Form	990
Form	<u>990</u>

Department of the Treasury Internal Revenue Service

** PUBLIC DISCLOSURE COPY ** Return of Organization Exempt From Income Tax

OMB No. 1545-0047

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



Α	For th	e 2023 calendar year, or tax year beginning and	d ending		
В	Check if applicab	C Name of organization		D Employer identifie	cation number
i		NATIONAL TUBEROUS SCLERUSIS			
	Addre	e ASSOCIATION			
	Name chang		-	95-30187	99
	Initial returr	Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	E Telephone number	
	Final returr	8737 COLLESVILLE ROAD	400	301-562-9	
	terminated			G Gross receipts \$	10,180,515.
X	Amer	SILVER SFRING, MD 20910		H(a) Is this a group re	turn
	Appli tion	F Name and address of principal officer: KAKI D. KOBDECK		for subordinates	? Yes X No
	pendi	SAME AS C ABOVE		H(b) Are all subordinates in	cluded? Yes No
<u> </u>	Tax-ex	empt status: 🗴 501(c)(3) 🚺 501(c) () (insert no.) 🗌 4947(a)(1)) or 📃 527	If "No," attach a	list. See instructions
	Websi			H(c) Group exemption	
		f organization: 🔀 Corporation 📄 Trust 🦳 Association 🦳 Other	L Year	of formation: 1975 N	I State of legal domicile: CA
Pa	art I	Summary			
Ð	1	Briefly describe the organization's mission or most significant activities: TO I			
Governance		EVERYONE AFFECTED BY TUBEROUS SCLEROSIS			
erné	2	Check this box if the organization discontinued its operations or dispo	osed of more	I _ I	
Ň	3				30
		Number of independent voting members of the governing body (Part VI, line 1b) $% \left(1-\frac{1}{2}\right) =0$			30
es	5	Total number of individuals employed in calendar year 2023 (Part V, line 2a)			26
Activities &	6	Total number of volunteers (estimate if necessary)			2234
Act	7 a				0.
	b	Net unrelated business taxable income from Form 990-T, Part I, line 11		7b Prior Year	0 . Current Year
				7,016,851.	6,747,948.
an	8	Contributions and grants (Part VIII, line 1h)		2,720,317.	2,815,353.
Revenue	9	Program service revenue (Part VIII, line 2g)		2,720,317.	36,732.
Be	10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)		-830,262.	416,350.
	11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		8,909,542.	10,016,383.
		Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) Grants and similar amounts paid (Part IX, column (A), lines 1-3)		1,032,155.	845,292.
	14			0.	0.
	40	Salaries, other compensation, employee benefits (Part IX, column (A), line 4)		2,896,346.	3,024,376.
ses	162	Professional fundraising fees (Part IX, column (A), line 11e)		0.	0.
Expenses	h	Total fundraising expenses (Part IX, column (D), line 25) 1,150,2	91.		
Ĕ	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		4,135,183.	4,597,980.
		Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)		8,063,684.	8,467,648.
	19	Revenue less expenses. Subtract line 18 from line 12		845,858.	1,548,735.
or				ginning of Current Year	End of Year
ets (20	Total assets (Part X, line 16)		14,827,937.	16,085,768.
Assets	21	Total liabilities (Part X, line 26)		2,373,091.	2,088,420.
Net /	-	Net assets or fund balances. Subtract line 21 from line 20		12,454,846.	13,997,348.
	<u> </u>			,,0100	

Part II Signature Block

Т

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

Sign	Signature of officer		Da	te	
-	KARI L. ROSBECK, PRESIDENT & CE	10 10			
	Type or print name and title				
	Print/Type preparer's name Preparer's	signature	Date	Check	PTIN
Paid	KRISTIN A. JACQUELIN, CPA KRIST	IN A. JACQUI	ELIN 09/27/2	4 self-employed	P01325865
Preparer	Firm's name CALIBRE CPA GROUP, PLLC	2	Fir	m's EIN 47 -0	0900880
Use Only	Firm's address 7501 WISCONSIN AVENUE,	SUITE 1200	WEST		
	BETHESDA, MD 20814		Ph	one no. 202 - 3	331-9880
May the II	RS discuss this return with the preparer shown above? See in	structions			X Yes No
I HA For	Paperwork Reduction Act Notice, see the separate instruct	ctions. 332001 12-2	21-23		Form 990 (2023)

SEE SCHEDULE O FOR ORGANIZATION MISSION STATEMENT CONTINUATION

	990 (2023) ASSOCIATION 95-3018799 Page 2 t III Statement of Program Service Accomplishments
r ai	
1	Check if Schedule O contains a response or note to any line in this Part III
	TO IMPROVE QUALITY OF LIFE FOR EVERYONE AFFECTED BY TUBEROUS SCLEROSIS
	COMPLEX BY CATALYZING NEW TREATMENTS, DRIVING RESEARCH TOWARD A CURE
	AND EXPANDING ACCESS TO LIFELONG SUPPORT.
	AND EXPANDING ACCESS TO LIFELONG SUPPORT.
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.
	Did the organization cease conducting, or make significant changes in how it conducts, any program services?
	If "Yes," describe these changes on Schedule O.
	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.
	(Code:) (Expenses \$ 5,022,281. including grants of \$ 845,292.) (Revenue \$ 2,621,353.
	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 MORE THAN \$37 MILLION INTO
	TSC RESEARCH PROJECTS THROUGH GRANTS AND CONTRACTS: \$20.6 MILLION IN
	(Code:) (Expenses \$ 895, 227. including grants of \$) (Revenue \$
	SUPPORT SERVICES. SEE SCHEDULE O FOR FULL PROGRAM DESCRIPTION.
4c	(Code:) (Expenses \$ 554,030 · including grants of \$) (Revenue \$
	PUBLIC HEALTH. SEE SCHEDULE O FOR FULL PROGRAM DESCRIPTION.
4.4	Other program services (Describe on Schedule O.)
4d	Other program services (Describe on Schedule O.) (Expenses \$ 287,855. including grants of \$) (Bevenue \$)
	Other program services (Describe on Schedule O.) (Expenses \$ 287,855. including grants of \$) (Revenue \$) Total program service expenses 6,759,393.
	(Expenses \$ 287,855. including grants of \$) (Revenue \$)

95-3018799 Page 3

	<u>990 (2023)</u> ASSOCIATION 95-3018	799	P	age 3
Pa	t IV Checklist of Required Schedules			
			Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)?			
	If "Yes," complete Schedule A	1	Х	
2	Is the organization required to complete Schedule B, Schedule of Contributors? See instructions	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		Х
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect			
	during the tax year? If "Yes," complete Schedule C, Part II	4	Х	
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or			
	similar amounts as defined in Rev. Proc. 98-19? If "Yes," complete Schedule C, Part III	5		х
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to			
•	provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I	6		х
7	Did the organization receive or hold a conservation easement, including easements to preserve open space,			
•	the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7		х
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete	<u> </u>		
Ū		8		х
9	Schedule D, Part III Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for			
3	amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services?			
		9		х
10	If "Yes," complete Schedule D, Part IV Did the organization, directly or through a related organization, hold assets in donor-restricted endowments	-		
10	or in quasi-endowments? If "Yes," complete Schedule D, Part V	10	Х	
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VII, IX, or X,			
	as applicable.			
2	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D,			
a		11a	Х	
h	Part VI Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total			
U		11b		х
~	assets reported in Part X, line 16? <i>If</i> "Yes," <i>complete Schedule D, Part VII</i> Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more of its total			- 23
C		11c		х
Ь	assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i> 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			- 23
u		11d	Х	
	Part X, line 16? If "Yes," complete Schedule D, Part IX	11e	X	
	Did the organization report an amount for other liabilities in Part X, line 25? <i>If</i> "Yes," <i>complete Schedule D, Part X</i> Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses	lie	- 23	
f	the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>	11f		х
10-				
IZd	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete	100		v
L	Schedule D, Parts XI and XII	12a		<u> </u>
a		104	х	
10	If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	12b 13	Λ	x
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E			X
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		
a	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			
		44	Х	
45	or more? If "Yes," complete Schedule F, Parts I and IV	14b	Λ	
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	4	х	
	foreign organization? If "Yes," complete Schedule F, Parts II and IV	15	<u> </u>	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to			х
	or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV	16		
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX,			v
	column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I. See instructions	17		<u> </u>
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines		v	
	1c and 8a? If "Yes," complete Schedule G, Part II	18	X	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes,"			v
	complete Schedule G, Part III	19		X
	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		<u> </u>
	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b		
21	Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or			
	domestic government on Part IX, column (A), line 1? If "Yes." complete Schedule I. Parts I and II	21	X	
332003	3 12-21-23	Form	330	(2023)

