organization required to complete Schedule B, Schedule of Contributors?	2	Х	
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		X
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect	_	37	
_	during the tax year? If "Yes," complete Schedule C, Part II	4	Х	
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or	_		, v
_	similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III	5		X
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to			<b> </b> ₩
_	provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I	6		X
7	Did the organization receive or hold a conservation easement, including easements to preserve open space,	_		<b> </b> ₩
_	the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete			, v
_	Schedule D, Part III	8		X
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for			
	amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services?	_		3,7
	If "Yes," complete Schedule D, Part IV	9		X
10	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments		37	
	or in quasi endowments? If "Yes," complete Schedule D, Part V	10	X	
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.			
а	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D,	l	37	
	Part VI	11a	X	
b	Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total	l		, v
	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII	11b		X
С	Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more of its total			<b> </b> ₩
	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII	11c		X
a	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		Х	
	Part X, line 16? If "Yes," complete Schedule D, Part IX	11d	X	
	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e	Λ	
f	3			x
40-	the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X	11f		
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete	40-		X
	Schedule D, Parts XI and XII	12a		Α.
D	Was the organization included in consolidated, independent audited financial statements for the tax year?	12b	Х	
40	If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional  Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E		21	Х
13		13 14a		X
		144		125
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000			
	or more? If "Yes," complete Schedule F, Parts I and IV	14b	х	
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any	170		
13	foreign organization? If "Yes," complete Schedule F, Parts II and IV	15	х	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to	"		
10	or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV	16		x
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX,	<del>     </del>		<del></del>
.,		17		X
18	column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I  Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines	<b> </b> ''		<del> </del>
10		18	х	
19	1c and 8a? If "Yes," complete Schedule G, Part II	10		
IJ	,	19		X
20a	complete Schedule G, Part III  Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		X
		20a 20b		<del>  ^</del>
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or	200		
۲۱	domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I. Parts I and II	21	х	
	domocao gorsannon on ridir in, coldinir y y, iniciri: Il res, complete ochequie I, Parts I and II			

Page 4 Part IV Checklist of Required Schedules (continued) Yes No Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III Х 22 23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes." complete Х 23 Schedule J 24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete Х 24a Schedule K. If "No," go to line 25a b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? 24b Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? 24c d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? 24d 25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I 25a Х 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 Х 25b 26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? If "Yes," complete Schedule L, Part II Х 26 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III ....... Х 27 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 current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If "Yes," complete Schedule L, Part IV ..... 28a **b** A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV ..... A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? If Х 28c "Yes," complete Schedule L, Part IV ...... Х Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M 29 29 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation Х contributions? If "Yes," complete Schedule M 30 Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I ..... Х 31 31 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes." complete 32 Х Schedule N, Part II Did the organization own 100% of an entity disregarded as separate from the organization under Regulations X sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I 33 Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Х 34 Х 35a Did the organization have a controlled entity within the meaning of section 512(b)(13)? 35a b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2 35b Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? Х 36 If "Yes," complete Schedule R, Part V, line 2 Did the organization conduct more than 5% of its activities through an entity that is not a related organization Х and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI 37 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Х Note: All Form 990 filers are required to complete Schedule O 38 Statements Regarding Other IRS Filings and Tax Compliance Check if Schedule O contains a response or note to any line in this Part V Yes No 30 1a Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable 1a Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable 0 Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming

(gambling) winnings to prize winners?

020) NATIONAL TUBEROUS SCLEROSIS ASSOCIATION
Statements Regarding Other IRS Filings and Tax Compliance (continued) Part V

				Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements,				
	filed for the calendar year ending with or within the year covered by this return	2a 22			
b	If at least one is reported on line 2a, did the organization file all required federal employment tax return	ns?	<b>2</b> b	Х	
	Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions	s)			
За	Did the organization have unrelated business gross income of \$1,000 or more during the year?		3a		X
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule	0	3b		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other a	uthority over, a			
	financial account in a foreign country (such as a bank account, securities account, or other financial a	ccount)?	4a		X
b	If "Yes," enter the name of the foreign country				
	See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Advanced in the Financi	counts (FBAR).			
5а	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		5a		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction		5b		X
С	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	e organization solicit			
	any contributions that were not tax deductible as charitable contributions?		6a		X
b	If "Yes," did the organization include with every solicitation an express statement that such contribution	ons or gifts			
	were not tax deductible?		6b		
7	Organizations that may receive deductible contributions under section 170(c).				
а	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and ser	vices provided to the payor?	7a	X	
b			7b	Х	-
С	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was	•	_		1 37
	to file Form 8282?		7с		X
d	If "Yes," indicate the number of Forms 8282 filed during the year	7d			Х
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit co		7e		X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contra		7f		
g h	If the organization received a contribution of qualified intellectual property, did the organization file Fo If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization		7g 7h		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained		/11		
Ü		•	8		
9	Sponsoring organizations maintaining donor advised funds.				
а	Did the appropriate propriation and the second distributions and appropriate 40000		9a		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		9b		
10	Section 501(c)(7) organizations. Enter:				
а	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:				
а	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.				
а	Is the organization licensed to issue qualified health plans in more than one state?		13a		
	<b>Note:</b> See the instructions for additional information the organization must report on Schedule O.				
b	Enter the amount of reserves the organization is required to maintain by the states in which the				
	organization is licensed to issue qualified health plans	13b			
С	Enter the amount of reserves on hand	13c			
14a	· · · · · · · · · · · · · · · · · · ·		14a		X
	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedul		14b		
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuner				,,
	excess parachute payment(s) during the year?		15		X
40	If "Yes," see instructions and file Form 4720, Schedule N.	:	40		v
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment	income?	16		X
	If "Yes," complete Form 4720, Schedule O.				

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

<u> </u>						X
Sec	tion A. Governing Body and Management					
		ı	1		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	1a	27			
	If there are material differences in voting rights among members of the governing body, or if the governing					
	body delegated broad authority to an executive committee or similar committee, explain on Schedule O.					
b	Enter the number of voting members included on 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	anv other			
	officer, director, trustee, or key employee?			2		Х
3	Did the organization delegate control over management duties customarily performed by or under the					
3				3		Х
			- 51-40			X
4	Did the organization make any significant changes to its governing documents since the prior Form 9		s filed?	4		X
5	Did the organization become aware during the year of a significant diversion of the organization's ass	ets?		5	77	Λ
6	Did the organization have members or stockholders?			6	_X_	
7a	Did the organization have members, stockholders, or other persons who had the power to elect or ap	point	one or			
	more members of the governing body?			7a	X	
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, st	ockho	lders, or			
	persons other than the governing body?			7b		Х
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the yea					
а	The governing body?	-	=	8a	Х	
b	Each committee with authority to act on behalf of the governing body?			8b	Х	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be read					
_	organization's mailing address? If "Yes." provide the names and addresses on Schedule O			9		Х
Sec	tion B. Policies (This Section B requests information about policies not required by the Internal Re					
	This Section B requests information about policies not required by the internal ne	<u>veriue</u>	Code.)		Yes	No
100	Did the organization have local chapters, branches, or affiliates?			10a	X	140
				IUa		
D	If "Yes," did the organization have written policies and procedures governing the activities of such ch			10b	х	
44-	· · · · · · · · · · · · · · · · · · ·				X	
	Has the organization provided a complete copy of this Form 990 to all members of its governing body	belo	e illing the form?	11a		
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.				37	
	Did the organization have a written conflict of interest policy? If "No," go to line 13			12a	X	
	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise			12b	X	
С	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Y	'es," c	escribe			
	in Schedule O how this was done			12c	_X_	
13	Did the organization have a written whistleblower policy?			13	X	
14	Did the organization have a written document retention and destruction policy?			14	X	
15	Did the process for determining compensation of the following persons include a review and approva	l by in	dependent			
	persons, comparability data, and contemporaneous substantiation of the deliberation and decision?					
а	The organization's CEO, Executive Director, or top management official			15a	X	
b	Other officers or key employees of the organization			15b	X	
	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	nent w	rith a			
	taxable entity during the year?			16a		X
b	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluat					
	in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organ	izatio	า'ร			
	exempt status with respect to such arrangements?			16b		
Sec	tion C. Disclosure					
17	List the states with which a copy of this Form 990 is required to be filed AL, AR, CA, FL, G	A,H	I, IL, IN, KS	KY	MD,	MA
18	Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, ar					
	for public inspection. Indicate how you made these available. Check all that apply.		. , , ,	• • • • • • • • • • • • • • • • • • • •		
	X Own website X Another's website X Upon request Other (explain	on S	chedule (1)			
19	Describe on Schedule O whether (and if so, how) the organization made its governing documents, co		,	financ	cial	
	statements available to the public during the tax year.				ui	
20	State the name, address, and telephone number of the person who possesses the organization's boo	ke an	d records			
20	THE ORGANIZATION - 301-562-9890	no an				
		091	0			
	O.S. COMBONIUM KOMD, MO. 400, BILINER BEKING, MD. 2	נכטי	. •			

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

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

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

- 1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.
- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
  - List all of the organization's current key employees, if any. See instructions for definition of "key employee."
- List the organization's five current highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and 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.

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

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

(A)	(B)	l	i ii Zu	((		ipon	out	(D)	(E)	(F)
Name and title	Average	(do			ition	l than c	one	Reportable	Reportable	Estimated
	hours per	box,	unles	ss per	son is	s both	an	compensation	compensation	amount of
	week (list any						,	from the	from related organizations	other compensation
	hours for	Individual trustee or director				p		organization	(W-2/1099-MISC)	from the
	related	tee or	ıstee			nsate		(W-2/1099-MISC)	(	organization
	organizations	Itrus	nal trı		oyee	om pe				and related
	below	ividua	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			organizations
-	line)	pul	Inst	0#ii	Key	Hig	For			
(1) CHRIS RUSSELL	5.00								•	•
CHAIR	0.00	Х		Х				0.	0.	0.
(2) PETER CRINO, MD, PHD	5.00								•	•
VICE CHAIR	0.00	Х		Х				0.	0.	0.
(3) TIM DILLS	5.00								•	•
IMMEDIATE PAST CHAIR	0.00	Х		Х				0.	0.	0.
(4) LAURA MARKS	5.00	.,		7.7						•
SECRETARY	0.00	Х		X				0.	0.	0.
(5) WILLIAM JOSEPH	5.00	.,		77						•
TREASURER	1.00	Х		X				0.	0.	0.
(6) JULIE BLUM	2.00	.,								0
BOARD MEMBER	0.00	Х						0.	0.	0.
(7) MATT BOLGER	2.00	7.7							0.	0
BOARD MEMBER	2.00	Х						0.	0.	0.
(8) CASSANDRA CARROLL BOARD MEMBER	0.00	х						0.	0.	0.
	2.00	Λ						0.	0.	0.
(9) MARK CARROLL BOARD MEMBER	1.00	Х						0.	0.	0.
(10) SARA CHIEFFO	2.00	Λ				$\vdash$		0.	0.	<b>U</b> •
BOARD MEMBER	0.00	Х						0.	0.	0.
(11) DAVID COIT	2.00	Λ				$\vdash$		0.	0.	<b>U</b> •
BOARD MEMBER	0.00	Х						0.	0.	0.
(12) MARGARET COX	2.00	Λ						0.	0.	0.
BOARD MEMBER	0.00	Х						0.	0.	0.
(13) BONNIE HOGUE DUFFY	2.00	Λ						0.	0.	<u> </u>
BOARD MEMBER	0.00	х						0.	0.	0.
(14) STEVEN GOLDSTEIN	2.00	21						0.	0.	<u></u>
BOARD MEMBER	0.00	х						0.	0.	0.
(15) ROB GRANDIA	2.00	22							0.	<u></u>
BOARD MEMBER		х						0.	0.	0.
(16) DANA HOLINKA	2.00	25						•	•	•
BOARD MEMBER		х						0.	0.	0.
(17) DARCY A. KRUEGER	2.00							· ·	•	<u> </u>
BOARD MEMBER	0.00	х						0.	0.	0.
	1 0.00								· · · ·	000

Form 990 (2020)

		~ ~			~ =	_	11000011111011	75 5010	155 Tage 9
tees, Key Emp	oloy	ees,	and	l Hig	ghes	t C	ompensated Employee	s (continued)	
(B)							(D)	(E)	(F)
Average hours per week	box	not c , unle:	heck ss pe	more rson i	than o	n an	Reportable compensation	Reportable compensation	Estimated amount of other
(list any hours for related	Individual trustee or director	In stit utional tru stee	Officer	Key employee	Highest compensated employee	Former	the organization (W-2/1099-MISC)	organizations (W-2/1099-MISC)	compensation from the organization and related organizations
2.00									
0.00	Х						0.	0.	0.
2.00									
	Х						0.	0.	0.
2.00									
0.00	Х						0.	0.	0.
2.00									
0.00	Х						0.	0.	0.
2.00									
	Х						0.	0.	0.
	Х						0.	0.	0.
2.00									
0.00	Х						0.	0.	0.
2.00									
0.00	Х						0.	0.	0.
2.00									
1.00	Х						0.	0.	0.
						<b>&gt;</b>			0.
I, Section A						ightharpoons			117,208.
						<u> </u>	1,030,829.	12,778.	117,208.
	(B) Average hours per week (list any hours for related organizations below line)  2.00 0.00 2.00 0.00 2.00 0.00 2.00 0.00 2.00 0.00 2.00 0.00 2.00 0.00 1.00	(do box offin (lost any hours for related organizations below line)  2.00  0.00  2.00  0.00  2.00  0.00  X  2.00  0.00  X	(do not cobox, unle officer are week (list any hours per week (list any hours for related organizations below line)  2.00 0.00 X	(B) Average hours per week (list any hours for related organizations below line)  2.00 0.00 X	(B) Average hours per week (list any hours for related organizations below line)  2.00  0.00  2.00  0.00  X  2.00  0.00  X	(B) Average hours per week (list any hours for related organizations below line)  2.00  0.00  2.00  0.00  X  2.00  0.00  X	(B) Average hours per week (list any hours for related organizations below line)  2.00 0.00 0.00 X 2.00 0.00 X	(B) Average hours per week (list any hours for related organizations below line)  2.00  0.00  2.00  0.00  X  0.00  2.00  0.00  X  0.00  0.00  X  0.00  0.00  X  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.00  0.	Research   Responsible   Responsi

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

Yes No

3 Did the organization list any former officer, director, trustee, key employee, or highest compensated employee on line 1a? If "Yes," complete Schedule J for such individual

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

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 X

#### **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.

the diganization: heport compensation for the edichad year chaing with or with	in the organization of tax year.	
(A) Name and business address	(B) Description of services	<b>(C)</b> Compensation
PSYCHOGENICS INC.	RESEARCH LAB	
20 GRAMERCY PARK SOUTH, NEW YORK, NY 10003	SERVICES	601,033.
VAN ANDEL RESEARCH INSTITUTE, 333 BOSTWICK		
AVE. NE, GRAND RAPIDS, MI 49503	LABORATORY SERVICES	144,738.
CAVAROCCHI RUSCIO DENNIS AND ASSOCIATES		
600 MARYLAND AVE. SW, WASHINGTON, DC 20024	GOVERNMENT RELATIONS	113,547.
GRAHAM-PELTON CONSULTING		
39 BEECHWOOD ROAD, SUMMIT, NJ 07901	DEVELOPMENT STRATEGY	109,122.