3

Form **990** (2023)

09560927 712177 71690.00001

<u>Form</u>	990 (2023) ASSOCIATION 95-3	01879	<u>)</u>	age 4
Par	t IV Checklist of Required Schedules (continued)			
			Yes	No
22	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	22		X
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		v	
04-	Schedule J	23	X	+
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If</i> "Yes," <i>answer lines 24b through 24d and complete</i>			
	Schedule K. If "No," go to line 25a	24a		x
b	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	·····		+
	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease		-	
	any tax-exempt bonds?	240	•	
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	240	1	
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	1	X
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and			
	that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete			
	Schedule L, Part I	251)	<u> </u>
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	26		<u> </u>
27	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% controll			v
	entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III	27		X
28	Was the organization a party to a business transaction with one of the following parties? (See the 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? <i>If</i>			
а		28		x
h	"Yes," complete Schedule L, Part IV			X
	A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? If		,	<u> </u>
U	"Yes," complete Schedule L, Part IV	280		x
29	Did the organization receive more than \$25,000 in noncash contributions? If "Yes," complete Schedule M	·····		X
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation	·····		
	contributions? If "Yes," complete Schedule M	30		x
31	Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	31		X
32	Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete			
	Schedule N, Part II	32		X
33	Did the organization own 100% of an entity disregarded as separate from the organization under Regulations			
	sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I	33		X
34	Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and			
	Part V, line 1		X	\vdash
	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a	1	X
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)	+
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization			v
07	If "Yes," complete Schedule R, Part V, line 2	36		<u> </u>
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization			x
20	and that is treated as a partnership for federal income tax purposes? <i>If</i> "Yes," <i>complete Schedule R, Part VI</i>	37		
38	Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? Note: All Form 990 filers are required to complete Schedule O		x	
Par		j 30	- 23	1
	Check if Schedule O contains a response or note to any line in this Part V			
		<u></u>	Yes	No
1a	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable	33	100	
	Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable 1b	0		
	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming			
	(gambling) winnings to prize winners?	1c	Х	
332004	4 12-21-23	For	m 990	(2023)
	4			

09560927 712177 71690.00001

ASSOCIATION

Form 990 (2023)

Par	t V Statements Regarding Other IRS Filings and Tax Compliance (continued)						
					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	26				
b	If at least one is reported on line 2a, did the organization file all required federal employment tax retur	ns?		2b	Х		
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?			3a		Х	
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule	ο.		3b			
	At any time during the calendar year, did the organization have an interest in, or a signature or other a						
	financial account in a foreign country (such as a bank account, securities account, or other financial a	Iccour	nt)?	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 A	ccoun	ts (FBAR).				
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?			5a		X	
	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transact			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 th	e orga	nization 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 contributi	ons o	r gifts				
	were not tax deductible?			6b			
7	Organizations that may receive deductible contributions under section 170(c).			_	v		
	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and ser	vices p	provided to the payor?	7a	X		
				7b	Х		
С	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was			_		v	
	to file Form 8282?	1		7c		X	
	If "Yes," indicate the number of Forms 8282 filed during the year	7d	+0	7.		Х	
e 4	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit con			7e 7f		X	
י מ	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contra If the organization received a contribution of qualified intellectual property, did the organization file Fo			7g			
-	If the organization received a contribution of qualified intellectual property, did the organization net of the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, airplanes, or other vehicles, did the organization received a contribution of cars, boats, airplanes, a			79 7h			
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained						
-		-	-	8			
9	Sponsoring organizations maintaining donor advised funds.			-			
а				9a			
b	 a Did the sponsoring organization make any taxable distributions under section 4966? b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? 						
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					
	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			
	Note: 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	401					
	organization is licensed to issue qualified health plans	13b					
	Enter the amount of reserves on hand	13c		140		x	
14a h	Did the organization receive any payments for indoor tanning services during the tax year?			14a 14b		- 23	
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remune			עדי			
.5	excess parachute payment(s) during the year?			15		х	
	If "Yes," see the instructions and file Form 4720, Schedule N.			15			
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment	inco	ne?	16		х	
	If "Yes," complete Form 4720, Schedule O.						
17	Section 501(c)(21) organizations. Did the trust, or any disqualified or other person engage in any ac	tivitie	s				
-	that would result in the imposition of an excise tax under section 4951, 4952 or 4953?			17			
	If "Yes," complete Form 6069.						
332005	5 12-21-23			Form	990	(2023)	

Form 990 (2023) ASSOCIATION

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.

	tion A. Governing Body and Management					-				
		1 1	20	_	Yes	N				
1 a	Enter the number of voting members of the governing body at the end of the tax year	_1a	30							
	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 0.		20							
b	Enter the number of voting members included on line 1a, above, who are independent		30							
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship	with any other								
	officer, director, trustee, or key employee?			2		Х				
3	Did the organization delegate control over management duties customarily performed by or under the									
	of officers, directors, trustees, or key employees to a management company or other person?			3		X				
4	Did the organization make any significant changes to its governing documents since the prior Form 99		·····	4		Х				
5	Did the organization become aware during the year of a significant diversion of the organization's asse	ets?		5		Х				
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 appoint one or more members of the governing body? b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or 										
	more members of the governing body?		7	a	X					
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, st	ockholders, or								
	persons other than the governing body?		7	b		Х				
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year	r by the following:								
	The governing body?			a	X					
b	Each committee with authority to act on behalf of the governing body?		<u></u>	b	X					
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be read	hed at the								
	organization's mailing address? If "Yes," provide the names and addresses on Schedule O		9	9		Х				
ec	tion B. Policies (This Section B requests information about policies not required by the Internal Re	venue Code.)								
			_		Yes	N				
0a	Did the organization have local chapters, branches, or affiliates?		1	Da	Х					
b	If "Yes," did the organization have written policies and procedures governing the activities of such cha	apters, affiliates,								
	and branches to ensure their operations are consistent with the organization's exempt purposes?		1)b	X					
1a	Has the organization provided a complete copy of this Form 990 to all members of its governing body			1a	Х					
b	b Describe on Schedule O the process, if any, used by the organization to review this Form 990.									
2a										
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise			2a 2b	X					
с	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Y									
	on Schedule O how this was done	,	1:	2c	x					
3	Did the organization have a written whistleblower policy?		·····	3	Х					
4	Did the organization have a written document retention and destruction policy?			4	Х					
5	Did the process for determining compensation of the following persons include a review and approval			-						
•	persons, comparability data, and contemporaneous substantiation of the deliberation and decision?	by macpondent								
а	The organization's CEO, Executive Director, or top management official		1	5a	х					
	Other officers or key employees of the organization			5b	x					
~	If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions.		···· 🗗							
6a	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangem	ent with a								
u			1	6a		Х				
h	If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluat			Ja						
D	in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organ									
	exempt status with respect to such arrangements?			3b						
ec	tion C. Disclosure			50						
	List the states with which a copy of this Form 990 is required to be filedAL , AR , CA , FL , G	Δ ΗΤ ΤΙ. ΤΝ	עכ ע	v	мп	м				
7 0										
8	Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, ar	a 990-1 (Section 501	(0)(3)5 01	iiy) a	valiat	Jie				
	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 Schedule O)			- 1					
9	Describe on Schedule O whether (and if so, how) the organization made its governing documents, con	ninct of interest polic	y, and tir	anc	iai					
~	statements available to the public during the tax year.	las analas a								
20	State the name, address, and telephone number of the person who possesses the organization's boot TSC ALLIANCE - $301-562-9890$	ks and records								
	8737 COLLESVILLE ROAD, 400, SILVER SPRING, MD 2091	.0								
						(202				

NATIONAL	TUBEROUS	SCLEROSIS
ASSOCIATI	ION	

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 the 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, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) 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.

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

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

		T	mzu			ipen	Jour			
(A)	(B)			ຼ (0	C)			(D)	(E)	(F)
Name and title	Average	(do	Position (do not check more than one				one	Reportable	Reportable	Estimated
	hours per	box	, unles cer an	ss pei	rson i	s both	n an	compensation	compensation	amount of
	week				recio	i/irus	lee)	from	from related	other
	(list any	irecto						the	organizations	compensation
	hours for related	e or d	tee			sated		organization (W-2/1099-MISC/	(W-2/1099-MISC/ 1099-NEC)	from the organization
	organizations	ruster	l trus		/ee	npen		1099-NEC)	1039-1120)	and related
	below	dual t	utiona	_	mploy	st col	5	1000 1120)		organizations
	line)	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) STEVEN ROBERDS	45.00		_							
CHIEF SCIENTIFIC OFFICER					x			237,208.	0.	26,563.
(2) KARI LUTHER ROSBECK	54.00									
PRESIDENT & CEO	1.00			х				223,746.	2,260.	29,417.
(3) DEAN RAGER-AGUIAR	45.00									
VICE PRESIDENT, TRANSLATIONAL RESEAR						X		177,725.	0.	28,091.
(4) CYNTHIA ARCURI	42.00									
CHIEF FINANCIAL OFFICER	1.00			Х				176,989.	9,315.	9,482.
(5) LISA MOSS	45.00									
VICE PRESIDENT, DONOR RELATIONS						X		124,914.	0.	24,144.
(6) JAYE ISHAM	45.00									
CHIEF OUTREACH OFFICER						Х		137,218.	0.	5,426.
(7) ASHLEY POUNDERS	45.00									
DIRECTOR OF MEDICAL AFFAIRS						X		115,372.	0.	13,076.
(8) WILLIAM JOSEPH	5.00									
CHAIR		Х		Х				0.	0.	0.
(9) PAUL WAXLAX	5.00									
VICE-CHAIR	1.00	Х		Х				0.	0.	0.
(10) BRITTANY SMITH	5.00									
TREASURER	1.00	Х		Х				0.	0.	0.
(11) LESLEY HOLMES	2.00									
SECRETARY		Х		Х				0.	0.	0.
(12) PETER CRINO	2.00									
IMMEDIATE PAST CHAIR		Х						0.	0.	0.
(13) DEREK BAUER	2.00									
BOARD MEMBER		Х						0.	0.	0.
(14) JULIE BLUM	2.00									
BOARD MEMBER		Х						0.	0.	0.
(15) MATT BOLGER	2.00									
BOARD MEMBER		Х						0.	0.	0.
(16) CHIP BURKHALTER	2.00									
BOARD MEMBER		Х						0.	0.	0.
(17) LISA CARLTON	2.00									
BOARD MEMBER		Х						0.	0.	0.
332007 12-21-23				_	_		_			Form 990 (2023)

332007 12-21-23

Form 990 (2023)

09560927 712177 71690.00001

A GGOOT A TON

Form 990 (2023) ASSOCIATI									95-30	110	199	Pa	age o
Part VII Section A. Officers, Directors, Trus	tees, Key Emp	oloy	ees,	anc	d Hig	ghes	st C	ompensated Employee	s (continued)				
(A) (B) (C) (D) (E)							(E)			(F)			
Name and title	Average	(do	not cl		ition		ne	Reportable	Reportable		Est	imate	d
	hours per	box	, unles	s per	rson i	s both	n an	compensation	compensatio	n	am	ount	of
	week		cer an	dad	irecto	or/trus	tee)	from	from related		C	other	
	(list any	ector						the	organizations			pensat	
	hours for related	or dir	9			ated		organization	(W-2/1099-MIS	6C/		om the	
	organizations	Istee	truste		e	pens		(W-2/1099-MISC/	1099-NEC)		•	anizati	
	below	ual tri	ional		ploye	t com		1099-NEC)				l relate	
	line)	ndividual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former				orga	nizatio	115
(18) DAVID COIT	2.00			0	l ≚	1 0							
BOARD MEMBER		х						0.		0.			0.
(19) MARK CARROLL	2.00												
BOARD MEMBER		х						0.		0.			0.
(20) JULIAN GANGOLLI	2.00												
BOARD MEMBER		х						0.		0.			Ο.
(21) TANJALA GIPSON	2.00												
BOARD MEMBER		х						0.		0.			Ο.
(22) JONATHAN GOLDSTEIN	2.00												
BOARD MEMBER		Х						0.		0.			0.
(23) STEVEN GOLDSTEIN	2.00												
BOARD MEMBER		Х						0.		0.			0.
(24) ROB GRANDIA	2.00												
BOARD MEMBER	0.00	Х						0.		0.			0.
(25) DANA HOLINKA	2.00												•
BOARD MEMBER	2 00	Х						0.		0.			0.
(26) SHAFALI JESTE	2.00	x						0.		0.			0
BOARD MEMBER								1,193,172.	11,57		136	5 1 0	0.
1b Subtotal								0.	, J /	0.	130), <u>_</u> _	0.
c Total from continuation sheets to Part VI								1,193,172.	11,57				
 d Total (add lines 1b and 1c) 2 Total number of individuals (including but n 											150	, <u> </u>	
compensation from the organization		030	11310	u ac	000	<i>y</i> wii	010			,			7
compensation nom the organization												Yes	No
3 Did the organization list any former officer,	director. truste	ee. k	kev e	mpl	ove	e. or	hia	hest compensated empl	ovee on	ſ			
line 1a? If "Yes," complete Schedule J for s			•	•	•		Ŭ	• •			3		Х
4 For any individual listed on line 1a, is the su										····			
and related organizations greater than \$150									-		4	х	
5 Did any person listed on line 1a receive or a										···· [
rendered to the organization? If "Yes." com										[5		Х
Section B. Independent Contractors													
1 Complete this table for your five highest co	mpensated ind	lepe	nder	nt co	ontra	actor	rs th	at received more than \$	100,000 of comp	ensat	ion fro	m	
the organization. Report compensation for t	he calendar ye	ear e	endin	g w	ith c	or wi	<u>thin</u>	the organization's tax ye	ear.				
(A) Name and business	address							(B) Description of s	arvices	C	(C) ompen		-
PSYCHOGENICS, INC.	2001035							RESEARCH LAB			ompen	1541101	<u> </u>
20 GRAMERCY PARK S, NEW Y	ORK. NY	1	00	03				SERVICES		1	,565	5.75	54.
VAN ANDEL RESEARCH INSTIT					WI	CK	_	RESEARCH LAB					
AVE, NE, GRAND RAPIDS, MI 49503 SERVICES								493	3,45	53.			
CAVAROCCHI RUSCIO DENNIS & ASSOCIATES, 600													
MARYLAND AVE SW, SUITE 22	0 EAST,							GOVERNMENT RI	ELATIONS		117	7,71	L4.
							Ţ						
9 Total number of independent contractors		at 1 1/-	nitaa	l to	the		+04	abovo) who reasived	ro than				
2 Total number of independent contractors (ir	ICIULIII I DUL NO	חוו זכ	meo	10	LIOS	e iis	ıeu	above) who received mo	าธแลก				