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

	TUBEROU	15	SC	ĿĿ	RU	1 <u>S</u> T	ຣ	ASSOCIATION	95-301	8/99
Part VII   Section A. Officers, Directors, Tru	ustees, Key En	nplo	yee	s, aı	nd F	ligh	est	Compensated Employe	es (continued)	
(A) (B) (C)								(D)	(E)	(F)
Name and title	Average			Pos		1		Reportable	Reportable	Estimated
Tunno and into	hours	(cl	heck				ly)	compensation	compensation	amount of
	per					Τ	,, 	from	from related	other
	week					ee /ee		the	organizations	compensation
	(list any	ector				eg u		organization	(W-2/1099-MISC)	from the
	hours for	rdire				ted er		(W-2/1099-MISC)		organization
	related	stee c	ruste			en sa				and related
	organizations	Individual trustee or director	Institutional trustee		Key employee	Highest compensated employee				organizations
	below	ividu	titutic	Officer	em b	hest	Former			
	line)	lnd	Inst	i#0	Key	Hig	For			
(27) TARA ZIMMERMAN	2.00									
BOARD MEMBER	0.00	Х						0.	0.	0.
(28) KARI L. ROSBECK	54.00									
PRESIDENT & CEO	1.00			Х				194,307.	3,598.	22,457.
(29) RICHARD GOLLUB	47.00							,	,	•
CFO	3.00			х				143,807.	9,180.	24,213.
(30) STEVEN L. ROBERDS	45.00							113,007.	3,100.	21/2130
CHIEF SCIENTIFIC OFFICER	0.00				х			208,882.	0.	21,307.
(31) JAYE D. ISHAM	45.00				77			200,002.	0.	21,307.
						x		110 070	0.	1 200
,	0.00					^		119,879.	0.	4,398.
(32) LISA M. MOSS	45.00	-				,,		100 573	0	10 510
SR. DIR. DONOR RELATIONS	0.00					X		109,573.	0.	18,518.
(33) APRIL COOPER	45.00					l		405 000		4 =00
DIR. COMMUNITY PROGRAMS	0.00					X		107,298.	0.	4,722.
(34) DEAN RAGER-AGUIAR	45.00								_	
DIR. PRECLINICAL RESEARCH	0.00					Х		147,083.	0.	21,593.
		•								
		-								
				L	L	L				
	•									
Total to Part VII, Section A, line 1c								1,030,829.	12 778	117,208.
TOTAL TO FAIT VII, OCCUOITA, IIILE TO								1,000,020.	12,110	

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Form 990 (2020) NATIONA
Part VIII Statement of Revenue

		Check if Schedule O	contains a response	or note to any lin	ne in this Part VIII			
			•	,	(A)	(B)	(C)	(D)
					Total revenue	Related or exempt	Unrelated	Revenue excluded from tax under
						function revenue	business revenue	sections 512 - 514
S G	1 2	Federated campaigns	1a	28,836.				
Contributions, Gifts, Grants and Other Similar Amounts				4,208.	-			
5 2		Membership dues		192,939.				
ts, Ar		Fundraising events			-			
ig ig		Related organizations		330,875.	-			
ıs,		Government grants (contri		<u>371,820.</u>	-			
i ti	f	All other contributions, gifts,		44.6.000				
ig H		similar amounts not included	above $1f 2$ ,	416,333.				
dit	g	Noncash contributions included in I	lines 1a-1f <b>1g</b> \$	91,027.				
<u>အ လ</u>	h	Total. Add lines 1a-1f		<b></b>	4,345,011.			
				Business Code				
ġ.	2 a	CONTRACT REVE	NUE	900099	791,210.	791,210.		
ξ	b	CONFERENCE RE	VENUE	900099	1,475.			1,475.
Sel	С							
an Sve	d							
Program Service Revenue	e							
Pro	f	All other program service	revenue					
	q	<b>-</b>			792,685.			
	3	Investment income (includ						
		other similar amounts)	-	•	11,188.			11,188.
	4	Income from investment o						
	5	Royalties						
	_	···- <b>,</b>	(i) Real	(ii) Personal				
	6 a	Gross rents	6a					
		Less: rental expenses	6b					
		Rental income or (loss)	6c					
		Net rental income or (loss)						
		Gross amount from sales of	(i) Securities	(ii) Other				
	/ a		05 545	(ii) Other	-			
	_	assets other than inventory	7a 87,545.		-			
	b	Less: cost or other basis	_ 06 063					
Revenue		and sales expenses	7b 86,963.		-			
ĕ		Gain or (loss)			500			F 0 0
		Net gain or (loss)		<b></b>	582.			582.
her	8 a	Gross income from fundraising	ng events (not					
₫		including $1,192$	<u>,939</u> of					
		contributions reported on	, I					
		Part IV, line 18			-			
		Less: direct expenses		51,504.	222			222
	С	Net income or (loss) from	fundraising events	<b>_</b>	982.			982.
	9 a	Gross income from gamin	~					
		Part IV, line 19	9a					
	b	Less: direct expenses	9b					
	С	Net income or (loss) from	gaming activities	<b>&gt;</b>				
	10 a	Gross sales of inventory, le	ess returns					
		and allowances	10a					
	b	Less: cost of goods sold	10b					
	С	Net income or (loss) from	sales of inventory	<b></b>				
g				Business Code	4			
on e	11 a	CHANGE INT-EN	DOWMENT	900099	-22,284.			-22,284.
ane	b							
Miscellaneous Revenue	С							
Mis		All other revenue			20.004			
		Total. Add lines 11a-11d			-22,284.	701 010	0	0 057
	12	Total revenue. See instruction	ons	<b>)</b>	5,128,164.	791,210.	0.	-8,057.

#### Part IX | Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A) Check if Schedule O contains a response or note to any line in this Part IX (C) Management and general expenses (B)
Program service
expenses (**D**)
Fundraising (A) Total expenses Do not include amounts reported on lines 6b. expenses 7b, 8b, 9b, and 10b of Part VIII. Grants and other assistance to domestic organizations 633,006. 633,006. and domestic governments. See Part IV, line 21 Grants and other assistance to domestic individuals. See Part IV, line 22 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16 ...... 52,782. 52,782. Benefits paid to or for members Compensation of current officers, directors, 667,009. 99,251. 335,572. 232,186. trustees, and key employees ..... Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) Other salaries and wages 1,374,953. 906,889. 115,728. 352,336. 7 Pension plan accruals and contributions (include 39,528. 25,520. 2,182. 11,826. section 401(k) and 403(b) employer contributions)  $10\overline{3},675.$ 47,194. 162,832. 11,963. Other employee benefits 9 138,470. 83,373. 20,023. 35,074. Payroll taxes 10 Fees for services (nonemployees): 11 Management 19,257. 11,733. 6,482. 1,042. Legal 27,285. 27,285. Accounting 112,980. 112,980. Lobbying Professional fundraising services. See Part IV, line 17 Investment management fees ..... Other. (If line 11g amount exceeds 10% of line 25, 376,676. 192,073. 6,480. 178,123. column (A) amount, list line 11g expenses on Sch O.) Advertising and promotion 12 207,621. 97,144. 5,374. 105,103. Office expenses 13 169,610. 110,221. 26,682. 32,707. 14 Information technology Royalties 15 119,343. 71,577. 17,454. 30,312. Occupancy 16 109,888. 100,966. 664. 8,258. 17 Travel Payments of travel or entertainment expenses 18 for any federal, state, or local public officials 63,378. 9,749. 53,553. 76. Conferences, conventions, and meetings 19 20 Payments to affiliates 21 70,346. 47,126. 6,541. 16,679. Depreciation, depletion, and amortization 22 8,049. 4,833. 1,184. 2,032. 23 Other expenses. Itemize expenses not covered 24 above (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.) 815,227. 815,227. PRECLINICAL CONSORTIUM NHD BIOSAMPLE REPOSIT 208,188. 208,188. 20,749. 40,684. DUES AND SUBSCRIPTIONS 19,935. d MISCELLANEOUS EXPENSES 5,078. 2,213. 1,226. 1,639. e All other expenses 5,422,190. 3,984,149. 496,454. 941,587. Total functional expenses. Add lines 1 through 24e 25 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. 33,120. 66,240. 33,120. 0. Check here X if following SOP 98-2 (ASC 958-720)

Form 990 (2020)
Part X Balance Sheet

Par	<u> t X</u>	Balance Sheet					
		Check if Schedule O contains a response or no	ote to any	y line in this Part X			
					<b>(A)</b> Beginning of year		<b>(B)</b> End of year
	1	Cash - non-interest-bearing			809,370.	1	1,097,500.
	2	Savings and temporary cash investments			1,227,121.	2	1,238,876.
	3	Pledges and grants receivable, net			2,033,626.	3	1,578,285.
	4	Accounts receivable, net			10,243.	4	113,491.
	5	Loans and other receivables from any current					
		trustee, key employee, creator or founder, sub	stantial c	ontributor, or 35%			
		controlled entity or family member of any of the		5			
	6	Loans and other receivables from other disqua					
		under section 4958(f)(1)), and persons describe	ed in sect	tion 4958(c)(3)(B) L		6	
S	7	Notes and loans receivable, net		7			
Assets	8	Inventories for sale or use				8	
Ä	9				251,370.	9	392,003.
	10a	Land, buildings, and equipment: cost or other					
		basis. Complete Part VI of Schedule D	10a	735,604.			
	b	Less: accumulated depreciation	80,221.	10c	510,367.		
	11	Investments - publicly traded securities	27,556.	11			
	12	Investments - other securities. See Part IV, line		12			
	13	Investments - program-related. See Part IV, line		13			
	14	Intangible assets		14			
	15	Other assets. See Part IV, line 11	5,911,809.	15	6,727,351.		
	16	Total assets. Add lines 1 through 15 (must eq	10,351,316.	16	11,657,873.		
	17	Accounts payable and accrued expenses			532,853.	17	435,478.
	18	Grants payable		18	100 006		
	19	Deferred revenue			54,700.	19	422,226.
	20	Tax-exempt bond liabilities				20	
	21	Escrow or custodial account liability. Complete				21	
es	22	Loans and other payables to any current or for					
Liabilities		trustee, key employee, creator or founder, sub					
jab.		controlled entity or family member of any of the				22	
_	23	Secured mortgages and notes payable to unre		· · · · · · · · · · · · · · · · · · ·		23	
	24	Unsecured notes and loans payable to unrelate				24	
	25	Other liabilities (including federal income tax, p					
		parties, and other liabilities not included on line	-	•	7,176.	0.5	1,337,608.
	00	of Schedule D			594,729.	25 26	2,195,312.
	26	Total liabilities. Add lines 17 through 25  Organizations that follow FASB ASC 958, ch		<b>▼</b>	334,123.	26	2,193,312.
S		and complete lines 27, 28, 32, and 33.	ieck nere				
nce	27	• • • • • •			5,661,364.	27	5,954,477.
ala	28	Net assets without donor restrictions  Net assets with donor restrictions	4,095,223.	28	3,508,084.		
d B	20	Organizations that do not follow FASB ASC	4,055,225	20	3,300,004.		
Fun		and complete lines 29 through 33.	936, CHE	ck liefe			
ō	29	Capital stock or trust principal, or current fund	c			29	
ets	30	Paid-in or capital surplus, or land, building, or				30	
1SS.	31	Retained earnings, endowment, accumulated i				31	
Net Assets or Fund Balances	32	Total net assets or fund balances			9,756,587.	32	9,462,561.
Ž	33	Total liabilities and net assets/fund balances			10,351,316.	33	11,657,873.
	00	Total habilities and het assets/fully baidfices			10,001,010.	JJ	Garage 990 (2000)

Form **990** (2020)

or audits, explain why on Schedule O and describe any steps taken to undergo such audits

Form 990 (2020)

#### SCHEDULE A

(Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service

## **Public Charity Status and Public Support**

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

Open to Public

Inspection

**Employer identification number** 

Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 Reason for Public Charity Status. (All organizations must complete this part.) See instructions. Part I The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.) A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i). A school described in section 170(b)(1)(A)(ii). (Attach Schedule E (Form 990 or 990-EZ).) 3 A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii). 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: 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). X 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.) A community trust described in section 170(b)(1)(A)(vi). (Complete Part II.) An agricultural research organization described in section 170(b)(1)(A)(ix) operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or 10 An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See section 509(a)(2). (Complete Part III.) An organization organized and operated exclusively to test for public safety. See section 509(a)(4). 11 12 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See section 509(a)(3). Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g. Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. You must complete Part IV, Sections A and B. Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). You must complete Part IV, Sections A and C. Type III functionally integrated. A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). You must complete Part IV, Sections A, D, and E. Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). You must complete Part IV, Sections A and D, and Part V. Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization. Enter the number of supported organizations Provide the following information about the supported organization(s). (i) Name of supported (ii) EIN (iii) Type of organization (v) Amount of monetary (vi) Amount of other your governing document? (described on lines 1-10 organization support (see instructions) support (see instructions) No above (see instructions))

Total

# Schedule A (Form 990 or 990-EZ) 2020 NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 Page 2 Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Sec	ction A. Public Support						
Cale	ndar year (or fiscal year beginning in)	(a) 2016	<b>(b)</b> 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
1	Gifts, grants, contributions, and						
	membership fees received. (Do not						
	include any "unusual grants.")	4517826.	3949953.	4105376.	5527543.	4345011.	22445709.
2	Tax revenues levied for the organ-						
	ization'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	4517826.	3949953.	4105376.	5527543.	4345011.	22445709.
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)						3416325.
	Public support. Subtract line 5 from line 4.						19029384.
Sec	ction B. Total Support						
Cale	ndar year (or fiscal year beginning in) 🕨	(a) 2016	<b>(b)</b> 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
7	Amounts from line 4	4517826.	3949953.	4105376.	5527543.	4345011.	22445709.
8	Gross income from interest,						
	dividends, payments received on						
	securities loans, rents, royalties,						
	and income from similar sources	15,431.	10,393.	13,784.	27,444.	11,188.	78,240.
9	Net income from unrelated business						
	activities, whether or not the	4.4.400					
	business is regularly carried on	44,490.					44,490.
10	Other income. Do not include gain						
	or loss from the sale of capital	1 600	640	1 010			4 000
	assets (Explain in Part VI.)	1,683.	642.	1,243.	714.		4,282.
11	• • • • • • • • • • • • • • • • • • • •					1 7	22572721.
12	Gross receipts from related activities,	•	,				,774,339.
13	First 5 years. If the Form 990 is for th	-		•			<b>.</b> —
Sac	organization, check this box and storetion C. Computation of Publi	c Support Per	centage				<b>P</b>
		• • •		volumn (f))		14	84.30 %
14						15	
15	Public support percentage from 2019 33 1/3% support test - 2020. If the control of the control o						
104	<b>stop here.</b> The organization qualifies						
h	33 1/3% support test - 2019. If the o						
~	and <b>stop here.</b> The organization qual						. $\Box$
17:	10% -facts-and-circumstances test		• • •		 2.13 16a or 16b a		
.,,	and if the organization meets the facts	-					
	meets the facts-and-circumstances te		•	-		viriow the organiz	<b>.</b> .
h	10% -facts-and-circumstances test	o o		,			
~	more, and if the organization meets th	ū				•	, 0 0.
	organization meets the facts-and-circu		•				ightharpoonup
_18	Private foundation. If the organization						<u> </u>