\$100,000 of compensation from the organization 3 SEE PART VII, SECTION A CONTINUATION SHEETS 332008 12-21-23

Form **990** (2023)

3

Form 990ASSOCIAT						D I	0		95-301	8799
Part VII Section A. Officers, Directors, Tru	ees (continued)									
(A) Name and title	(B) Average hours	(cl	(C) Position (check all that apply)				ly)	(D) Reportable compensation	(E) Reportable compensation	(F) Estimated amount of
	per week (list any hours for related organizations below line)	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest com pensated em ployee	Former	from the organization (W-2/1099-MISC)	from related organizations (W-2/1099-MISC)	other compensation from the organization and related organizations
(27) JESSICA KREFTING BOARD MEMBER	2.00	x						0.	0.	0.
(28) DARCY KRUEGER BOARD MEMBER	2.00	x						0.	0.	0.
(29) PATROSKI LAWSON BOARD MEMBER	2.00	x						0.	0.	0.
(30) KRISTI LENGYEL BOARD MEMBER	2.00	x						0.	0.	0.
(31) HEATHER LENS BOARD MEMBER	2.00	x						0.	0.	0.
(32) LAURA MARKS BOARD MEMBER	2.00	x						0.	0.	0.
(33) DIANE MCSWAIN BOARD MEMBER	2.00	x						0.	0.	0.
(34) MUSTAFA SAHIN BOARD MEMBER	2.00	x						0.	0.	0.
(35) SEAN SHILLINGER BOARD MEMBER	2.00	 X						0.	0.	0.
(36) VANESSA VAZQUEZ BOARD MEMBER	2.00	x						0.	0.	0.
(37) TARA ZIMMERMAN BOARD MEMBER	2.00	x						0.	0.	0.
		-								
		-								
		-								
		-								
		-								
Total to Part VII, Section A, line 1c										
,,										

332201 04-01-23

95-3018799 i

			ASSOCIATION				95-3018	799 Page 9
Pa	rt V	/111						
			Check if Schedule O contains a response	or note to any line		(5)	(0)	
					(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514
<i>6</i> 0	-1	2	Federated campaigns 1a	40,093.				
Contributions, Gifts, Grants and Other Similar Amounts	'		Membership dues 1b	1,100.				
ъ б			Fundraising events	1,179,453.				
ifts, r Ai			Related organizations	572,625.				
nila nila			Government grants (contributions) 1e					
ons Sin			All other contributions, gifts, grants, and					
utio		•	similar amounts not included above 1f	4,954,677.				
0 <u>t</u>		a	Noncash contributions included in lines 1a-1f	, , .				
and		-	Total. Add lines 1a-1f		6,747,948.			
<u> </u>				Business Code	, ,			
ø	2	а	CONTRACT REVENUE	900099	2,548,976.	2,548,976.		
Program Service Revenue	-	b	CONFERENCE REVENUE	900099	266,377.	72,377.		194,000.
Ser		c			,	,		, ,
E a		d						
Be		e						
Pro			All other program service revenue					
			Total. Add lines 2a-2f		2,815,353.			
	3		Investment income (including dividends, intere		· ·			
	-		other similar amounts)		36,732.			36,732.
	4		Income from investment of tax-exempt bond p		·			
	5		Royalties	r				
	-		(i) Real	(ii) Personal				
	6	а	Gross rents 6a					
	-		Less: rental expenses 6b					
			Rental income or (loss) 6c					
			Net rental income or (loss)					
	7		Gross amount from sales of (i) Securities	(ii) Other				
	-		assets other than inventory 7a					
		b	Less: cost or other basis					
e			and sales expenses 7b					
evenue		с	Gain or (loss) 7c					
Rev			Net gain or (loss)					
erF	8		Gross income from fundraising events (not					
Other			including \$ 1,179,453. of					
-			contributions reported on line 1c). See					
			Part IV, line 18 8a	258,687.				
		b	Less: direct expenses 8b	164,132.				
			Net income or (loss) from fundraising events		94,555.			94,555.
			Gross income from gaming activities. See					
			Part IV, line 19 9a					
		b	Less: direct expenses 9b					
			Net income or (loss) from gaming activities					
	10		Gross sales of inventory, less returns					
			and allowances 10a	a				
		b	Less: cost of goods sold 10	b				
		с	Net income or (loss) from sales of inventory					
				Business Code				
sno	11	а	CHANGE IN INTEREST OF AFFILIATE	900099	320,800.			320,800.
ane		b						
eve		с						
Miscellaneous Revenue		d	All other revenue	900099	995.			995.
2			Total. Add lines 11a-11d		321,795.			
	12		Total revenue. See instructions		10,016,383.	2,621,353.	٥.	647,082.
332009	9 12-	21-	23					Form 990 (2023)

10

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

95-3018799 Page 10

Form 990 (ASSOCIATION	
Part IX	Stateme	ent of Functional Expense	S

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

0000	Charle if Schedule O contains a reason				
	Check if Schedule O contains a respons	(A)	(B)	(C)	(D)
	not include amounts reported on lines 6b,	Total expenses	Program service	Management and	Fundraising
	8b, 9b, and 10b of Part VIII.		expenses	general expenses	expenses
1	Grants and other assistance to domestic organizations				
	and domestic governments. See Part IV, line 21	696,542.	696,542.		
2	Grants and other assistance to domestic				
	individuals. See Part IV, line 22				
3	Grants and other assistance to foreign				
	organizations, foreign governments, and foreign				
	individuals. See Part IV, lines 15 and 16	148,750.	148,750.		
		110,750.	140,750.		
4	Benefits paid to or for members				
5	Compensation of current officers, directors,		420 070	100.004	1 6 0 6 2
	trustees, and key employees	703,405.	439,278.	102,064.	162,063.
6	Compensation not included above to disqualified				
	persons (as defined under section 4958(f)(1)) and				
	persons described in section 4958(c)(3)(B)				
7	Other salaries and wages	1,867,712.	1,166,420.	271,060.	430,232.
8	Pension plan accruals and contributions (include			-	•
•	section 401(k) and 403(b) employer contributions)	52,530.	33,680.	5,461.	13,389.
~		222,386.	142,119.	24,273.	55,994.
9	Other employee benefits	178,343.	113,532.	20,556.	44,255.
10	Payroll taxes	1/0,343.	113,334.	20,330.	44,400.
11	Fees for services (nonemployees):				
а	Management				
b	Legal	17,690.	11,342.	2,750.	3,598.
с	Accounting	23,250.	14,907.	3,614.	4,729.
	Lobbying	116,364.	74,606.	18,090.	23,668.
	Professional fundraising services. See Part IV, line 17				
f	- · · F				
g					
y		219,360.	140,642.	34,102.	44,616.
	column (A), amount, list line 11g expenses on Sch 0.)	8,473.	5,492.	9.	2,972.
12	Advertising and promotion				
13	Office expenses	328,107.	172,198.	9,714.	146,195.
14	Information technology	161,819.	80,801.	15,642.	65,376.
15	Royalties				
16	Occupancy	144,753.	91,950.	16,592.	36,211.
17	Travel	352,743.	294,269.	5,315.	53,159.
18	Payments of travel or entertainment expenses				
	for any federal, state, or local public officials				
19	Conferences, conventions, and meetings	447,239.	404,633.	7,811.	34,795.
	F	447,255.	101,055.	,,011.	54,755
20					
21	Payments to affiliates	CO 210			11 000
22	Depreciation, depletion, and amortization	69,312.	52,790.	5,255.	11,267.
23	Insurance	13,070.	8,319.	1,511.	3,240.
24	Other expenses. Itemize expenses not covered				
	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 0.)				
а	PRECLINICAL CONSORTIUM	2,321,442.	2,321,442.		
b	NHD BIOSAMPLE REPOSIT	328,386.	328,386.		
c	DUES AND SUBSCRIPTIONS	39,981.	13,730.	12,520.	13,731.
	DOED AND DODDERITIONS	55,501.	15,750.	12,520.	13,731.
d		F 001	2 565	1 605	0.0.1
	All other expenses	5,991.	3,565.	1,625.	801.
25	Total functional expenses. Add lines 1 through 24e	8,467,648.	6,759,393.	557,964.	1,150,291.
26	Joint costs. Complete this line only if the organization				
	reported in column (B) joint costs from a combined				
	educational campaign and fundraising solicitation.				
	Check here X if following SOP 98-2 (ASC 958-720)	43,084.	21,542.	21,542.	0.
332010	0 12-21-23	- 1			Form 990 (2023)
		11			(2020)

11

09560927 712177 71690.00001

NATIONAL TUBEROUS SCLEROSIS

Form 990 (2023)
Part X Balance Sheet

ASSOCIATION

IU		Check if Schedule O contains a response or note to	h anv lir	ne in this Part X			
			5 arry m		(A)		(B)
					Beginning of year		End of year
	1	Cash - non-interest-bearing			1,711,209.	1	1,487,710.
	2	Savings and temporary cash investments	694,859.	2	700,650.		
	3	Pledges and grants receivable, net	5,280,316.	3	4,306,013.		
	4	Accounts receivable, net			181,490.	4	350,534.
	5	Loans and other receivables from any current or fo					
		trustee, key employee, creator or founder, substan	tial cont	tributor, or 35%			
		controlled entity or family member of any of these p	persons			5	
	6	Loans and other receivables from other disqualified	l persor	ns (as defined			
		under section 4958(f)(1)), and persons described in	sectior	n 4958(c)(3)(B)		6	
ŝ	7	Notes and loans receivable, net				7	
Assets	8	Inventories for sale or use				8	
Ř	9	Prepaid expenses and deferred charges			277,696.	9	283,821.
	10a	Land, buildings, and equipment: cost or other					
		basis. Complete Part VI of Schedule D	0a	811,270.			
	b		0b	417,309.	463,272.	10c	393,961.
	11	Investments - publicly traded securities				11	1,752,986.
	12	Investments - other securities. See Part IV, line 11				12	
	13	Investments - program-related. See Part IV, line 11			13		
	14	Intangible assets		14			
	15	Other assets. See Part IV, line 11	6,219,095.	15	6,810,093.		
	16	Total assets. Add lines 1 through 15 (must equal li			14,827,937.	16	16,085,768.
	17	Accounts payable and accrued expenses			891,501.	17	813,246.
	18	Grants payable		18			
	19	Deferred revenue			285,264.	19	189,493.
	20	Tax-exempt bond liabilities			20		
	21	Escrow or custodial account liability. Complete Par	t IV of S	Schedule D		21	
es	22	Loans and other payables to any current or former					
Liabilities		trustee, key employee, creator or founder, substan	tial cont	tributor, or 35%			
iab		controlled entity or family member of any of these p	persons	·		22	
-	23	Secured mortgages and notes payable to unrelated	d third p	parties		23	
	24	Unsecured notes and loans payable to unrelated the				24	
	25	Other liabilities (including federal income tax, paya					
		parties, and other liabilities not included on lines 17	7-24). Co	omplete Part X	1 100 200		1 005 601
		of Schedule D			1,196,326.		1,085,681.
	26	Total liabilities. Add lines 17 through 25			2,373,091.	26	2,088,420.
s		Organizations that follow FASB ASC 958, check	here	X			
Ce		and complete lines 27, 28, 32, and 33.			E 1E1 220		6 272 050
alar	27	Net assets without donor restrictions	5,151,339.	27	6,372,958.		
ä	28			······	7,303,507.	28	7,624,390.
ŭ		Organizations that do not follow FASB ASC 958,	check	here			
Net Assets or Fund Balances		and complete lines 29 through 33.					
ts c	29	Capital stock or trust principal, or current funds				29	
sse	30	Paid-in or capital surplus, or land, building, or equip		F		30	
μĂ	31	Retained earnings, endowment, accumulated incor			10 151 016	31	12 007 240
R	32	Total net assets or fund balances			12,454,846.	32	13,997,348.
	33	Total liabilities and net assets/fund balances			14,827,937.	33	16,085,768. Form 990 (2023

Form **990** (2023)

332011 12-21-23

NATIONAL	TUBEROUS	SCLEROSIS
ASSOCIATI	ION	

Form	ASSOCIATION	95-	3018	799	Pag	_{ge} 12
Pa	rt XI Reconciliation of Net Assets					
	Check if Schedule O contains a response or note to any line in this Part XI					
1	Total revenue (must equal Part VIII, column (A), line 12)	1		,016		
2	Total expenses (must equal Part IX, column (A), line 25)	2		,467		
3	Revenue less expenses. Subtract line 2 from line 1	3		,548		
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	12	,454	, 84	<u>16.</u>
5	Net unrealized gains (losses) on investments	5		-6	, 23	33.
6	Donated services and use of facilities	6				
7	Investment expenses	7				
8	Prior period adjustments	8				
9	Other changes in net assets or fund balances (explain on Schedule O)	9				0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32,					
	column (B))	10	13	,997	,34	<u>18.</u>
Pa	rt XII Financial Statements and Reporting					
	Check if Schedule O contains a response or note to any line in this Part XII			<u></u>		X
					Yes	No
1	Accounting method used to prepare the Form 990: Cash X Accrual Other					
	If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule	0.				
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?			2a		X
	If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed	on a				
	separate basis, consolidated basis, or both:					
	Separate basis Consolidated basis Both consolidated and separate basis					
b	Were the organization's financial statements audited by an independent accountant?			2b	X	
	If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate	basis,				
	consolidated basis, or both:					
	Separate basis X Consolidated basis Both consolidated and separate basis					
С	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the	audit,				
	review, or compilation of its financial statements and selection of an independent accountant?			2c	X	
	If the organization changed either its oversight process or selection process during the tax year, explain on Sche	edule O				
3a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the					
	Uniform Guidance, 2 C.F.R. Part 200, Subpart F?			3a		X
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required	ed aud	it			
	or audits, explain why on Schedule O and describe any steps taken to undergo such audits			3b		

Form **990** (2023)