# Schedule A (Form 990 or 990-EZ) 2020 NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 Page 3 Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Se	ction A. Public Support	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,					
Cale	ndar year (or fiscal year beginning in)	(a) 2016	<b>(b)</b> 2017	(c) 2018	(d) 2019	(e) 2020	(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 per-						
	formed, 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 bus-						
	iness under section 513						
4	Tax revenues levied for the organ-						
	ization'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						
78	Amounts included on lines 1, 2, and						
	3 received from disqualified persons						
k	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						
	Add lines 7a and 7b						
	Public support. (Subtract line 7c from line 6.)						
	ction B. Total Support		T		T	T	T
	ndar year (or fiscal year beginning in)	(a) 2016	<b>(b)</b> 2017	(c) 2018	(d) 2019	(e) 2020	(f) Total
	Amounts from line 6						
108	Gross income from interest, dividends, payments received on						
	securities loans, rents, royalties,						
	and income from similar sources						
K	Unrelated business taxable income (less section 511 taxes) from businesses						
	, , , , , , , , , , , , , , , , , , ,						
	acquired after June 30, 1975  Add lines 10a and 10b						
	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						
13	assets (Explain in Part VI.)  Total support. (Add lines 9, 10c, 11, and 12.)						
	First 5 years. If the Form 990 is for the	ne organization's fi	rst second third	fourth or fifth tax	vear as a section 5	i01(c)(3) organizatio	on .
•	check this box and stop here	•			-		
Se	ction C. Computation of Publi						
15	Public support percentage for 2020 (I	ine 8, column (f), d	livided by line 13, o	column (f))		15	%
16	Public support percentage from 2019	Schedule A, Part	III, line 15			16	%
Se	ction D. Computation of Inves	tment Income	e Percentage				
17	Investment income percentage for 20	<b>)20</b> (line 10c, colur	mn (f), divided by li	ne 13, column (f))		17	%
18	Investment income percentage from	<b>2019</b> Schedule A,	Part III, line 17			18	%
19	a 33 1/3% support tests - 2020. If the					3 1/3%, and line 1	7 is not
	more than 33 1/3%, check this box ar	nd <b>stop here.</b> The	organization quali	fies as a publicly s	supported organiza	tion	<b>&gt;</b>
k	33 1/3% support tests - 2019. If the	organization did r	not check a box on	line 14 or line 19a	a, and line 16 is mo	ore than 33 1/3%, a	and
	line 18 is not more than 33 1/3%, che	ck this box and st	t <b>op here.</b> The orga	nization qualifies a	as a publicly suppo	orted organization	
20	Private foundation. If the organization	n did not check a	box on line 14, 19a	a, or 19b, check th	nis box and see ins	tructions	

### Part IV | Supporting Organizations

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

### Section A. All Supporting Organizations

- 1 Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.
- 2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in **Part VI** how the organization determined that the supported organization was described in section 509(a)(1) or (2).
- **3a** Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer lines 3b and 3c below.
- **b** Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in **Part VI** when and how the organization made the determination.
- c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.
- **4a** Was any supported organization not organized in the United States ("foreign supported organization")? *If* "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.
- **b** Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in **Part VI** how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.
- c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.
- 5a Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).
- **b Type I or Type II only.** Was any added or substituted supported organization part of a class already designated in the organization's organizing document?
- c Substitutions only. Was the substitution the result of an event beyond the organization's control?
- Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI.
- 7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).
- 8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).
- 9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in Part VI.
- **b** Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes." provide detail in **Part VI.**
- c Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI.
- 10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.
  - **b** Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)

		Yes	No
	1		
	•		
	2		
	3a		
	OI:		
	3b		
	3с		
	4a		
	4b		
	4c		
	5a		
	5b		
	5c		
	6		
	7		
	8		
	9a		
	9b		
	9c		
	10-		
	10a		
	10b		
n 9	90 or 99	0-EZ)	2020

Part IV   Supporting Organizations (continued)   Yes   No   No   No   No   No   No   No   N		dule A (Form 990 or 990-EZ) 2020 NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3	01879	9 Pa	age <b>5</b>
11. Has the organization accepted a gift or combibution from any of the following persons?  2 A A person with directly or influently controls, either able or together with persons described in lines 11b and 11c below, the governing body of a supported organization?  3 A Fall Part VIII.  Section B. Type I Supporting Organizations  1 Directly the governing body, members of the governing body, diffuses acting in their efficial capacity, or membership of one or organization or the properties governing body, members of the governing body, diffuses acting in their efficial capacity, or membership of one or more supported organizations have the power to regularity appoint or elect at least a majority of the organizations of officers, directors, or furthers at all times during the tax year? If Yor, "describe in Part VI bow the supported organization of effectively organizations at all times during the tax year? If Yor," describe in Part VI bow the supported organizations of effectively organizations and the properties or supported organization organization organizations, or furthers at all times the organization organization organizations and the organization or an esupported organizations, describe how the provers to appoint and/or remove efficient, directors, or trustees were allocated among the supported organizations or the than the supported organization organization organization or the third than the supported organization org	Pai	t IV Supporting Organizations (continued)			N1 -
a A person who directly or indirectly controls, either alone or together with persons described in lines 11b and 11c below, the governing body of a supported organization?  b A stainly member of a person described in line 11a above? A 55% controlled entity of a person described in line 11a above? A 55% controlled entity of a person described in line 11a above? Bettin B Type I Supporting Organizations  1 Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization of order or more supported organizations have the power to regularly appoint or elect at least a majority of the organization of effectively operated, supervised, or controlled the organization secribles. If the organization operated are one of the owners to appoint and order review effectively operated, supervised, or controlled the organization operated to excess to appoint and order organization operated to excess to appoint and order consideration of the supported organization operated organization operated or the benefit of any supported organization? If "Yes," explain in Part VI how providing such heards careled out the purposes of the supported organizations of the supporting organization.  2 Did the organization provide to the benefit carely are purposes of the supported organizations? If "Yes," explain in Part VI how control or nareagement of the supporting Organizations.  1 Were a majority of the organization is directors or trustees during the tax year also a majority of the directors or trustees of each of the organization is supported organizations, by the last day of the fifth month of the organization provide to each of its supported organizations, by the last day of the fifth month of the organization provide to each of its supported organizations, to the extent not previously provided?  1 Did the organization provide to each of its supported organizations, to the	11	Has the organization accented a gift or contribution from any of the following persons?		res	NO
11a b A family member of a pesson described in lier 1at above? c A 35% controlled entity of a person described in lier 11a or 11b above? # "yes" to line 11a, 11b, or 11c, provide					
b A family member of a person described in line 11a above?  A 25% controlled entity of a person described in line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide described in Part VI.  Section B. Type I Supporting Organizations  Did the geverning body, members of the governing body, officers acting in their official capacity, or membership of one or more supported regarization have the power to regulately appoint or elect at least a majority of the organization's officers, directors, or fundees that furnished the transported organization's expense of the companies of the organization's expense of the companies of t	-		11a		
c A 35% controlled entity of a person described in line 11a or 11b above? #"Yes" to line 11a, 11b, or 11c, provide detail in Part VI.  Section B. Type I Supporting Organizations  1 Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization is officers, and the provents of the power to regularly appoint or elect at least a majority of the organization of one or more supported organizations and or more officers, directors, or trustees were allocated among the supported organization of province or province organization of the supported organization org	b				
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the organization maintained a close and continuous working relationship with the supported organization(s).  3 By reason of the relationship described in line 2, above, did the organization's supported organizations have a significant voice in the organization's involvement, one or more of the organization's usupported organizations played in this regand.  5 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).  1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).  2 Activities Test. Answer lines 2a and 2b below.  2 Activities Test. Answer lines 2a and 2b below.  3 Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organizations and explain how these activities that, but for the organization determined that these activities described in line 2a, above, constitute activities that, but for the organization in Part VI the reasons for the organization's involvement.  3 Did the activities but for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.  3 Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? If "Yes," "No" "Porvide details in Part VI.  5 Did the organization exercise a substantial degree of direction over the policies, programs, and activities of	2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported			
3 By reason of the relationship described in line 2, above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.  Section E. Type III Functionally Integrated Supporting Organizations  1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).  a The organization satisfied the Activities Test. Complete line 2 below. b The organization is the parent of each of its supported organizations. Complete line 3 below. c The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions).  2 Activities Test. Answer lines 2a and 2b below. a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization's activities during the tax year directly furthered their exempt purposes, how the organization was responsive? If "Yes," then in Part VI identify those supported organization was responsive? If succeed the organization determined that these activities described in line 2a, above, constitute activities that, but for the organization determined that these activities described in line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's position that its supported organization(s) would have engaged in these activities but for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.  3 Parent of Supported Organizations Answer lines 3a and 3b below.  a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? If "Yes" or		organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how			
income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.  Section E. Type III Functionally integrated Supporting Organizations  1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).  a The organization is the parent of each of its supported line 2 below. b The organization is the parent of each of its supported organizations. Complete line 3 below. c The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions).  2 Activities Test. Answer lines 2a and 2b below. a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities duststantially all of its activities. b Did the activities described in line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's position that its supported organization(s) would have engaged in these activities but for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.  3 Parent of Supported Organizations. Answer lines 3a and 3b below. a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? If "Yes" or "No" provide details in Part VI.  b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each	3		2		
Section E. Type III Functionally Integrated Supporting Organizations  1		significant voice in the organization's investment policies and in directing the use of the organization's			
Section E. Type III Functionally Integrated Supporting Organizations  1		income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's			
1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).  a		supported organizations played in this regard.	3		
a	Sec	tion E. Type III Functionally Integrated Supporting Organizations			
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a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? If "Yes" or "No" provide details in Part VI.  b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each	2	· · · · · · · · · · · · · · · · · · ·	<b>Z</b> D		
trustees of each of the supported organizations? If "Yes" or "No" provide details in Part VI.  b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each					
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each	а		30		
	h	•	Ja		
			3b		

Schedule A (Form 990 or 990-EZ) 2020 NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 Page 6 Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations ☐ Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 ( explain in Part VI). See instructions. All other Type III non-functionally integrated supporting organizations must complete Sections A through E. (B) Current Year Section A - Adjusted Net Income (A) Prior Year (optional) 1 Net short-term capital gain 2 Recoveries of prior-year distributions 3 Other gross income (see instructions) 3 4 4 Add lines 1 through 3. 5 5 Depreciation and depletion Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or 6 maintenance of property held for production of income (see instructions) 7 Other expenses (see instructions) 8 Adjusted Net Income (subtract lines 5, 6, and 7 from line 4) 8 (B) Current Year Section B - Minimum Asset Amount (A) Prior Year (optional) 1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): a Average monthly value of securities 1a **b** Average monthly cash balances 1b **c** Fair market value of other non-exempt-use assets 1c d Total (add lines 1a, 1b, and 1c) 1d e Discount claimed for blockage or other factors (explain in detail in Part VI): 2 Acquisition indebtedness applicable to non-exempt-use assets 2 3 3 Subtract line 2 from line 1d. Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, 4 see instructions). 5 Net value of non-exempt-use assets (subtract line 4 from line 3) 5 6 6 Multiply line 5 by 0.035. 7 Recoveries of prior-year distributions 7 8 Minimum Asset Amount (add line 7 to line 6) Section C - Distributable Amount **Current Year** 1 Adjusted net income for prior year (from Section A, line 8, column A) 1 Enter 0.85 of line 1. 2 Minimum asset amount for prior year (from Section B, line 8, column A) 3 3 Enter greater of line 2 or line 3. 4 4 5 5 Income tax imposed in prior year Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions). 6

Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see

Schedule A (Form 990 or 990-EZ) 2020

instructions).

Schedule A (Form 990 or 990-EZ) 2020 NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 Page 7

Pai	rt V │ Type III Non-Functionally Integrated 509(	(a)(3) Supporting Orga	nizations (continued)	
Sect	ion D - Distributions			Current Year
_1	Amounts paid to supported organizations to accomplish exer	mpt purposes	1	
2	Amounts paid to perform activity that directly furthers exemp			
	organizations, in excess of income from activity	2		
3	Administrative expenses paid to accomplish exempt purpose	3		
_4_	Amounts paid to acquire exempt-use assets	4		
_5_	Qualified set-aside amounts (prior IRS approval required - pro	5		
_6_	Other distributions (describe in Part VI). See instructions.	6		
_7_	Total annual distributions. Add lines 1 through 6.		7	
8	Distributions to attentive supported organizations to which the	ne organization is responsive		
	(provide details in Part VI). See instructions.		8	
_9_	Distributable amount for 2020 from Section C, line 6		9	
10	Line 8 amount divided by line 9 amount	Т	10	
Sect	ion E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2020	(iii) Distributable Amount for 2020
1	Distributable amount for 2020 from Section C, line 6			
2	Underdistributions, if any, for years prior to 2020 (reason-			
	able cause required - explain in Part VI). See instructions.			
_3_	Excess distributions carryover, if any, to 2020			
a	From 2015			
b	From 2016			
<u>c</u>	From 2017			
d	From 2018			
e	From 2019			
f	Total of lines 3a through 3e			
g	Applied to underdistributions of prior years			
<u>h</u>	Applied to 2020 distributable amount			
<u>i</u>	Carryover from 2015 not applied (see instructions)			
<u>j_</u>	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4	Distributions for 2020 from Section D,			
	line 7: \$			
	Applied to underdistributions of prior years			
	Applied to 2020 distributable amount			
<u> </u>	Remainder. Subtract lines 4a and 4b from line 4.			
5	Remaining underdistributions for years prior to 2020, if			
	any. Subtract lines 3g and 4a from line 2. For result greater			
	than zero, explain in Part VI. See instructions.			
6	Remaining underdistributions for 2020. Subtract lines 3h			
	and 4b from line 1. For result greater than zero, explain in			
	Part VI. See instructions.			
7	Excess distributions carryover to 2021. Add lines 3j			

Schedule A (Form 990 or 990-EZ) 2020

and 4c.
 B Breakdown of line 7:
 a Excess from 2016
 b Excess from 2017
 c Excess from 2018
 d Excess from 2019
 e Excess from 2020

Schedule A (Form 990 or 990-EZ) 2020 NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 Page 8 Part VI Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a, and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.) SCHEDULE A, PART II, LINE 10, EXPLANATION FOR OTHER INCOME: INCOME FROM ACTIVITIES NOT REGULARLY CARRIED ON 2016 AMOUNT: \$ 1,683. 642. 2017 AMOUNT: \$ 2018 AMOUNT: \$ 1,243. 714. 2019 AMOUNT: \$ 2020 AMOUNT: \$ 0.

#### \*\* PUBLIC INSPECTION COPY \*\*

### Schedule B

(Form 990, 990-EZ, or 990-PF)

Department of the Treasury Internal Revenue Service

### **Schedule of Contributors**

➤ Attach to Form 990, Form 990-EZ, or Form 990-PF.

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

OMB No. 1545-0047

2020

Name of the organization

Employer identification number

#### NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

95-3018799

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

X 501(c)( 3 ) (enter number) organization

4947(a)(1) nonexempt charitable trust **not** treated as a private foundation

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

4947(a)(1) nonexempt charitable trust treated as a private foundation

501(c)(3) taxable private foundation

Check if your organization is covered by the General Rule or a Special Rule.

Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

#### **General Rule**

For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

#### **Special Rules**

For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000; or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 exclusively for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions exclusively for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received nonexclusively religious, charitable, etc., contributions totaling \$5,000 or more during the year \_\_\_\_\_\_ \bigsim \frac{1}{2} \frac{1}

Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990, 990-EZ, or 990-PF), but it **must** answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

LHA For Paperwork Reduction Act Notice, see the instructions for Form 990, 990-EZ, or 990-PF.

Schedule B (Form 990, 990-EZ, or 990-PF) (2020)

Name of organization Employer identification number

# NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

95-3018799

Part I	Contributors (see instructions). Use duplicate copies of Part I if addition	al space is needed.	
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1		\$371,820.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2		\$ 291,000.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
3		\$\$	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
4		\$165,000.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
5		\$\$	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
6		\$\$ 100,000.	Person X Payroll Noncash (Complete Part II for noncash contributions.)