332012 12-21-23

SCHEDULE A				Dublic Che	rity Status an			nnort		OMB No. 1545-0047
(Form 990)				2023						
				omplete if the orgar 494		2023				
Department of the Treasury Internal Revenue Service				A		Open to Public Inspection				
		the organizatio			Form990 for instructior OUS SCLEROSIS	ormation.	Employor	identification number		
Nan		ule of gallizatio		CIATION	OD2 2CTEVO21	5				5-3018799
Pa	rt I	Reason			(All organizations must c	omplete tł	nis part.) S	ee instruction		5 5010755
					For lines 1 through 12, cl					
1	Ŭ	A church, cor	vention of chu	urches, or associatio	on of churches described	in sectio	n 170(b)(1	I)(A)(i).		
2		A school dese	cribed in secti	ion 170(b)(1)(A)(ii).(Attach Schedule E (Form	n 990).)				
3		A hospital or	a cooperative	hospital service orga	anization described in se	ection 170	(b)(1)(A)(ii	i).		
4			-	ation operated in co	njunction with a hospital	described	in sectio	n 170(b)(1)(A	(iii). Enter	the hospital's name,
_		city, and state	-	with a large of the former	N				- 14	1 %-
5					llege or university owned	or operat	ed by a go	ivernmental u	nit describe	ed in
6		-		Complete Part II.) vernment or governm	nental unit described in	section 17	70(h)(1)(A)	(v)		
7	X	-		0	ntial part of its support fr			.,	e general r	oublic described in
-		-		omplete Part II.)		3			5	
8		A community	trust describe	ed in section 170(b)	(1)(A)(vi). (Complete Par	t II.)				
9		An agricultura	al research org	anization described	in section 170(b)(1)(A)(i x) operate	ed in conju	inction with a	land-grant	college
		or university o	or a non-land-g	rant college of agric	ulture (see instructions).	Enter the I	name, city	, and state of	the college	e or
10		university:			11					
10		0		, ()	than 33 1/3% of its supp t to certain exceptions; a			,	• •	0
					(less section 511 tax) fro					-
				mplete Part III.)	(,,,,,,,,					
11		An organizati	on organized a	and operated exclusion	ively to test for public sat	ety. See	section 50)9(a)(4).		
12		An organizati	on organized a	and operated exclusi	ively for the benefit of, to	perform t	ne functio	ns of, or to ca	rry out the	purposes of one or
		more publicly	supported or	ganizations describe	d in section 509(a)(1) o	r section	509(a)(2).	See section &	509(a)(3). (Check the box on
		-	-	• •	f supporting organizatior				-	
а					upervised, or controlled	• • • •	-			
			-	complete Part IV, Se	gularly appoint or elect a	majonty c	in the direct		es of the st	ipporting
b		¬ ~		• •	or controlled in connect	ion with it	s supporte	d organizatio	n(s), by hav	vina
				-	anization vested in the sa			•		•
		organizatio	n(s). You mus	t complete Part IV,	Sections A and C.					
с		Type III fun	ctionally inte	grated. A supportin	g organization operated	in connect	ion with, a	and functional	ly integrate	ed with,
	_		•	. , .). You must complete I					
d		_ ,,	-	•	oorting organization oper				0	()
				0	ation generally must sat			•	an attentiv	/eness
е		- ·	•	,	written determination from				I. Type III	
-			•		nally integrated supporti				., .,	
f	Ente	er the number of	of supported o	organizations						
g			-	about the supporte		(iii) is the even	ainstina listad			
	((i) Name of suppo organization 		(ii) EIN	(iii) Type of organization (described on lines 1-10	in your governi		(v) Amount of support (see ir	-	(vi) Amount of other support (see instructions)
					above (see instructions))	Yes	No			
_										
Tota	al									

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

95-3018799 Page 2

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) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total	
1	Gifts, grants, contributions, and							
	membership fees received. (Do not							
	include any "unusual grants.")	5527543.	4345011.	5769053.	7016851.	6496698.	<u>29155156.</u>	
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	5527543.	4345011.	5769053.	7016851.	6496698.	29155156.	
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)						4732702.	
6	Public support. Subtract line 5 from line 4.						24422454.	
	ction B. Total Support							
	ndar year (or fiscal year beginning in)	(a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	(f) Total	
	Amounts from line 4	5527543.	4345011.	5769053.	7016851.	6496698.	29155156.	
8	Gross income from interest,							
	dividends, payments received on							
	securities loans, rents, royalties,		11 100	2 2 2 2	0 000		01 555	
	and income from similar sources	27,444.	11,188.	3,809.	2,382.	36,732.	81,555.	
9	Net income from unrelated business							
	activities, whether or not the							
	business is regularly carried on							
10	Other income. Do not include gain							
	or loss from the sale of capital	F14			1 - 400	0.05	1 1 0 0 1	
	assets (Explain in Part VI.)	714.			15,492.	995.	17,201.	
	Total support. Add lines 7 through 10						29253912.	
	Gross receipts from related activities,	•	,				,557,404.	
13	First 5 years. If the Form 990 is for th							
800	organization, check this box and stor						·····	
	ction C. Computation of Publi						02 40	
	Public support percentage for 2023 (I					14	83.48 % 82.01 %	
	Public support percentage from 2022					15		
108	33 1/3% support test - 2023. If the contract have the end of the superior test is a support test of the superior test is a support test of the superior test of t						37	
la	stop here. The organization qualifies		-		line 15 in 00 1/00/			
D	33 1/3% support test - 2022. If the c							
47-	and stop here. The organization qual		•••		10 160 or 166 o			
1/a	10% -facts-and-circumstances test							
	and if the organization meets the fact meets the facts-and-circumstances te			-		-		
Ь	10% -facts-and-circumstances test	-		• • • •		7a and line 15 is		
N	more, and if the organization meets th	-						
	organization meets the facts-and-circu							
18	Private foundation. If the organizatio		-					
		Schedule A (Form 990) 2023						

Schedule A (Form 990) 2023

Part II

NATIONAL TUBEROUS SCLEROSIS	NATIONAL	TUBEROUS	SCLEROSIS
-----------------------------	----------	----------	-----------

Schedule A (Form 990) 2023 ASSOCIATION 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.)

Section A. Public Support						
Calendar year (or fiscal year beginnin	ig in) (a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	3 (f) Total
1 Gifts, grants, contributions, ar	nd					
membership fees received. (D	o not					
include any "unusual grants.")					
2 Gross receipts from admission merchandise sold or services formed, or facilities furnished any activity that is related to t organization's tax-exempt pur	per- in the					
3 Gross receipts from activities						
are not an unrelated trade or l						
4 Tax revenues levied for the or						
ization's benefit and either pa	°					
5 The value of services or facilit	ies					
furnished by a governmental u	unit to					
the organization without charg	ge					
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1,	2, and					
3 received from disqualified p	ersons					
b Amounts included on lines 2 and 3 receifrom other than disqualified persons that exceed the greater of \$5,000 or 1% of that amount on line 13 for the year	it ie					
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from	n line 6.)					
Section B. Total Support						
Calendar year (or fiscal year beginnin	ig in) (a) 2019	(b) 2020	(c) 2021	(d) 2022	(e) 2023	3 (f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received securities loans, rents, royaltie and income from similar source	es,					
b Unrelated business taxable incom	10					
(less section 511 taxes) from bus	inesses					
acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated bu activities not included on line whether or not the business is regularly carried on	usiness 10b,					
12 Other income. Do not include or loss from the sale of capita assets (Explain in Part VI.)	ป ี					
13 Total support. (Add lines 9, 10c, 11,						
14 First 5 years. If the Form 990) is for the organization's f	irst, second, third,	fourth, or fifth tax	year as a section s	501(c)(3) orgar	ization,
check this box and stop here						
Section C. Computation of	f Public Support Per	rcentage				
15 Public support percentage for	r 2023 (line 8, column (f), c	divided by line 13,	column (f))		15	%
16 Public support percentage fro					16	%
Section D. Computation of						
17 Investment income percentag			ine 13, column (f))		17	%
18 Investment income percentag					18	%
19a 33 1/3% support tests - 2023						ine 17 is not
more than 33 1/3%, check thi						
b 33 1/3% support tests - 202						
line 18 is not more than 33 1/						
20 Private foundation. If the org	janization did not check a	box on line 14, 19	a, or 19b, check t	his box and see in		<u></u>
332023 12-21-23					Scheo	lule A (Form 990) 2023
		16)			

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

1

2

3a

3b

3c

4a

4b

4c

5a

5b

5c

6

7

8

9a

9b

9c

Yes No

Schedule A (Form 990) 2023 ASSC Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of 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?
- 6 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).
- 8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? *If* "Yes." *complete Part I of Schedule L (Form 990).*
- **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 on 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 on 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.)