Name of organization Employer identification number

# NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

95-3018799

Part I	Contributors (see instructions). Use duplicate copies of Part I if add	ditional space is needed.	
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7		\$\$	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
			Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
			Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
			Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)

Name of organization Employer identification number

# NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

95-3018799

Part II	Noncash Property (see instructions). Use duplicate copies of Part II if a	additional space is needed.	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		\$	
(a) No. from Part I	(b)  Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		\$	
(a) No. from Part I	(b)  Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		\$	
(a) No. from Part I	(b)  Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		\$	
(a) No. from Part I	(b)  Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		\$	
(a) No. from Part I	(b)  Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
		\$	

Name of organization

Employer identification number

	AL TUBEROUS	SCLEROSIS	ASSOCIATION	95-3018799
Part III	Exclusively religious, cl	haritable, etc., contrib	utions to organizations described in section 501(c)(7), (8), or (1	0) that total more than \$1,000 for the year
	from any one contribut	or. Complete columns	(a) through (e) and the following line entry. For organizations	

(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held			
		1			
Transferee's name, address, a	(e) Transfer of gift	Relationship of transferor to transferee			
(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held			
(e) Transfer of gift					
Transferee's name, address, a	nd ZIP + 4	Relationship of transferor to transferee			
(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held			
Transferee's name, address, a	(e) Transfer of gift	Relationship of transferor to transferee			
(IA) Down and of the					
(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held			
(e) Transfer of gift					
Transferee's name, address, a	nd ZIP + 4	Relationship of transferor to transferee			
	(b) Purpose of gift  Transferee's name, address, and (b) Purpose of gift	(e) Transfer of gift  Transferee's name, address, and ZIP + 4  (b) Purpose of gift  (c) Use of gift  Transferee's name, address, and ZIP + 4  (b) Purpose of gift  (c) Use of gift			

#### **SCHEDULE C**

(Form 990 or 990-EZ)

# **Political Campaign and Lobbying Activities**

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

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

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service

► Complete if the organization is described below. ► Attach to Form 990 or Form 990-EZ.

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

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

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

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

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

•	Section 501(c)(4), (5), or (6) organizat	tions: Complete Part III.			
Nan	ne of organization			Em	ployer identification number
		L TUBEROUS SCLER			95-3018799
Pa	art I-A Complete if the org	janization is exempt und	er section 501(c)	or is a section 527 o	rganization.
2 3	Provide a description of the organize Political campaign activity expendite Volunteer hours for political campaigns.	ures gn activities		<b>&gt;</b>	\$
	·	anization is exempt und		·	
1	Enter the amount of any excise tax	incurred by the organization und	der section 4955	<b>?</b>	\$
	Enter the amount of any excise tax				
	If the organization incurred a section				
	Was a correction made? If "Yes," describe in Part IV.				tes INO
		janization is exempt und	er section 501(c).	except section 5010	c)(3).
2	Enter the amount directly expended Enter the amount of the filing organ exempt function activities	by the filing organization for se ization's funds contributed to ot	ction 527 exempt functions for se	ion activities	\$
3	Total exempt function expenditures		•		•
_	line 17b				
	Did the filing organization file Form				
5	Enter the names, addresses and en made payments. For each organiza contributions received that were propolitical action committee (PAC). If	tion listed, enter the amount pai omptly and directly delivered to	d from the filing organiz a separate political orga	ation's funds. Also enter t anization, such as a separa	he amount of political
	<b>(a)</b> Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds. If none, enter -0	contributions received and

Schedule C (Form 990 or 990-EZ) 2020 NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 Page 2						
Part II-A Complete if the org section 501(h)).						
	ation belongs to an affi	liated group (and list in	Part IV each affiliated	group member's name	e, address, EIN,	
	re of excess lobbying e					
B Check ▶ ☐ if the filing organization	ation checked box A ar	nd "limited control" pro	visions apply.			
	its on Lobbying Exper ditures" means amou			<b>(a)</b> Filing organization's totals	(b) Affiliated group totals	
1a Total lobbying expenditures to infl	uence public opinion (	grassroots lobbying)		895.		
<b>b</b> Total lobbying expenditures to infl	<b>b</b> Total lobbying expenditures to influence a legislative body (direct lobbying)					
c Total lobbying expenditures (add l				123,014.		
d Other exempt purpose expenditur				5,350,680.		
e Total exempt purpose expenditure	es (add lines 1c and 1d	)		5,473,694.		
f Lobbying nontaxable amount. Ent	er the amount from the	following table in both	n columns.	423,685.		
If the amount on line 1e, column (a)	<b>I</b>	bying nontaxable am				
Not over \$500,000	20% of	the amount on line 1e.				
Over \$500,000 but not over \$1,00	0,000 \$100,00	00 plus 15% of the exce	ess over \$500,000.			
Over \$1,000,000 but not over \$1,5	500,000 \$175,00	00 plus 10% of the exce	ess over \$1,000,000.			
Over \$1,500,000 but not over \$17	,000,000 \$225,00	00 plus 5% of the exces	ss over \$1,500,000.			
Over \$17,000,000	\$1,000,	000.				
g Grassroots nontaxable amount (er	nter 25% of line 1f)			105,921.		
h Subtract line 1g from line 1a. If ze	ro or less, enter -0			0.		
i Subtract line 1f from line 1c. If zer				0.		
j If there is an amount other than ze	ero on either line 1h or	line 1i, did the organiza	ation file Form 4720	_		
reporting section 4911 tax for this					Yes No	
(Some organizations t	hat made a section 50	eraging Period Under 01(h) election do not l ate instructions for lir	nave to complete all o	of the five columns be	elow.	
	Lobbying Exper	nditures During 4-Yea	r Averaging Period			
Calendar year (or fiscal year beginning in)	<b>(a)</b> 2017	<b>(b)</b> 2018	(c) 2019	(d) 2020	(e) Total	
2a Lobbying nontaxable amount	416,065.	450,555.	445,393.	423,685.	1,735,698.	
b Lobbying ceiling amount (150% of line 2a, column(e))					2,603,547.	
c Total lobbying expenditures	146,199.	149,340.	165,226.	123,014.	583,779.	
d Grassroots nontaxable amount	104,016.	112,639.	111,348.	105,921.	433,924.	
e Grassroots ceiling amount (150% of line 2d, column (e))					650,886.	

823.

2,491.

1,797.

Schedule C (Form 990 or 990-EZ) 2020

895.

650,886.

6,006.

f Grassroots lobbying expenditures

# Schedule C (Form 990 or 990-EZ) 2020 NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 Page 3 Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description		(a)		(b)	
	e lobbying activity.	Yes	No	Amo	ount
	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:				
b	Volunteers?  Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?  Media advertisements?				
	Mailings to members, legislators, or the public?				
	Publications, or published or broadcast statements?				
	Grants to other organizations for lobbying purposes?				
	Direct contact with legislators, their staffs, government officials, or a legislative body?				
	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?  Other activities?				
j	Total. Add lines 1c through 1i				
	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				
	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?  t III-A   Complete if the organization is exempt under section 501(c)(4), section				
Par	t III-A Complete if the organization is exempt under section 501(c)(4), sectio 501(c)(6).	n 501(c)(5)	, or sec	tion	
				Yes	No
1	Were substantially all (90% or more) dues received nondeductible by members?		. 1		
2	Did the organization make only in-house lobbying expenditures of \$2,000 or less?		. 2		
3	Did the organization agree to carry over lobbying and political campaign activity expenditures from the		3		
	t III-B Complete if the organization is exempt under section 501(c)(4), sectio 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered answered "Yes."				3, is
1	Dues, assessments and similar amounts from members		. 1		
2	Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of politic expenses for which the section 527(f) tax was paid).	cal			
а	Current year		2a		
b	Carryover from last year		2b		
С	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 exc	ess			
	does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and personable estimates of nondeductible lobbying estimates of nondeductible lobbying estimates of nondeductible estimates of nond	olitical			
	expenditure next year?		4		
5	Taxable amount of lobbying and political expenditures (See instructions)		. 5		
Par	t IV Supplemental Information				
	de the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group ctions); and Part II-B, line 1. Also, complete this part for any additional information.	) list); Part II-A,	lines 1 a	nd 2 (See	

### **SCHEDULE D** (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

► Complete if the organization answered "Yes" on Form 990,
Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.

► Attach to Form 990.

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

OMB No. 1545-0047 Open to Public Inspection

Name of the organization

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

**Employer identification number** 95-3018799

Pai			or Accounts. Complete if the
	organization answered "Yes" on Form 990, Part IV, line		(h) Funds and other assessments
	Tatal accept as and of case	(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year		
2	Aggregate value of contributions to (during year)		
3	Aggregate value of grants from (during year)		
4	Aggregate value at end of year	witing that the accept hold in depart of in	and funda
5	Did the organization inform all donors and donor advisors in w	_	
6	are the organization's property, subject to the organization's education inform all grantees, donors, and donor actions are the organization inform all grantees, donors, and donor actions are the organization inform all grantees, donors, and donor actions are the organization inform all grantees, donors, and donor actions are the organization inform all grantees, donors, and donor actions are the organization inform all grantees, donors, and donor actions are the organization inform all grantees.		
U	for charitable purposes and not for the benefit of the donor or		
	• •		
Pai			
1	Purpose(s) of conservation easements held by the organization		
•	Preservation of land for public use (for example, recreat	`	f a historically important land area
	Protection of natural habitat	· —	f a certified historic structure
	Preservation of open space		
2	Complete lines 2a through 2d if the organization held a qualification	ed conservation contribution in the form	of a conservation easement on the last
	day of the tax year.		Held at the End of the Tax Year
а	Total number of conservation easements		
b			
С	Number of conservation easements on a certified historic stru		
	Number of conservation easements included in (c) acquired at		
	listed in the National Register		2d
3	Number of conservation easements modified, transferred, rele		
	year ▶		
4	Number of states where property subject to conservation ease	ement is located	
5	Does the organization have a written policy regarding the period	odic monitoring, inspection, handling of	
	violations, and enforcement of the conservation easements it $% \left( 1\right) =\left( 1\right) \left( 1\right)$	holds?	Yes No
6	Staff and volunteer hours devoted to monitoring, inspecting, h	nandling of violations, and enforcing cons	servation easements during the year
	<b>&gt;</b>		
7	Amount of expenses incurred in monitoring, inspecting, handle	ing of violations, and enforcing conserva	tion easements during the year
	<b>&gt;</b> \$		
8	Does each conservation easement reported on line 2(d) above	•	
	and section 170(h)(4)(B)(ii)?		
9	In Part XIII, describe how the organization reports conservation	·	
	balance sheet, and include, if applicable, the text of the footnote	ote to the organization's financial statem	ents that describes the
Do	organization's accounting for conservation easements.  t III Organizations Maintaining Collections of	Art Historical Transuras or Ot	thar Similar Assats
Pai			ther Sillilar Assets.
	Complete if the organization answered "Yes" on Form		
1a	If the organization elected, as permitted under FASB ASC 958	, ,	
	of art, historical treasures, or other similar assets held for public	,	•
	service, provide in Part XIII the text of the footnote to its finance		
b	If the organization elected, as permitted under FASB ASC 958	•	
	art, historical treasures, or other similar assets held for public	exhibition, education, or research in furti	nerance of public service,
	provide the following amounts relating to these items:		<b>.</b>
	(i) Revenue included on Form 990, Part VIII, line 1		
_			
2	If the organization received or held works of art, historical trea		ai gain, provide
_	the following amounts required to be reported under FASB AS	_	•
a	Revenue included on Form 990, Part VIII, line 1		
D	Assets included in Form 990, Part X		🖊 🔻

191,620.

94,712.

Schedule D (Form 990) 2020

81,710

10,017.

510,367

109,910.

84,695.

e Other

**d** Equipment

Total. Add lines 1a through 1e. (Column (d) must equal Form 990. Part X. column (B). line 10c.)

	(FUIII 990) 2020	142711		
Part VII	Investments -	- Other Se		

Part VII	Investments - Other Securities.			
( ) 5	Complete if the organization answered "Yes" o			
	otion of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end	-of-year market value
. ,	al derivatives		+	
	held equity interests			
(3) Other				
(A)				
(B) (C)				
(D)				
(E)				
(F)				
(G)				
(H)				
	b) must equal Form 990, Part X, col. (B) line 12.)			
Part VIII	Investments - Program Related.			
	Complete if the organization answered "Yes" of	on Form 990, Part IV, line	e 11c. See Form 990, Part X, line 13.	
	(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end	-of-year market value
(1)				
(2)				
(3)				
(4)				
(5)				
(6)				
(7)				
(8)			_	
(9)				
Total. (Col. (	b) must equal Form 990, Part X, col. (B) line 13.)  Other Assets.			
Faitix		Faura 000 Dart IV line	114 Cas Farms 000 Part V line 15	
	Complete if the organization answered "Yes" (a)	on Form 990, Part IV, line Description	e 11d. See Form 990, Part X, line 15.	(b) Book value
(4) TN	TEREST IN NET ASSETS OF	·		5,893,521.
	PERATING LEASE RIGHT-OF-U			833,830.
(3)	DIMITING BEADE RIGHT OF C	OL ADDLI		033,030.
(4)				
(5)				
(6)				
(7)				
(8)				
(9)				
Total. (Colu	ımn (b) must equal Form 990, Part X. col. (B) line	15.)	<b>&gt;</b>	6,727,351.
Part X	Other Liabilities.	,		
	Complete if the organization answered "Yes" of	on Form 990, Part IV, line	e 11e or 11f. See Form 990, Part X, line 25.	
1.	(a) Description of liability			(b) Book value
	deral income taxes			
	FERRED RENT & LEASE INCE	NTIVE		1,336,433.
(3) DU	JE TO AFFILIATE			1,175.
(4)				
(5)				
(6)				
(7)				
(8)				
(9)	<u> </u>	25.		1,337,608.
	<i>umn (b) must equal Form 990, Part X, col. (B) line</i> or for uncertain tax positions. In Part XIII, provide			
LIQUIIILY	i ioi antocitam tax positions, in i alt Alli, pitviut		.o ano organización o inicitoral statemento til	at roporto tito

organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII

032054 12-01-20 Schedule D (Form 990) 2020

#### SCHEDULE F (Form 990)

Department of the Treasury

Internal Revenue Service

### **Statement of Activities Outside the United States**

► Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.

➤ Attach to Form 990.

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

Inspection

Name of the organization

**Employer identification number** 

			ASSOCIATION		95-3018799
Part I General Information on Activitie		es Outside the United States.	Complete if the organ	ization answered "Yes" on	
	Form 990, Part IV, line	e 14b.			

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

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

United States.	nbe in Part v the	organization s į	procedures for monitoring the use of its	grants and other assistance outs	ide trie
3 Activities per Region. (The (a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors	n be duplicated if additional space is n (d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	eeded.)  (e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
EUROPE (INCLUDING ICELAND & GREENLAND)	0	in the region	GRANTMAKING		34,032.
MIDDLE EAST AND NORTH AFRICA	0	0	GRANTMAKING		18,750.
EUROPE (INCLUDING ICELAND & GREENLAND)	0	0		PRECLINICAL RESEARCH STUDIES	58,944.
3 a Subtotalb Total from continuation	0	0			111,726.
sheets to Part I c Totals (add lines 3a and 3b)	0	0			111,726.

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

Schedule F (Form 990) 2020

Part II Grants and Other	er Assistance to Org	ganizations or Entities (	Outside the United States. C	omplete if the o	rganization answered	d "Yes" on Form	990, Part IV, line 15, for	any
recipient who rec	ceived more than \$5,	000. Part II can be dupli	cated if additional space is nee	ded.				
1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	I (C) REGION	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			RESEARCH ON TUBEROUS SCLEROSIS COMPLEX	18,750.	WIRE	0.		
		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA,	PROGRAMMATIC SUPPORT	34,032.	WIRE	0.		

2	Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax								
	exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter						<b>&gt;</b>		(
3	Enter total number of c	other organizations of	or entities						2

Part III Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 16.

Part III can be duplicated if ac	dditional space is needed	d.					
(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	<b>(e)</b> Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)

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

Schedule F (Form 990) 2020

032075 12-03-20 Schedule F (Form 990) 2020

### **SCHEDULE G**

Department of the Treasury

Internal Revenue Service

(Form 990 or 990-EZ)

## **Supplemental Information Regarding Fundraising or Gaming Activities**

Complete if the organization answered "Yes" on Form 990, Part IV, line 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.

► Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

2020

Open to Public Inspection

Name of the organization

NATTONAL TUBEROUS SCLEROSTS ASSOCIATION 95-3018799

	Complete if the organization answer				ine 17. Form 990-EZ	
<ul> <li>Indicate whether the organization rais</li> <li>a Mail solicitations</li> <li>b Internet and email solicitations</li> <li>c Phone solicitations</li> <li>d In-person solicitations</li> <li>2 a Did the organization have a written of key employees listed in Form 990, P</li> <li>b If "Yes," list the 10 highest paid individed to compensated at least \$5,000 by the</li> </ul>	sed funds through any of the following sed funds through any of the following Solicitate for oral agreement with any individual art VII) or entity in connection with puriously or entities (fundraisers) pursured	tion of tion of fundra (includ	non-g gover lising ling of onal fu	overnment grants nment grants events ficers, directors, trus undraising services?	Yes	
(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
Total						
List all states in which the organization or licensing.	on is registered or licensed to solicit	contrib	utions	or has been notified	it is exempt from re	gistration

Schedule G (Form 990 or 990-EZ) 2020 NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 Page 2

Fundraising Events. Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000. (a) Event #1 **(b)** Event #2 (c) Other events (d) Total events VIRTUAL COMEDY FOR A (add col. (a) through 9 WALKS CURE col. (c)) (event type) (event type) (total number) 660,000. 179,147. 406,278. 1,245,425. 1 Gross receipts 626,454. 175,292. 391,193. 1,192,939. 2 Less: Contributions 33,546. 3,855. 15,085. 3 Gross income (line 1 minus line 2) 52,486. 4 Cash prizes 33,308. 756. 4,129. 5 Noncash prizes 38,193. Direct Expenses 6 Rent/facility costs \_\_\_\_\_ 8,091. 8,091. 2,739. 58. 137. 2,934. 7 Food and beverages 2,286. 180. 1,979. 127. 8 Entertainment 9 Other direct expenses ..... 51,504. **10** Direct expense summary. Add lines 4 through 9 in column (d) 11 Net income summary. Subtract line 10 from line 3, column (d) 982. Gaming. Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a. (b) Pull tabs/instant (d) Total gaming (add (a) Bingo (c) Other gaming Revenue col. (a) through col. (c)) bingo/progressive bingo Gross revenue 2 Cash prizes Direct Expenses Noncash prizes Rent/facility costs Other direct expenses % Yes Yes % Yes 6 Volunteer labor No 7 Direct expense summary. Add lines 2 through 5 in column (d) 8 Net gaming income summary. Subtract line 7 from line 1, column (d) ...... **9** Enter the state(s) in which the organization conducts gaming activities: a Is the organization licensed to conduct gaming activities in each of these states? **b** If "No," explain: 10a Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year? **b** If "Yes," explain:

Schedule G (Form 990 or 990-EZ) 2020 NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	95-3018799 Page 3
11 Does the organization conduct gaming activities with nonmembers?	Yes No
12 Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity formed	
to administer charitable gaming?	Yes No
13 Indicate the percentage of gaming activity conducted in:	
a The organization's facility	13a   %
<b>b</b> An outside facility	
14 Enter the name and address of the person who prepares the organization's gaming/special events books and record	
14 Enter the name and address of the person who prepares the organization's gaming/special events books and record	S.
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 amo	ount
of gaming revenue retained by the third party > \$	
c If "Yes," enter name and address of the third party:	
The state of the s	
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>b</b> Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in	Tule
organization's own exempt activities during the tax year ▶ \$  Part IV Supplemental Information. Provide the explanations required by Part I, line 2b, columns (iii) and (v):	and Dort III lines 0. Ob. 10b
	and Part III, lines 9, 9b, 10b,
15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.	
-	

Schedule G	G (Form 990 or 990-EZ)	NATIONAL	TUBEROUS	SCLEROSIS	ASSOCIATION	95-3018799	Page 4
Part IV	(Form 990 or 990-EZ)  Supplemental Infor	mation <sub>(continue</sub>	ed)				
			<u> </u>				

#### SCHEDULE I (Form 990)

Part I

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

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

► Attach to Form 990.

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

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

2020
Open to Public

Inspection

Name of the organization

**General Information on Grants and Assistance** 

Department of the Treasury Internal Revenue Service

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number
95-3018799

criteria used to award the grants or assis	stance?	J	,	,	J	,	X Yes No
2 Describe in Part IV the organization's pro	ocedures for moni	toring the use of grant	funds in the United	States.			
Part II Grants and Other Assistance to	Domestic Organi	zations and Domestic	Governments. C	omplete if the orga	anization answered "\	es" on Form 990, Part	IV, line 21, for any
recipient that received more than \$	5,000. Part II car	be duplicated if additi	onal space is need	ed.		_	
Name and address of organization or government	( <b>b)</b> EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
BRIGHAM & WOMAN'S HOSPITAL							
75 SAINT FRANCIS STREET BOSTON , MA 02115	04-2312909	501(C)(3)	55,436.	0.			RESEARCH GRANTS
UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER - 5323 HARRY HINES							
BLVD DALLAS, TX 75287	75-6002868	501(C)(3)	56,250.	0.			RESEARCH GRANTS
YALE UNIVERSITY							
P.O.BOX 1873 NEW HAVEN , CT 06508	06-0646973	501(C)(3)	56,011.	0.			RESEARCH GRANTS
AMERICAN THORACIC SOCIETY 25 BROADWAY, 18TH FLOOR NEW YORK, NY 10004	06-1548706	501(C)(3)	5,500.	0.			RESEARCH GRANTS
CHILDREN'S HOSPITAL MEDICAL CENTER SPONSORED PRGS ACTG ML 4900, 3333 BURNET AVE CINCINNATI, OH			,				
45229	31-0833936	501(C)(3)	50,000.	0.			CLINICAL RESEARCH GRANTS
NATIONAL ORGANIZATION FOR RARE DISORDERS - 55 KENOSIA AVENUE - DANBURY, CT 06810	13-3223946	501(C)(3)	65,000.	0.			TSC TRAVEL AND LODGING ASSISTANCE PROGRAM
2 Enter total number of section 501(c)(3) as	nd government or	ganizations listed in th	e line 1 table				<u>▶ 13.</u>
3 Enter total number of other organizations	s listed in the line	1 table					
LHA For Panerwork Reduction Act Notice	see the Instruct	ions for Form 990					Schedule I (Form 990) 2020

Part II Continuation of Grants and Other	Assistance to Do	mestic Organizations	and Domestic Go	<b>overnments</b> (Scho T	edule I (Form 990), Pa I	rt II.) T	1
(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
NORTHWESTERN UNIVERSITY							
7TH FLOOR, RUBLOFF BUILDING							
CHICAGO, IL 60611	36-2167818	501(C)(3)	75,001.	0.			RESEARCH GRANTS
	33 2237323		70,002.				
CHILDREN'S HOSPITAL CORPORATION							
300 LONGWOOD AVENUE							
BOSTON , MA 02115	04-2774441	501(C)(3)	150,001.	0.			RESEARCH GRANTS
BOSTON CHILDREN'S HOSPITAL							
300 LONGWOOD AVENUE							
BOSTON , MA 02115	04-2774441	501(C)(3)	57,409.	0.			CLINICAL RESEARCH GRANT
UNIVERSITY OF CALIFORNIA BERKELEY							
1608 FOURTH ST, STE. 220							
BERKELEY, CA 94710	94-6002123	501(C)(3)	9,375.	0.			RESEARCH GRANT
UNIVERSITY OF ALABAMA							
1720 2ND AVE. SOUTH, AB990							
BIRMINGHAM, AL 35294	63-6005396	501(C)(3)	15,533.	0.			CLINICAL RESEARCH GRANT
DIMINOMIN, III 33234	03 0003330	301(0)(3)	13,333.	· ·			CHINICIA KADAMCII GIGINI
UNIVERSITY OF TENNESSEE HEALTH							
SCIENCE CTR 910 MADISON AVE.,							
STE. 823 - MEMPHIS, TN 38103	62-6001636	501(C)(3)	18,511.	0.			RESEARCH GRANT
			·				
VANDERBILT UNIVERSITY							
1161 21ST AVE. SOUTH							
NASHVILLE, TN 37232	35-2528741	501(C)(3)	9,375.	0.			RESEARCH GRANT
							<u> </u>

Part III Grants and Other Assistance to Domestic Individuals Part III can be duplicated if additional space is needed.	. Complete if the	organization answe	ered "Yes" on Form 9	90, Part IV, line 22.	
(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 noncash assistance
Part IV Supplemental Information. Provide the information req	uired in Part I, lin	e 2; Part III, column	(b); and any other ac	Iditional information.	
PART I, LINE 2:					
THE TSC ALLIANCE HAS FUNDED MORE TI	HAN \$27.7	MILLION I	N RESEARCH	ON TSC	
SINCE 1984. DIRECTED BY STEVEN L.	ROBERDS,	PH.D, CHI	EF SCIENTI	FIC OFFICER,	
THE TSC ALLIANCE RESEARCH GRANTS PI	ROGRAM FU	NDS RESEAR	CH FOCUSED	ON TSC WITH	
PRIORITIES SET BY THE RESEARCHERS	rogether	WITH THE I	SC ALLIANC	Е.	
COLLABORATIONS BETWEEN BASIC AND C	LINICAL R	ESEARCHERS	ARE ENCOU	RAGED AND	
FOSTERED, AND THE TSC ALLIANCE IS V	WORKING T	O INCREASE	FUNDING F	OR RESEARCH	
ON TSC. THROUGH THE TSC ALLIANCE I					
BE SUBMITTED FOR: POSTDOCTORAL FELI					

# SCHEDULE J (Form 990)

**Compensation Information** 

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

Complete if the organization answered "Yes" on Form 990, Part IV, line 23.
 ► Attach to Form 990.
 ► Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public Inspection

Internal Revenue Service Name of the organization

Part I Questions Regarding Compensation

Department of the Treasury

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number 95-3018799

			Yes	No
1a	Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990,			
	Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.			
	First-class or charter travel Housing allowance or residence for personal use			
	Travel for companions Payments for business use of personal residence			
	Tax indemnification and gross-up payments  Health or social club dues or initiation fees			
	Discretionary spending account Personal services (such as maid, chauffeur, chef)			
b	If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or			
	reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain	1b		
2	Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors,			
	trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a?	2		
3	Indicate which, if any, of the following the organization used to establish the compensation of the organization's			
	CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to			
	establish compensation of the CEO/Executive Director, but explain in Part III.			
	X Compensation committee			
	Independent compensation consultant  X Compensation survey or study			
	X Approval by the board or compensation committee			
4	During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing			
	organization or a related organization:			
а	Receive a severance payment or change-of-control payment?	4a		Х
b	Participate in or receive payment from a supplemental nonqualified retirement plan?	4b		Х
С	Participate in or receive payment from an equity-based compensation arrangement?	4c		Х
	If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.			
	Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.			
5	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation			
	contingent on the revenues of:			
а	The organization?	5a	Х	
	Any related organization?	5b		Х
	If "Yes" on line 5a or 5b, describe in Part III.			
6	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation			
	contingent on the net earnings of:			
а	The organization?	6a	X	
b	Any related organization?	6b		Х
	If "Yes" on line 6a or 6b, describe in Part III.			
7	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments			
	not described on lines 5 and 6? If "Yes," describe in Part III	7		X
8	Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the			
	initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III	8		Х
9	If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in			
	Regulations section 53.4958-6(c)?	9		

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

Schedule J (Form 990) 2020

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

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

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

(A) Name and Title		(B) Breakdown of	W-2 and/or 1099-MI	SC compensation	(C) Retirement and other deferred	(D) Nontaxable benefits	(E) Total of columns	(F) Compensation in column (B)	
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation	compensation	benefits	(B)(i)-(D)	reported as deferred on prior Form 990	
(1) KARI L. ROSBECK	(i)	176,975.	17,191.	141.	6,045.	17,047.	217,399.	0.	
PRESIDENT & CEO	(ii)	3,277.	318.	3.	112.	316.			
(2) RICHARD GOLLUB	(i)	131,082.	12,338.	387.	4,504.	19,255.		0.	
CFO	(ii)	8,367.	788.	25.	288.	1,229.	10,697.	0.	
(3) STEVEN L. ROBERDS	(i)	190,616.	17,998.	268.	6,407.	15,963.	231,252.	0.	
CHIEF SCIENTIFIC OFFICER	(ii)	0.	0.	0.	0.	0.	0.	0.	
(4) DEAN RAGER-AGUIAR	(i)	140,752.	6,188.	143.	4,674.	17,982.	169,739.	0.	
DIR. PRECLINICAL RESEARCH	(ii)	0.	0.	0.	0.	0.	0.	0.	
	(i)								
	(ii)								
	(i)								
	(ii)								
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Part III   Supplemental Information
Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.
PART I, LINE 5:
KARI LUTHER ROSBECK, RICHARD GOLLUB, STEVE ROBERDS, DEAN AGUIAR, JAYE
ISHAM, LISA MOSS AND APRIL COOPER ALL HAVE INCENTIVE COMPENSATION EQUAL TO
A PERCENTAGE OF THEIR SALARIES BASED ON KEY PERFORMANCE OBJECTIVES AS
ESTABLISHED BY THE COMPENSATION COMMITTEE.
PART I, LINE 6:
KARI LUTHER ROSBECK, RICHARD GOLLUB, STEVE ROBERDS, DEAN AGUIAR, JAYE
ISHAM, LISA MOSS AND APRIL COOPER ALL HAVE INCENTIVE COMPENSATION EQUAL TO
A PERCENTAGE OF THEIR SALARIES BASED ON KEY PERFORMANCE OBJECTIVES AS
ESTABLISHED BY THE COMPENSATION COMMITTEE.

# **SCHEDULE M** (Form 990)

**Noncash Contributions** 

OMB No. 1545-0047

Open to Public Inspection

Department of the Treasury Internal Revenue Service

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

➤ Attach to Form 990.

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

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

Pai	rt I Types of Property				•			
		(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 10	(d) Method of de noncash contribu	etermin	•	s
1	Art - Works of art		itomo contributou	Tomin coo, i are viii, iiiio i g				
2	Art - Historical treasures							
3	Art - Fractional interests							
4	Books and publications							
5	Clothing and household goods	Х		422.	FMV			
6	Cars and other vehicles			122	1114			
7	Boats and planes							
8	Intellectual property							
9		X	6	87,545.	EM7			
	Securities - Publicly traded			07,545	LIIV			
10	Securities - Closely held stock							
11	Securities - Partnership, LLC, or							
40	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	77		2 0 6 0	T347.7			
19	Food inventory	X	2	3,060.	FMV			
20	Drugs and medical supplies							
21	Taxidermy							
22	Historical artifacts							
23	Scientific specimens							
24	Archeological artifacts							
25	Other ()							
26	Other							
27	Other							
28	Other (			<u> </u>				
29	Number of Forms 8283 received by the organization	zation during	the tax year for c	ontributions				
	for which the organization completed Form 82	83, Part V, D	onee Acknowledg	ement <b>29</b>			0	
							Yes	No
30a	During the year, did the organization receive by	y contributio	n any property rep	orted in Part I, lines 1 throu	gh 28, that it			
	must hold for at least three years from the date	e of the initia	l contribution, and	which isn't required to be u	ised for			
	exempt purposes for the entire holding period	?				30a		X
b	If "Yes," describe the arrangement in Part II.							
31	Does the organization have a gift acceptance p	policy that re	quires the review	of any nonstandard contribu	itions?	31	X	
32a	Does the organization hire or use third parties	or related or	ganizations to soli	cit, process, or sell noncash				
	contributions?					32a		X
b	If "Yes," describe in Part II.							
33	If the organization didn't report an amount in c	olumn (c) foi	a type of property	for which column (a) is che	ecked,			
	describe in Part II.							

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule M (Form 990) 2020

Schedule M	(Form 990) 2020	NATIONAL	TUBEROUS	SCLERO	SIS ASS	OCTATION	95-30187	99 Page <b>2</b>
Part II	Supplemental is reporting in Part this part for any actions.	Information. t I, column (b), the dditional information	Provide the infor number of contrion.	mation require butions, the nu	d by Part I, lin umber of items	es 30b, 32b, an s received, or a	d 33, and whether the combination of both. Al	organization so complete
-								

#### **SCHEDULE O**

Internal Revenue Service

(Form 990 or 990-EZ)
Department of the Treasury

# Supplemental Information to Form 990 or 990-EZ

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

Attach to Form 990 or 990-EZ.