332024 12-21-23

10a 10b Schedule A (Form 990) 2023

09560927 712177 71690.00001

ASSOCIATION

Pá	art IV	Supporting Organizations (continued)			
				Yes	No
11	Has t	he organization accepted a gift or contribution from any of the following persons?			
á	a Aper	son who directly or indirectly controls, either alone or together with persons described on lines 11b and			
	11c b	elow, the governing body of a supported organization?	11a		
ł	b A fan	nily member of a person described on line 11a above?	11b		
Ċ	A 359	% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide			
	detail	in Part VI.	11c		
Se	ction	B. Type I Supporting Organizations			
				Yes	No
1	more direc effect	the governing body, members of the governing body, officers acting in their official capacity, or membership of one or supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, tors, or trustees at all times during the tax year? <i>If "No," describe in</i> Part VI <i>how the supported organization(s)</i> tively operated, supervised, or controlled the organization's activities. If the organization had more than one supported dization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the			
	•	bried organizations and what conditions or restrictions, if any, applied to such powers during the tax year.	1	ľ	
2		ne organization operate for the benefit of any supported organization other than the supported			
	orgar	ization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in			
	Part	VI how providing such benefit carried out the purposes of the supported organization(s) that operated,			
	suna	uised or controlled the supporting organization	2		

<u></u>	
Section C. Type II Supporting Organizations	

Schedule A (Form 990) 2023

 1
 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed
 Image: Control or management of the support of the support of the same persons that control or managed
 Image: Control of the support of the support of the same persons that control or managed
 Image: Control of the support of the support of the support of the same persons that control or managed
 Image: Control of the support of the supp

Sec	ction D. All Type III Supporting Organizations			
			Yes	No
1	Did the organization provide to each of its supported organizations, by the last day of the fifth month of the			
	organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax			
	year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the			
	organization's governing documents in effect on the date of notification, to the extent not previously provided?	1		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported			
	organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how			
	the organization maintained a close and continuous working relationship with the supported organization(s).	2		
3	By reason of the relationship described on 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	3		

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).
	oneon the box next to the method that the organization ased to satisfy the integral rart rest during the year	(,

a ____ The organization satisfied the Activities Test. Complete line 2 below.

b		The organization	is the parent o	f each of its sup	oported organizations	6. Complete line 3 below.
---	--	------------------	-----------------	-------------------	-----------------------	---------------------------

с		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) to which the organization was responsive? If "Yes," then in **Part VI identify those 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 constituted substantially all of its activities.
- b Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the reasons 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 of its supported organizations? *If "Yes," describe in* **Part VI** *the role played by the organization in this regard.*

2a ______ 2b _____ 3a _____ 3b _____

Yes No

332025 12-21-23

Schedule A (Form 990) 2023

09560927 712177 71690.00001

2023.04030 NATIONAL TUBEROUS SCLEROS 71690.02

18

NATIONAL	TUBEROUS	SCLEROSIS
ASSOCIATI	ION	

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

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

Schedule A (Form 990) 2023

332026 12-21-23

Schedule A (Form 990) 2023

	t V Type III Non-Functionally Integrated 509	(a)(3) Supporting Orga	nizations (5-3018/99 Page 7
		allo Supporting Orga	nizations (continu	<u>led)</u>	0
-	on D - Distributions				Current Year
1	Amounts paid to supported organizations to accomplish exer			1	
2	Amounts paid to perform activity that directly furthers exemp	or purposes of supported		2	
<u> </u>	organizations, in excess of income from activity Administrative expenses paid to accomplish exempt purpose	o of our ported or conizations		2 3	
<u>3</u> 4	Amounts paid to acquire exempt-use assets)	4		
5	Qualified set-aside amounts (prior IRS approval required - pro		5		
6	Other distributions (<i>describe in</i> 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			
Ū	(provide details in Part VI). See instructions.	lo organization lo rooponervo		8	
9	Distributable amount for 2023 from Section C, line 6			9	
10	Line 8 amount divided by line 9 amount			10	
		(i)	(ii)		(iii)
Secti	on E - Distribution Allocations (see instructions)	Excess Distributions	Underdistribution Pre-2023	าร	Distributable Amount for 2023
1	Distributable amount for 2023 from Section C, line 6				
2	Underdistributions, if any, for years prior to 2023 (reason-				
	able cause required - explain in Part VI). See instructions.				
3	Excess distributions carryover, if any, to 2023				
а	From 2018				
b	From 2019				
c	From 2020				
d	From 2021				
e	From 2022				
f	Total of lines 3a through 3e				
g	Applied to underdistributions of prior years				
h	Applied to 2023 distributable amount				
i	Carryover from 2018 not applied (see instructions)				
j	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.				
4	Distributions for 2023 from Section D,				
	line 7: \$				
а	Applied to underdistributions of prior years				
b	Applied to 2023 distributable amount				
c	Remainder. Subtract lines 4a and 4b from line 4.				
5	Remaining underdistributions for years prior to 2023, 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 2023. Subtract lines 3h				
	and 4b from line 1. For result greater than zero, explain in				
	Part VI. See instructions.				
7	Excess distributions carryover to 2024. Add lines 3j				
	and 4c.				
8	Breakdown of line 7:				
	Excess from 2019				
	Excess from 2020				
	Excess from 2021				
	Excess from 2022				
е	Excess from 2023				

Schedule A (Form 990) 2023

332027 12-21-23

				SCLEROSIS	
Schedule A	(Form 990) 2023	ASSOCIAT			95-3018799 Page 8
Part VI	Part IV, Section A, lines 1, line 1; Part IV, Section D, I	2, 3b, 3c, 4b, 4c, ines 2 and 3; Part	5a, 6, 9a, 9b, 9c, ⁻ IV, Section E, line	11a, 11b, and 11c; Part IV, s 1c, 2a, 2b, 3a, and 3b; Pa	Part II, line 17a or 17b; Part III, line 12; Section B, lines 1 and 2; Part IV, Section C, art V, line 1; Part V, Section B, line 1e; Part V, art for any additional information.
332028 12-21-2	23			21	Schedule A (Form 990) 2023
				4 T	

Schedule of Contributors

** PUBLIC DISCLOSURE COPY **

Attach to Form 990, 990-EZ, or 990-PF. Go to www.irs.gov/Form990 for the latest information. OMB No. 1545-0047

2023

Employer identification number

NATIONAL	TUBEROUS	SCLEROSIS
ASSOCIATI	ION	

ASSOCIATI

Schedule B

Department of the Treasury

Organization type (check one):

Internal Revenue Service Name of the organization

(Form 990)

95-3018799

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

X 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), 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 ______\$

Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990), 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).