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

2020
Open to Public Inspection

OMB No. 1545-0047

Name of the organization

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number 95-3018799

FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:

RESEARCH GRANTS AND POSTDOCTORAL FELLOWSHIPS, \$4.4 MILLION INTO THE

NATURAL HISTORY DATABASE AND BIOSAMPLE REPOSITORY, \$4.1 MILLION INTO

THE PRECLINICAL CONSORTIUM AND \$0.7 MILLION INTO THE CLINICAL RESEARCH

CONSORTIUM.

GRANT AND FELLOWSHIP APPLICATIONS ARE REVIEWED IN A THREE-STEP PROCESS:

(1) ALL APPLICATIONS ARE REVIEWED BY A COMMITTEE COMPRISED OF

SCIENTISTS KNOWLEDGEABLE ABOUT THE TOPIC AREA FOR SCIENTIFIC MERIT AND

OF CAREGIVERS OR ADULTS AFFECTED BY TSC FOR POTENTIAL IMPACT ON THE

LIVES OF THOSE AFFECTED BY TSC; (2) THE SCIENCE AND MEDICAL COMMITTEE

OF THE BOARD OF DIRECTORS EVALUATES THE GRANT REVIEW COMMITTEE'S

RECOMMENDATIONS AND THE RELEVANCE OF THE APPLICATIONS TO THE TSC

ALLIANCE'S FUNDING PRIORITIES; AND (3) THE BOARD OF DIRECTORS THEN

REVIEWS THE RECOMMENDATIONS OF THE SCIENCE AND MEDICAL COMMITTEE AND

MAKES FINAL APPROVAL FOR FUNDING. FOR A COMPLETE LIST OF CURRENTLY

FUNDED PROJECTS AND AN ARCHIVE OF PAST AWARDEES, PLEASE VISIT

TSALLIANCE.ORG/GRANTS.

IMPLEMENTED IN 2006, THE TSC NATURAL HISTORY DATABASE CAPTURES CLINICAL

DATA TO DOCUMENT THE IMPACT OF THE DISEASE ON A PERSON'S HEALTH OVER

THEIR LIFETIME. THE DATABASE SERVES AS A RESOURCE OF INFORMATION THAT

HELPS TSC RESEARCHERS BETTER UNDERSTAND THE PROGRESSION OF THE DISEASE,

DESIGN HYPOTHESIS-DRIVEN QUESTIONS TO HASTEN THE DISCOVERY OF NEW

TREATMENTS AND IDENTIFY PERSONS WITH TSC WHO ARE ELIGIBLE TO

PARTICIPATE IN RESEARCH STUDIES. AS OF DECEMBER 2020, 2,268 PEOPLE WITH

Name of the organization **Employer identification number** NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 TSC WERE ENROLLED IN THE PROJECT FROM AMONG 18 U.S.-BASED SITES AND THROUGH THE TSC ALLIANCE. THE TSC ALLIANCE PROVIDES FUNDING TO PARTICIPATING CLINICS TO PERFORM DATA ENTRY, MONITORS THE INTEGRITY OF THE DATABASE, AND MAKES DATA AVAILABLE TO INVESTIGATORS TO ANSWER SPECIFIC RESEARCH QUESTIONS AND IDENTIFY POTENTIAL PARTICIPANTS FOR CLINICAL TRIALS AND STUDIES. IN 2020, THE TSC ALLIANCE ADDED A COVID-19 SUB-PROJECT TO ADDRESS DETAILED OUESTIONS ABOUT COVID-19 INFECTION IN INDIVIDUALS WITH TSC. BUILDING UPON THE NATURAL HISTORY DATABASE, THE TSC BIOSAMPLE REPOSITORY IS A TSC ALLIANCE-DIRECTED PROJECT INITIATED IN 2014 THAT WILL IMPACT RESEARCH OVER THE NEXT TEN YEARS OR MORE. THE TSC ALLIANCE'S SCIENCE AND MEDICAL COMMITTEE IDENTIFIED THIS AS A GAP THAT CAN ONLY BE FILLED EFFECTIVELY WITH LEADERSHIP OF THE TSC ALLIANCE, GUIDED BY A STEERING COMMITTEE OF CLINICIANS AND RESEARCHERS. HIGH-QUALITY BIOSAMPLES SUCH AS BLOOD, DNA, AND TISSUES LINKED TO DETAILED CLINICAL DATA ARE CRITICAL FOR RESEARCHERS TO UNDERSTAND WHY TSC IS SO DIFFERENT FROM PERSON TO PERSON. SAMPLES IN THE REPOSITORY ARE LINKED TO DETAILED CLINICAL DATA IN OUR EXISTING TSC NATURAL HISTORY DATABASE (NHD) AND ARE AVAILABLE TO QUALIFIED RESEARCHERS WORLDWIDE. SAMPLES ARE HOUSED AT AND DISTRIBUTED FROM THE VAN ANDEL INSTITUTE IN GRAND RAPIDS, MI, UNDER CONTROL OF THE TSC ALLIANCE. THE TSC BIOSAMPLE REPOSITORY ENDED 2020 WITH 1,571 BIOSAMPLES: 421 BLOOD SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 358 BUCCAL SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 29 TISSUE SAMPLES FROM INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 374 BLOOD SAMPLES FROM THE TSC CLINICAL RESEARCH CONSORTIUM COLLABORATIVE

PROJECTS, AND 389 DNA SAMPLES FROM THE TSC AUTISM CENTER OF EXCELLENCE

Name of the organization **Employer identification number** NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 NETWORK AUTISM BIOMARKER STUDY. WE CONTINUE TO GROW THE BIOSAMPLE REPOSITORY BY COLLECTING BLOOD SAMPLES ANNUALLY FROM PARTICIPANTS WHO VOLUNTEER TO DO SO, ENABLING RESEARCHERS TO STUDY CHANGES IN PROTEINS AND OTHER MOLECULES IN THE BLOOD OVER TIME; ADDING ADDITIONAL TSC CLINICS AS PARTICIPATING BIOSAMPLE REPOSITORY COLLECTION SITES; AND COLLECTING BLOOD USING MOBILE PHLEBOTOMY, ENABLING PEOPLE TO DONATE SAMPLES REGARDLESS OF WHERE THEY LIVE IN THE US AND WHETHER THEY ARE SEEN AT A TSC CLINIC. IN 2020, WE ACQUIRED 65 BLOOD SAMPLES VIA MOBILE PHLEBOTOMY, INCLUDING 4 FROM PARTICIPANTS WHO WERE DIAGNOSED WITH COVID-19. TO ENCOURAGE AND ENABLE MORE RESEARCHERS TO UTILIZE BIOSAMPLES, THE TSC ALLIANCE FUNDED THREE SEED GRANTS IN 2020, TOTALING \$60,000, TO LABS WHO SUBMITTED MERITORIOUS AND INNOVATIVE IDEAS FOR RESEARCH ON TSC BIOSAMPLES. THE TSC ALLIANCE LAUNCHED THE TSC PRECLINICAL CONSORTIUM IN 2015 TO

THE TSC ALLIANCE LAUNCHED THE TSC PRECLINICAL CONSORTIUM IN 2015 TO
HELP ADVANCE MORE DRUG CANDIDATES INTO CLINICAL TESTING. TO ACHIEVE
THIS END, THE PRECLINICAL CONSORTIUM PROVIDES THE INFRASTRUCTURE TO
FOSTER COLLABORATION BETWEEN ACADEMIA AND PHARMACEUTICAL INDUSTRY
RESEARCHERS AND FOR ACCESS TO RESOURCES DESIGNED TO HELP FACILITATE
DRUG DEVELOPMENT IN TSC. COLLABORATING WITH THE TSC COMMUNITY, THE
CONSORTIUM HAS IDENTIFIED AND IMPLEMENTED ROBUST AND REPRODUCIBLE CELL
AND ANIMAL MODELS FOR TSC MANIFESTATIONS INCLUDING TUMORS, EPILEPSY,
AND TSC-ASSOCIATED NEUROPSYCHIATRIC DISORDERS (TAND). THE TSC ALLIANCE
HAS LICENSES TO USE SPECIFIC TSC MOUSE MODELS FOR EXPERIMENTS CARRIED
OUT BY THE PRECLINICAL CONSORTIUM, AND ALL MOUSE LICENSE AGREEMENTS
INCLUDE THE RIGHTS FOR THE TSC ALLIANCE TO PERFORM EXPERIMENTS UNDER
CONTRACT FOR COMMERCIAL ENTITIES. THIS ENSURES DATA GENERATED BY THE
PRECLINICAL CONSORTIUM CAN BE USED TO ACCELERATE THE DEVELOPMENT OF NEW

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

TREATMENTS BY COMMERCIAL ENTITIES AS WELL AS ACADEMIC INVESTIGATORS.

EXPERIMENTS ARE EXECUTED AT PARTNERING RESEARCH INSTITUTIONS TO ENSURE

CONSISTENCY IN TESTING, DATA ACQUISITION AND INTERPRETATION. EPILEPSY

STUDIES ARE CONDUCTED AT PSYCHOGENICS (US), AND THE TUMOR GRAFT MODEL

AND CELL-BASED ASSAYS ARE CONDUCTED AT PORSOLT (FRANCE). THE VAN ANDEL

RESEARCH INSTITUTE, A NON-PROFIT RESEARCH ORGANIZATION, MAINTAINS A

COLONY OF TSC2+/- AJ MICE AND L7-CRE-TSC2 MICE ON BEHALF OF THE

PRECLINICAL CONSORTIUM.

TWICE A YEAR, THE PRECLINICAL CONSORTIUM HAS A CALL FOR COMPOUND NOMINATIONS TO CONTINUE TO REFRESH OUR PIPELINE BASED ON THE LATEST DATA AND NOVEL IDEAS. THE NOMINATIONS ARE PEER-REVIEWED BY CONSORTIUM MEMBERS AND PRIORITIZED BY THE PRECLINICAL CONSORTIUM STEERING COMMITTEE FOR FUNDING BY THE TSC ALLIANCE. IF THE TSC ALLIANCE FUNDS THE STUDY, THE DATA ARE SHARED WITH THE CONSORTIUM FOR TRANSPARENCY AND STIMULATION OF ADDITIONAL HYPOTHESES. AN ANNUAL FACE-TO-FACE MEMBERS MEETING IS TYPICALLY HELD EACH YEAR IN APRIL TO KEEP MEMBERS ENGAGED AND ALIGNED ON THE CONSORTIUM'S STRATEGY AND PRIORITIES. PARTNERSHIP WITH PHARMACEUTICAL COMPANIES IS AN IMPORTANT ASPECT OF THE CONSORTIUM, AS THESE ORGANIZATIONS HAVE THE INFRASTRUCTURE TO EFFICIENTLY MOVE PRECLINICAL RESEARCH FINDINGS TO CLINICAL TESTING AND EVENTUALLY COMMERCIAL DISTRIBUTION. AS OF DECEMBER 2020, 7 COMPANIES WERE ACTIVE MEMBERS OF THE CONSORTIUM. THE CONSORTIUM HAS HAD 14 COMPANY MEMBERS SINCE 2016. THERE IS NATURAL TURNOVER OF INDUSTRY MEMBERSHIP, PRINCIPALLY DRIVEN BY RESEARCH DATA GENERATED BY TESTING THEIR DRUGS. DUE TO INTELLECTUAL PROPERTY CONSIDERATIONS, MOST COMPANIES FULLY FUND THEIR STUDIES THROUGH THE TSC ALLIANCE, WHICH ALLOWS THE COMPANY TO KEEP ITS DATA CONFIDENTIAL. THESE CONFIDENTIAL STUDIES ALSO INCUR A 10%

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

OVERHEAD PAID BY THE COMPANY, WHICH IS A SOURCE OF REVENUE FOR THE TSC

ALLIANCE. SINCE INCEPTION, THE CONSORTIUM HAS HELPED ADVANCE THE

EVALUATION OF DRUGS FOR TSC BY CONDUCTING 54 STUDIES, EVALUATING 44

CANDIDATE DRUGS. IN 2020, THE TSC PRECLINICAL CONSORTIUM EVALUATED 13

CANDIDATE DRUGS IN MOUSE MODELS AND SCREENED AN ADDITIONAL 10 COMPOUNDS

IN CELL-BASED MODELS OF TSC.

FORM 990, PART III, LINE 4A (CONT'D): IN 2012, THE TSC ALLIANCE HELPED CREATE THE TSC CLINICAL RESEARCH CONSORTIUM IN PARTNERSHIP WITH INVESTIGATORS RUNNING CLINICAL STUDIES TO ENSURE CLINICAL RESEARCH IN TSC IS AS EFFICIENT AND EFFECTIVE AS POSSIBLE. SINCE THEN, TSC CLINICAL RESEARCH CONSORTIUM INVESTIGATORS HAVE BEEN AWARDED MORE THAN \$35 MILLION BY THE NATIONAL INSTITUTES OF HEALTH (NIH) THROUGH COMPETITIVE GRANT PROCESSES. TSC ALLIANCE PERSONNEL SERVE ON THE LEADERSHIP TEAM FOR THE CONSORTIUM, ACTIVELY TRACK ENROLLMENT, AND RAISE COMMUNITY AWARENESS TO HELP IDENTIFY POTENTIAL PARTICIPANTS FOR CLINICAL STUDIES. TSC ALLIANCE ALSO PROVIDES SUPPLEMENTAL FINANCIAL SUPPORT TO ACCELERATE OR EXPAND NIH-FUNDED STUDIES. THE PREVENT TRIAL - PREVENTING EPILEPSY USING VIGABATRIN IN INFANTS WITH TSC - IS THE FIRST PREVENTATIVE TRIAL IN THE UNITED STATES FOR ANY FORM OF EPILEPSY AND HAS COMPLETED ENROLLMENT OF 86 PARTICIPANTS. WE EXPECT THE FIRST RESULTS IN DECEMBER 2021 AND FINAL RESULTS IN LATE 2022 OR EARLY 2023. THIS TRIAL BUILDS DIRECTLY UPON THE CLINICAL RESEARCH CONSORTIUM'S FIRST CLINICAL STUDY, WHICH IDENTIFIED SPECIFIC EEG CHANGES IN INFANTS WITH TSC PRIOR TO THE ONSET OF SEIZURES. IN THE PREVENT TRIAL, INFANTS WITH TSC RECEIVE REGULAR EEG MONITORING, AND THOSE WHO DEVELOP EEG ABNORMALITIES ARE PLACED ON EITHER VIGABATRIN OR PLACEBO. ANY INFANT WHO SUBSEQUENTLY DEVELOPS

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

CLINICAL SEIZURES IS IMMEDIATELY PLACED ON STANDARD TREATMENT. THIS

TRIAL WILL DETERMINE WHETHER TREATMENT WITH VIGABATRIN PRIOR TO THE

ONSET OF CLINICAL SEIZURES IN TSC IS BENEFICIAL TO CHILDREN'S

DEVELOPMENTAL AND NEUROLOGIC OUTCOMES. MORE DETAILS ABOUT THIS STUDY

ARE ONLINE AT WWW.CLINICALTRIALS.GOV/CT2/SHOW/NCT02849457.

IMMEDIATELY AFTER THE PREVENT TRIAL ENROLLMENT COMPLETED, A SIMILAR CLINICAL TRIAL BEGAN ENROLLING NEWBORNS WITH TSC UTILIZING A SIMILAR PROTOCOL BUT TESTING THE EFFECTS OF SIROLIMUS INSTEAD OF VIGABATRIN. THE STOPPING TSC ONSET AND PROGRESSION 2 (STOP-2) TRIAL OPENED AT CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER, AND THE TSC ALLIANCE IS CONTRIBUTING \$200,000 TO ENABLE THE TRIAL TO BE EXPANDED TO ADDITIONAL SITES ACROSS THE COUNTRY IN 2021. TSC ALLIANCE IS ALSO PROVIDING SUPPLEMENTAL FUNDING AND COLLECTING BLOOD SAMPLES FOR THE DEVELOPMENTAL SYNAPTOPATHIES CONSORTIUM (DSC), AN NIH-FUNDED PROJECT THAT INCLUDES STUDIES OF TSC AND THE RELATED RARE DISORDERS PHELAN-MCDERMID SYNDROME AND PTEN HAMARTOMA SYNDROME. THESE THREE RARE DISEASES SEEM TO AFFECT CERTAIN SHARED PATHWAYS INFLUENCING THE DEVELOPMENT OF BRAIN CONNECTIONS, OR SYNAPSES. RESEARCHERS IN THIS STUDY ARE TRYING TO FIND EARLIER SIGNS OF AUTISM SPECTRUM DISORDER (ASD) AND INTELLECTUAL DISABILITY (ID) TO GAIN A BETTER UNDERSTANDING OF ASD/ID IN INDIVIDUALS WITH TSC AND ENABLE EFFECTIVE TREATMENTS AND INTERVENTIONS FOR ASD/ID TO BE FOUND. THE DSC WAS RENEWED LAST YEAR FOR A SECOND 5-YEAR FUNDING PERIOD. TSC ALLIANCE FUNDS A PORTION OF CLINICAL RESEARCH COORDINATORS' SALARIES AT 5 SITES AND WILL BEGIN FUNDING A 2-YEAR CLINICAL FELLOWSHIP IN TSC BEGINNING 2021.

Name of the organization **Employer identification number** NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 ALLIANCE STIMULATES COLLABORATION AND INNOVATION THROUGH CONVENING EXPERTS AND STAKEHOLDERS WITHIN AND OUTSIDE THE TSC FIELD. THE FIRST INNOVATION WORKSHOP WAS HELD IN 2020 AND FOCUSED ON NEWBORN SCREENING. THIS WORKSHOP'S GOALS INCLUDED: DEFINE THE CRITICAL PATH - OR RATE-LIMITING STEPS - OF DEVELOPING A SCREENING ASSAY TO ENABLE NOMINATION OF TSC TO THE RECOMMENDED UNIFORM SCREENING PANEL; SPECIFY THE IMMEDIATE NEXT STEPS NEEDED ALONG THE CRITICAL PATH; RECOMMEND COMPONENTS OF A FUNDING OPPORTUNITY ANNOUNCEMENT TO ELICIT THE BEST IDEAS AND APPLICANTS TO IMPLEMENT THOSE NEXT STEPS; AND ENABLE TSC ALLIANCE TO FUND THE MOST MERITORIOUS APPLICATIONS WITHIN 100 DAYS AFTER THE WORKSHOP. ORIGINALLY, THE TSC ALLIANCE HAD PLANNED TO HOST AN IN-PERSON WORKSHOP TO BE HELD IN EARLY JUNE. HOWEVER, DUE TO THE NOVEL CORONAVIRUS PANDEMIC, THE INNOVATION WORKSHOP WAS RE-IMAGINED AS A SERIES OF VIRTUAL MEETINGS PUNCTUATED BY ONLINE DISCUSSION USING THE PLATFORM POWERNOODLE. THE FINAL CUMULATIVE DISCUSSION WILL TAKE PLACE IN EARLY JANUARY 2021 AND WILL BE FOLLOWED BY AN FOA IN THE FIRST QUARTER OF 2021.

FORM 990, PART III, LINE 4B, PROGRAM SERVICE ACCOMPLISHMENTS:

ACTIVE FUTURE LEADERS (6 VOLUNTEERS) AND PAST FUTURE LEADERS (8

VOLUNTEERS) WHO HAVE AGREED TO REMAIN AS LEADERS FOR OTHER YOUNG ADULTS

WITH TSC.

EDUCATION PARENT MENTORS ATTENDED 115 SCHOOL MEETINGS (IEPS, EVALUATION

TEAM MEETINGS, 504 PLAN MEETINGS, RESOLUTION MEETINGS, AND MEDIATIONS)

IN PERSON, THROUGH SKYPE/ FACETIME, AND VIA CONFERENCE CALLS TO SUPPORT

FAMILIES IN ATTAINING EDUCATIONAL SERVICES FOR THEIR CHILDREN

Name of the organization

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

THROUGHOUT THE COUNTRY. SEVERAL SCHOOL SYSTEMS ALSO REQUESTED "TSC 101"

IN AN EFFORT TO HELP THEM UNDERSTAND THE COMPLEXITIES OF TSC AND

LEARNING ISSUES FOR CHILDREN WITH TSC.

THE COMMUNITY PROGRAMS TEAM SUPPORTS A NETWORK OF 33 VOLUNTEER BRANCHES

OF THE ORGANIZATION, CALLED COMMUNITY ALLIANCES, DIVIDED INTO 2

REGIONS, WITH A COMMUNITY PROGRAM MANAGER ASSIGNED TO EACH REGION TO

MANAGE THE DAY-TO-DAY ACTIVITIES WITHIN THEIR REGIONS. AS OF DECEMBER

31, 2020, THERE WERE 98 LEADERSHIP POSITIONS (50 COMMUNITY ALLIANCE

CHAIRS, CO-CHAIRS, VICE CHAIRS AND 48 WALK/FUNDRAISING CHAIRS AND

CO-CHAIRS) WITH 3 OPEN POSITIONS. IN 2020, THESE COMMUNITY ALLIANCES

PROVIDED LOCAL TSC EDUCATION AND PERSONAL SUPPORT THROUGHOUT THE

COUNTRY TO 4,988 FAMILIES/INDIVIDUALS LIVING WITH TSC.

TO HELP THE TSC COMMUNITY NAVIGATE THE CHALLENGES OF COVID-19, THE TSC

ALLIANCE CREATED A SECTION OF OUR WEBSITE DEDICATED TO SHARING

IMPORTANT INFORMATION ABOUT THE PANDEMIC SPECIFICALLY CURATED TO MEET

THE NEEDS OF THOSE IMPACTED BY TSC. THE TSC ALLIANCE COVID-19 LANDING

PAGE, WWW.TSALLIANCE.ORG/COVID-19, INCLUDES RESOURCES FOR TSC MEDICAL

PROFESSIONALS (WITH THE HELP OF OUR PROFESSIONAL ADVISORY BOARD);

VACCINE POSITION STATEMENT; LISTING OF TSC CLINICS OFFERING TELEHEALTH;

FDA DRUG SHORTAGES; SUPPLY CHAIN UPDATES; CO-PAY SAVINGS PROGRAMS

DURING COVID-19; COVID-19 FAQS; COMMUNITY EDUCATIONAL RESOURCES; AND

WEBINAR SERIES. THERE WERE 23,447 VIEWS ON THE COVID-19 LANDING PAGE

IN 2020.

THE TSC ALLIANCE ALSO LAUNCHED A WEEKLY EDUCATIONAL SERIES ON MARCH 23
WITH PROGRAMMING LASTING 11 WEEKS. THIS EFFORT INCLUDED FIVE VIRTUAL

**Employer identification number** Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 TOWN HALLS IN PARTNERSHIP WITH OTHER NONPROFIT ORGANIZATIONS AS WELL AS HOSTING TWO WORLD FORUM WEBINARS FOR TSCI ON MAY 12 AND 26. MARCH 20: TSC/LAM VIRTUAL TOWN HALL: COVID-19 UPDATE, CO-HOSTED WITH THE LAM FOUNDATION - APRIL 10: VIRTUAL TOWN HALL: ACCESSIBILITY TO CARE, CO-HOSTED WITH THE CHILD NEUROLOGY FOUNDATION AND DUP150 ALLIANCE MAY 1: VIRTUAL TOWN HALL: ACCESSIBILITY TO TREATMENTS (INCLUDING DRUG SUPPLY), CO-HOSTED WITH THE DRAVET SYNDROME FOUNDATION AND LGS FOUNDATION - MAY 15: VIRTUAL TOWN HALL: RESCUE MEDS, SEIZURE TRACKER AND A FUTURE GLIMPSE AT FORECASTING SEIZURE RISK, CO-HOSTED WITH SEIZURE TRACKER MAY 22: TSC/LAM VIRTUAL TOWN HALL: MOVING ON FROM SHELTER IN PLACE, CO-HOSTED WITH THE LAM FOUNDATION THE TSC ALLIANCE ALSO PRESENTED 15 WEBINARS ON TOPICS OF RELEVANCE TO TSC INDIVIDUALS AND FAMILIES, INCLUDING SCHOOLING AT HOME, ANXIETY, SELF-CARE, FILING FOR UNEMPLOYMENT, RESEARCH UPDATES, COMMUNITY PROGRAMS UPDATE, REMOTE BEHAVIORAL INTERVENTIONS AND OTHERS. FORUMS WERE HELD, PROVIDING A PLATFORM FOR CAREGIVERS, TEENS, SIBLINGS AND ADULTS WITH TSC TO OPENLY DISCUSS ISSUES RELATED TO COVID-19 AND TSC. IN TOTAL, THERE WERE 9,151 VIEWS OF THE WEBINAR AND TOWN HALL SERIES. THE TSC ALLIANCE CO-HOSTED 3 VIRTUAL REGIONAL CONFERENCES WITH THE LAM FOUNDATION FEATURING REGIONAL PROFESSIONALS IN MEMPHIS, GAINSVILLE AND DENVER. THESE EVENTS ATTRACTED A TOTAL OF 818 REGISTERED ATTENDEES, INCLUDING 636 ATTENDEES ON THE DAY OF THE CONFERENCE, 1,106 SUBSEQUENT

VIDEO VIEWS, AND 424 VISITS TO THE VIRTUAL EXHIBIT HALLS. THERE WERE 21

Name of the organization  NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
SPEAKERS FROM 12 DIFFERENT INSTITUTES, REPRESENTING TSC CI	INICS, TSC
CENTERS OF EXCELLENCE OR LAM CLINICS.	
FORM 990, PART III, LINE 4C, PROGRAM SERVICE ACCOMPLISHMENTS:  ACCOUNTS BOTH HAVE 2,400-PLUS FOLLOWERS.  THE TSC ALLIANCE'S PODCAST SERIES, CALLED TSC NOW, PRODUCED 11 EPISODES WITH 1,906 DOWNLOADS. SIX ISSUES OF THE ELECTRONIC, TSC MATTERS, WERE DISTRIBUTED TO 1,006 SUBSCRIBERS.	
ACCOUNTS BOTH HAVE 2,400-PLUS FOLLOWERS.	
THE TSC ALLIANCE'S PODCAST SERIES, CALLED TSC NOW, PRODUCE	ED 11 EPISODES
THE TSC ALLIANCE'S ONLINE EDUCATIONAL PLATFORM, TSC ACADEM	Y, INTRODUCED
3 NEW COURSES COVERING THE TOPICS OF CBD, FDA REVIEW PROCE	SS AND STATE
AND LOCAL ADVOCACY.	
TO INCREASE PUBLIC AWARENESS, THE TSC ALLIANCE PARTICIPATE	D IN THE
SIXTH ANNUAL TSC GLOBAL AWARENESS DAY ON MAY 15 AS WELL AS	TSC
AWARENESS MONTH THROUGHOUT MAY. THE TSC ALLIANCE AGAIN HEA	AVILY PROMOTED
INFANTILE SPASMS AWARENESS WEEK, DECEMBER 1 TO 7. THIS AWA	ARENESS
CAMPAIGN INCLUDED A SOCIAL MEDIA CAMPAIGN AND TARGETED NAT	CIONAL PRINT
PUBLICATIONS, MEDICAL TRADE MAGAZINES AND PODCASTS, RESULT	ING IN 10
MEDIA PLACEMENTS, 31.7 MILLION-PLUS IMPRESSIONS AND 550-PL	US SOCIAL
ENGAGEMENTS. IN 2020, THE TSC ALLIANCE'S VARIOUS NEWS RELE	EASES
CULMINATED IN 694 MILLION IMPRESSIONS.	
FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:	
GOVERNMENT RELATIONS EFFORTS FOCUS ON INCREASING FEDERAL A	AND STATE
APPROPRIATIONS FOR TSC RESEARCH, RAISING AWARENESS, AND CO	DLLABORATING
WITH GOVERNMENT PARTNERS TO DRIVE TSC RESEARCH FORWARD AND	) IMPROVE

Name of the organization

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number 95-3018799

CLINICAL CARE AND TREATMENT OPTIONS FOR INDIVIDUALS WITH TSC.

ON THE STATE LEVEL, THE TSC ALLIANCE ADVOCATED FOR STATE FUNDING FOR TSC CENTERS IN MISSOURI AND MARYLAND, RESULTING IN AT LEAST \$500,000 IN STATE APPROPRIATIONS. THE ANNUAL TSC ALLIANCE MARCH ON CAPITOL HILL TO ADVOCATE FOR FEDERAL FUNDING FOR THE TUBEROUS SCLEROSIS COMPLEX RESEARCH PROGRAM (TSCRP) AT THE DEPARTMENT OF DEFENSE'S (DOD) CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP) TOOK PLACE IN EARLY MARCH 2020. MORE THAN 120 MEMBERS OF THE TSC COMMUNITY PARTICIPATED AND ASKED THEIR SENATORS AND REPRESENTATIVES TO SIGN ONTO DEAR COLLEAGUE LETTERS IN SUPPORT OF THE TSCRP. MANY OTHER ADVOCATES WHO WERE NOT ABLE TO TRAVEL TO WASHINGTON, DC MET WITH THEIR SENATORS AND REPRESENTATIVES IN THEIR HOME STATES TO MAKE THE CASE FOR CONTINUED FUNDING. THE FY21 HOUSE DEAR COLLEAGUE LETTER WAS CO-SPONSORED BY REPRESENTATIVES MARKWAYNE MULLIN (R-OK) AND DAVE LOEBSACK (D-IA) AND CLOSED WITH 216 SIGNERS. THE FY21 SENATE DEAR COLLEAGUE LETTER, SPONSORED BY SENATORS KEVIN CRAMER (R-ND) AND JON TESTER (D-MT), CLOSED WITH 35 SIGNATURES. SENATORS CRAMER AND TESTER WERE BOTH NEW SPONSORS FOR FY21.

IN FY2021, THE TSC RESEARCH PROGRAM AT THE CDMRP RECEIVED AN \$8 MILLION

APPROPRIATION, BRINGING THE CUMULATIVE FUNDING TO \$97 MILLION SINCE

2002 AS A RESULT OF OUR SUCCESSFUL GRASSROOTS EFFORTS.

RESEARCH PERFORMED THROUGH THIS PROGRAM HAS RECENTLY LED TO ADDITIONAL

CLINICAL TRIALS INCLUDING DETERMINING IF IMATINIB, A DRUG FDA-APPROVED

FOR CANCER, CAN SAFELY IMPROVE LEVELS OF VEGF-D, A BIOMARKER OF

LYMPHANGIOLEIOMYOMATOSIS (LAM), A LIFE-THREATENING LUNG MANIFESTATION

Name of the organization

**Employer identification number** 

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 OF TSC, FUNDED IN FY2013; TESTING A COMBINATION OF TWO DRUGS TO TREAT LAM FUNDED IN FY2012; A MULTI-SITE CLINICAL TRIAL TESTING THE EFFICACY OF AN EXPERIMENTAL TOPICAL RAPAMYCIN CREAM TO TREAT THE DISFIGURING FACIAL TUMORS, CALLED FACIAL ANGIOFIBROMAS, CAUSED BY TSC FUNDED IN FY2010; A CLINICAL RESEARCH NETWORK WAS CREATED TO TEST POTENTIAL NEW THERAPIES, TO VALIDATE BIOMARKERS, AND TO LEARN THE NATURAL HISTORY OF LEADING TO A CLINICAL TRIAL FUNDED IN FY2012. DATA OBTAINED FROM AN FY2010 TSCRP CLINICAL RESEARCH AWARD TO DEFINE EARLY AUTISM PREDICTORS IN TSC AND AN FY2014 TSCRP AWARD FOR A PILOT CLINICAL TRIAL IS BEING TESTED IN A LARGE, NIH-FUNDED CLINICAL TRIAL LOOKING AT THE EFFECTIVENESS OF A BEHAVIORAL INTERVENTION STRATEGY, JASPER, TO IMPROVE OUTCOMES IN CHILDREN WITH AUTISM. THE TSCRP HAS ALSO FUNDED RESEARCH TO DEVELOP ANIMAL MODELS OF TSC THAT HAVE SEIZURES, ENABLING A BETTER UNDERSTANDING OF THE ETIOLOGY OF TSC. BASED ON DATA FROM TSCRP-FUNDED ANIMAL MODELS OF TSC THAT HAVE SEIZURES AND SHARE PATHOLOGY RELATED TO THAT OF TRAUMATIC BRAIN INJURY, AN INDUSTRY-SPONSORED CLINICAL TRIAL DEMONSTRATED THE EFFECTIVENESS THE MTOR INHIBITOR, EVEROLIMUS, AT TREATING EPILEPSY IN MANY INDIVIDUALS WITH TSC. NONE OF THIS PROGRESS WOULD HAVE BEEN POSSIBLE WITHOUT THE CRITICAL SUPPORT PROVIDED THROUGH THE TSCRP. EXPENSES \$ 149,611. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0. GLOBAL OUTREACH WORKS TO ADDRESS UNMET NEEDS WITHIN THE GLOBAL TSC COMMUNITY. THE PROGRAM PROVIDES THE OPPORTUNITY FOR THE TSC ALLIANCE TO SHARE EXPERIENCES AND ASSIST IN THE START-UP OF SUPPORT OF TSC-RELATED ORGANIZATIONS IN OTHER COUNTRIES. A GLOBAL ALLIANCE IS A STRUCTURED

GROUP OF EMPOWERED AND CARING VOLUNTEERS WHO WORK CLOSELY WITH THE TSC

ALLIANCE TO FACILITATE LOCAL CONNECTIONS FOR INDIVIDUALS AND FAMILIES

Name of the organization **Employer identification number** NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 AFFECTED BY TSC AND RAISE REVENUE AND AWARENESS WHILE SUPPORTING THE MISSION OF THE ORGANIZATION. THE TSC ALLIANCE HAS SIX GLOBAL PARTNERSHIPS, INCLUDING: TS ALLIANCE OF ISRAEL, TS CANADA ST, TS ALLIANCE OF MEXICO, TS ALLIANCE FOUNDATION (IN THAILAND), HUNGARIAN FOUNDATION FOR TUBEROUS SCLEROSIS, AND TS ALLIANCE OF INDIA. THIS TS ALLIANCE RECOGNIZES 10 TSC CLINICS IN GLOBAL ALLIANCE COUNTRIES. EXPENSES \$66,927. INCLUDING GRANTS OF \$0. REVENUE \$0. 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 TSC ALLIANCE PARTICIPATED IN AND PRESENTED AT 22 PROFESSIONAL MEETINGS IN 2020 INCLUDING: AMERICAN THORACIC SOCIETY (ATS) BOARD MEETING; NATIONAL INSTITUTE FOR NEUROLOGICAL DISORDERS AND STROKE (NINDS) COUNCIL MEETING; EPILEPSY LEARNING HEALTHCARE SYSTEM (ELHS) HIGH-LEVEL VIRTUAL LEARNING SESSION; DRUG INFORMATION ASSOCIATION (DIA) CONFERENCE ON PATIENT ENGAGEMENT; NINDS NONPROFIT FORUM; ATS PUBLIC ADVISORY ROUNDTABLE (ATS PAR) MEET THE EXPERTS, PATIENT/FAMILY EDUCATION FORUM; EPILEPSY LEADERSHIP COUNCIL (ELC) STEERING COMMITTEE MEETING; VIRTUAL WORLD ORPHAN DRUG CONGRESS; VIRTUAL EPILEPSY PIPELINE CONFERENCE; EVERYLIFE FOUNDATION FOR RARE DISEASES NEWBORN SCREENING BOOTCAMP; HEALTH RESEARCH ALLIANCE (HRA) MEMBERS MEETING; ATS LEADERSHIP SUMMIT; GLOBAL GENES RARE PATIENT ADVOCACY UN-SUMMIT; FASTERCURES PARTNERSHIP MATURITY MODEL WORKSHOP; ELHS FALL LEARNING SESSION; GLOBAL GENES: HOW PATIENTS IMPACT THE 505(B)(2) REGULATORY PROCESS; NATIONAL ASSOCIATION OF MANAGED CARE PHYSICIANS; INTERNATIONAL

Name of the organization  NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
TSC RESEARCH CONFERENCE; EPILEPSY DAY AT DISNEYLAND; GLOBA	L GENES RARE
ENTREPRENEUR'S BOOTCAMP; AMERICAN EPILEPSY SOCIETY; AND MI	LKEN
INSTITUTE FUTURE OF HEALTH SUMMIT.	
EXPENSES \$ 24,324. INCLUDING GRANTS OF \$ 0. REVENUE \$	0.
FORM 990, PART VI, SECTION A, LINE 6:	
MEMBERSHIP IS AVAILABLE TO ANY PERSON WHO SUBSCRIBES TO TH	E PURPOSES AND
OBJECTIVES OF THE CORPORATION, WITHOUT REGARD TO RACE, REL	IGION, GENDER,
SEXUAL ORIENTATION, AGE, COLOR, NATIONAL ORIGIN OR MENTAL	OR PHYSICAL
HANDICAP OR DISABILITY. THERE SHALL BE NO LIMIT TO THE NUM	BER OF MEMBERS IN
THE CORPORATION.	
1) THERE MAY BE ONE OR MORE CLASSES OF MEMBERSHIP AS DETER	MINED BY THE
BOARD.	
2) MEMBERSHIP IS NOT TRANSFERABLE OR ASSIGNABLE.	
FORM 990, PART VI, SECTION A, LINE 7A:	
THE TSC ALLIANCE IS A MEMBERSHIP-BASED ORGANIZATION, WHICH	MEANS MEMBERS
HELP ELECT THE BOARD OF DIRECTORS. THE TSC ALLIANCE MEMBER	SHIP PROGRAM
ALLOWED INDIVIDUALS TO STATE THEIR INTENT TO BE A MEMBER F	OR THE PURPOSE OF
GOVERNANCE. THERE WERE NO LEVELS TO MEMBERSHIP IN 2020. AN	YONE CAN BE A
MEMBER AT NO COST.	
FORM 990, PART VI, SECTION B, LINE 11B:	
THE FORM 990 IS REVIEWED, IN DETAIL, BY THE BOARD OF DIREC	TORS' AUDIT
COMMITTEE. RECOMMENDATIONS ARE MADE BY THE COMMITTEE MEMBE	RS FOR ANY
CHANGES/EDITS/ADDITIONS. AFTER THOSE HAVE BEEN INCORPORATE	D, THE AUDIT

Name of the organization

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Employer identification number 95-3018799

COMMITTEE VOTES WHETHER TO APPROVE AND THEN FORWARD THE 990 TO THE FINANCE

AND EXECUTIVE COMMITTEES. THE FINANCE AND EXECUTIVE COMMITTEES PERFORM THE

FINAL REVIEW AND THEN VOTE WHETHER TO APPROVE ON BEHALF OF THE BOARD OF

DIRECTORS. A COPY OF THE APPROVED 990 IS SHARED WITH THE ENTIRE BOARD PRIOR

TO ITS FILING WITH THE IRS.

FORM 990, PART VI, SECTION B, LINE 12C:

ANNUALLY EACH MEMBER OF THE BOARD OF DIRECTORS WILL RECEIVE NOTICE OF THE
ORGANIZATION'S CONFLICT OF INTEREST STATEMENT. EACH MEMBER WILL BE PROVIDED
WITH A STATEMENT TO MAKE DISCLOSURE OF ANY POTENTIAL CONFLICT OF INTEREST.

IF DURING THE COURSE OF THE YEAR A POTENTIAL CONFLICT OF INTEREST ARISES
THAT HAS NOT PREVIOUSLY BEEN DISCLOSED, THE BOARD MEMBER WILL MAKE WRITTEN
NOTICE OF A POTENTIAL CONFLICT OF INTEREST AND RECUSE HIMSELF OR HERSELF
FROM ANY DISCUSSIONS AND VOTES IN CONNECTION WITH THE ISSUE IDENTIFIED. ANY
TIME A MEMBER IS RECUSED FROM DISCUSSION ON AN ISSUE, THE MINUTES OF
COMMITTEE MEETING AND BOARD MEETING WILL DULY RECORD SUCH ACTIONS.

THE FOLLOWING POTENTIAL CONFLICTS OF INTEREST WERE DISCLOSED FOR 2020:

BOARD MEMBER MUSTAFA SAHIN, PH.D., M.D., IS EMPLOYED AT BOSTON CHILDREN'S
HOSPITAL, WHICH RECEIVED \$132,409 IN GRANTS AND \$13,935 IN FEES FOR
SERVCIES FOR PARTICIPATION IN THE TSC NATURAL HISTORY DATABASE.

BOARD MEMBER DARCY KRUEGER, MD, MPA, IS EMPLOYED AT THE CINCINNATI

CHILDREN'S HOSPITAL MEDICAL CENTER, WHICH RECEIVED A \$50,000 GRANT PAYMENT

FOR HIS WORK ON STOP-2 AND \$26,335 IN FEES FOR SERVICES FOR PARTICIPATION

IN THE TSC NATURAL HISTORY DATABASE.

Name of the organization **Employer identification number** NATIONAL TUBEROUS SCLEROSIS ASSOCIATION 95-3018799 FORM 990, PART VI, SECTION B, LINE 15: THE COMPENSATION COMMITTEE REVIEWS AND APPROVES THE SALARIES OF THE PRESIDENT/CEO, CHIEF SCIENTIFIC OFFICER, CONTROLLER & CFO, AND ANY EMPLOYEE APPEARING ON THE FORM 990, IN ACCORDANCE WITH THE TSC ALLIANCE BYLAWS. SUCH REVIEW AND APPROVAL OCCURS INITIALLY UPON HIRING, UPON ANNUAL REVIEWS AND WHENEVER MODIFIED. THE ORGANIZATION'S EXECUTIVE REMUNERATION HAS BEEN STRUCTURED TO ENSURE THAT IT: IS REASONABLE; PROVIDES A COMPETITIVE COMPENSATION PROGRAM TO RETAIN, ATTRACT AND REWARD KEY EMPLOYEES AND ACHIEVES CLEAR ALIGNMENT BETWEEN TOTAL REMUNERATION AND DELIVERED BUSINESS AND PERSONAL PERFORMANCE OVER THE SHORT AND LONG-TERMS. THE COMPENSATION IS REVIEWED BY THE COMPENSATION COMMITTEE TO ENSURE: COMPARABILITY, PROPER REVIEW, AND SUBSTANTIATION IN SETTING THE COMPENSATION. FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990: AL,AR,CA,FL,GA,HI,IL,IN,KS,KY,MD,MA,MI,MN,MS,NH,NJ,NM,NY,NC,OR,PA,RI,SC,TN UT, VA, WI, WV FORM 990, PART VI, SECTION C, LINE 19: ALL GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY AND FINANCIAL STATEMENTS ARE AVAILABLE UPON WRITTEN REQUEST.

#### **SCHEDULE R** (Form 990)

Related Organizations and Unrelated Partnerships

• Complete if the organization answered "Yes" on Form 990, Part IV, line 33, 34, 35b, 36, or 37.

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Attach to Form 990.

Department of the Treasury Internal Revenue Service Name of the organization

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

OMB No. 1545-0047

Open to Public Inspection

Employer identification number

95-3018799

(a)	(b)	(c)	(d)	(e)			(f)	
Name, address, and EIN (if applicable) of disregarded entity			I	<b>I</b>				
Part II Identification of Related Tax-Exempt Organizations during the tax year.	zations. Complete if the organiza	tion answered "Yes" on Form 990	0, Part IV, line 34, I	pecause it had one	or more	related tax-exe	mpt	
(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		(f) ct controlling entity	conf	<b>g)</b> 512(b)(13) trolled tity?
		loreign country)		501(c)(3))		<b>,</b>	Yes	No
TSC ALLIANCE ENDOWMENT FUND, INC 52-1926919, 8737 COLESVILLE ROAD, SUITE 400,							100	110
SILVER SPRING, MD 20910	SUPPORT ORG	MARYLAND	501(C)(3)	LINE 12B, II	N/A			Х
								<u> </u>

		0 11 20 1	", " = 000	D 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	
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	t had one or more related
Partill	organizations treated as a partnership during the tax year.				
	organizations treated as a partnership daring the tax year.				

(a)	(b)	(c)	(d)	(e)	(f)	(g)	(1	h)	(i)	(j)	(k)
Name, address, and EIN of related organization	Primary activity	Legal domicile (state or foreign	Direct controlling	Predominant income (related, unrelated, excluded from tax under sections 512-514)	Share of total	Share of end-of-year assets	Dienroportionata		Code V-UBI	General c	Percentage
		country)		sections 512-514)			Yes	No	K-1 (Form 1065)	Yes No	<u> </u>
	1										
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	1										
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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>(b)</b> Primary activity	(c) Legal domicile (state or foreign country)	(d) Direct controlling entity	(e) Type of entity (C corp, S corp, or trust)	<b>(f)</b> Share of total income	(g) Share of end-of-year assets	(h) Percentage ownership		tion b)(13) rolled tity?
		country						Yes	No

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Yes No

1a

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

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

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

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

b	Gift, grant, or capital contribution to related organization(s)				1b		X	
С	Gift, grant, or capital contribution from related organization(s)				1c	Х		
					1d		X	
е	Loans or loan guarantees by related organization(s)				1e		X	
f	Dividends from related organization(s)				1f		X	
g	Sale of assets to related organization(s)				1g		X	
h	Purchase of assets from related organization(s)				1h		X	
i	Exchange of assets with related organization(s)				1i		X	
j	Lease of facilities, equipment, or other assets to related organization(s)				1j		X	
							X	
k	k Lease of facilities, equipment, or other assets from related organization(s)  I Performance of services or membership or fundraising solicitations for related organization(s)  m Performance of services or membership or fundraising solicitations by related organization(s)  n Sharing of facilities, equipment, mailing lists, or other assets with related organization(s)  o Sharing of paid employees with related organization(s)  p Reimbursement paid to related organization(s) for expenses  q Reimbursement paid by related organization(s) for expenses							
- 1	Performance of services or membership or fundraising solicitations for related organi	ization(s)			11		X	
m	Performance of services or membership or fundraising solicitations by related organic	zation(s)			1m		X	
n	Sharing of facilities, equipment, mailing lists, or other assets with related organization	n(s)			1n	X		
0	Sharing of paid employees with related organization(s)				10	Х		
р	Reimbursement paid to related organization(s) for expenses				1p		X	
q	Reimbursement paid by related organization(s) for expenses				1q		X	
	Other transfer of cash or property to related organization(s)				1r		X	
s	Other transfer of cash or property from related organization(s)				1s		X	
2	If the answer to any of the above is "Yes," see the instructions for information on who	o must complete th	is line, including covered relat	ionships and transaction thresholds.				
	(a) Name of related organization	(b) Transaction type (a-s)	(c) Amount involved	(d) Method of determining amount in	/olved			
1) ′	ISC ALLIANCE ENDOWMENT FUND, INC.	С	330,875.CA	ASH				
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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)	Are all partners sec 501(c)(3) orgs.?	(g) Share of end-of-year assets	Dispretion allocat	opor- late tions?	Genera manag partn Yes	(k) Al or Percentage ging ownership
									000) 0000