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

	B (Form 990) (2023)			Page 2
			Emplo	yer identification number
	NAL TUBEROUS SCLEROSIS IATION		95	-3018799
				5010,99
Part I	Contributors (see instructions). Use duplicate copies of Part I if additional	space is needed.		1
(a)	(b)	(c)		(d)
No.	Name, address, and ZIP + 4	Total contribution	ns	Type of contribution
1				Person X
				Payroll
		\$ 1,397,8	60.	Noncash
				(Complete Part II for noncash contributions.)
				,
(a)	(b)	(c)		(d)
No.	Name, address, and ZIP + 4	Total contribution	ns	Type of contribution
2				Person X
				Payroll
		\$964,2	44.	Noncash
				(Complete Part II for
				noncash contributions.)
(a)	(b)	(c)		(d)
No.	Name, address, and ZIP + 4	Total contribution	ns	Type of contribution
3				
				Person X Payroll
		\$266,2	50.	Noncash
				(Complete Part II for
				noncash contributions.)
(a)	(b)	(c)		(d)
No.	Name, address, and ZIP + 4	Total contribution	ns	Type of contribution
1				
4				Person X Payroll
		\$185,8	02.	Noncash
				(Complete Part II for
				noncash contributions.)
(a)	(b)	(c)		(d)
No.	Name, address, and ZIP + 4	Total contribution	ns	Type of contribution
5				Person X
	·			Person <u>X</u> Payroll
		\$182,6	11.	Noncash
				(Complete Part II for
				noncash contributions.)
(a)	(b)	(c)		(d)
No.	Name, address, and ZIP + 4	Total contribution	ns	Type of contribution
6				Person X
				Payroll
		\$180,2	13.	Noncash
				(Complete Part II for
				noncash contributions.)

Schedule B (Form 990) (2023)

323452 12-26-23

24 2023.04030 NATIONAL TUBEROUS SCLEROS 71690.02

Page 2

	B (Form 990) (2023)		Page 2
	rganization NAL TUBEROUS SCLEROSIS		Employer identification number
	IATION		95-3018799
Part I	Contributors (see instructions). Use duplicate copies of Part I if additiona	l space is needed.	
(a)	(b)	(c)	(d)
No.	Name, address, and ZIP + 4	Total contribution	ns Type of contribution
7		\$572,6	Person X Payroll
(a)	(b)	(c)	(d) Turne of contribution
8	Name, address, and ZIP + 4	Total contribution \$145,0	Person X Payroll
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributior	(d) ns Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributior	(d) ns Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contribution	(d) ns Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No	(b) Name address and ZIP + 4	(c)	(d)
<u>No.</u>	Name, address, and ZIP + 4	S	ns Type of contribution Person Payroll Noncash (Complete Part II for noncash contributions.)

Schedule B (Form 990) (2023)

323452 12-26-23

	B (Form 990) (2023)		Page 3
	rganization NAL TUBEROUS SCLEROSIS		Employer identification number
	IATION		95-3018799
Part II	Noncash Property (see instructions). Use duplicate copies of Part II if	f additional space is needed	i.
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate (See instructions.	
		_ _ _ _ \$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate (See instructions.	
		- - - - \$\$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate (See instructions.	
		_ _ _ \$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate (See instructions)	
		- - - - \$\$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate (See instructions.	
		- - - \$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate (See instructions.	
		_ _ _ _ \$	

323453 12-26-23

Schedule B (Form 990) (2023)

09560927 712177 71690.00001

Schedule	B (Form 990) (2023)			Page 4				
Name of o	organization		Emp	loyer identification number				
	NAL TUBEROUS SCLEROSIS							
	IATION			5-3018799				
Part III	from any one contributor. Complete columns (a)) through (e) and the following line ent	ry. For organizations					
	completing Part III, enter the total of exclusively religious,	charitable, etc., contributions of \$1,000 or	ess for the year. (Enter this info. once.)	<u> </u>				
(a) No.	Use duplicate copies of Part III if additional	space is needed.						
from	(b) Purpose of gift	(c) Use of gift	(d) Descriptio	n of how gift is held				
Part I								
			<u> </u>					
		(e) Transfer of git	t					
	Transferee's name, address, a	nd ZIP + 4	Relationship of transfere	or to transferee				
(a) No			<u> </u>					
(a) No. from	(b) Purpose of gift	(c) Use of gift	(d) Descriptio	n of how gift is held				
Part I								
			<u> </u>					
	· · · · · · · · · · · · · · · · · · ·							
	(e) Transfer of gift							
	Transferee's name, address, a	nd ZIP + 4	Relationship of transfere	or to transferee				
(a) No.		I						
from	(b) Purpose of gift	(c) Use of gift	(d) Descriptio	n of how gift is held				
Part I								
		(e) Transfer of gif	t					
	Transferee's name, address, a	nd ZIP + 4	Relationship of transfere	or to transferee				
(a) No.		1						
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Descriptio	n of how gift is held				
Faili								
	(e) Transfer of gift							
	Transferee's name, address, a	nd ZIP + 4	Relationship of transfere	or to transferee				
		[
		[
202454 10 00	 			Schodulo B (Form 000) (0000)				
323454 12-26	0-20			Schedule B (Form 990) (2023)				

09560927 712177 71690.00001

²⁷ 2023.04030 NATIONAL TUBEROUS SCLEROS 71690.02

Department of the Treasury Internal Revenue Service	-	to www.irs.gov/Form990 for ins			-EZ.	Inspect	
If the organization ansv	vered "Yes" on	Form 990, Part IV, line 3, or Forn	n 990-EZ, Part V, line	46 (Political Camp	aign Acti	ivities), then:	
 Section 501(c)(3) org 	anizations: Com	plete Parts I-A and B. Do not com	plete Part I-C.				
 Section 501(c) (other 	than section 50	1(c)(3)) organizations: Complete P	arts I-A and C below. I	Do not complete Par	t I-B.		
 Section 527 organiza 	ations: Complete	e Part I-A only.					
If the organization ansv	vered "Yes" on	Form 990, Part IV, line 4, or Form	n 990-EZ, Part VI, line	e 47 (Lobbying Acti	vities), th	nen:	
 Section 501(c)(3) org 	anizations that h	nave filed Form 5768 (election und	er section 501(h)): Con	nplete Part II-A. Do r	not comp	lete Part II-B.	
 Section 501(c)(3) org 	anizations that h	nave NOT filed Form 5768 (electior	n under section 501(h))	: Complete Part II-B	. Do not o	complete Part II-/	Α.
If the organization ansv	vered "Yes" on	Form 990, Part IV, line 5 (Proxy 1	Гах) (see separate ins	tructions) or Form	990-EZ,	Part V, line 35c	(Proxy
Tax) (see separate instr							
	-	ions: Complete Part III.					
Name of organization		L TUBEROUS SCLERO	SIS			er identification	
	ASSOCIA					95-30187	99
Part I-A Comple	ete if the org	anization is exempt under	section 501(c) o	r is a section 52	27 orga	inization.	
		ation's direct and indirect political	campaign activities in	Part IV.			
2 Political campaign a	activity expendit	ures			\$_		
3 Volunteer hours for	political campai	gn activities					
D. I.I.D. Oameria							
		anization is exempt under		-			
	•	incurred by the organization under					
		incurred by organization managers			\$ _		
•		n 4955 tax, did it file Form 4720 fo	r this year?			Yes	No
4a Was a correction m						Yes	No
b If "Yes," describe in					-04(-)(
	-	anization is exempt under		-		5).	
		I by the filing organization for secti			\$ _		
2 Enter the amount of	f the filing organ	ization's funds contributed to othe	r organizations for sec	tion 527			
exempt function act					\$_		
	-	. Add lines 1 and 2. Enter here and					
					\$_		
00						Yes	No No
		nployer identification number (EIN)		•			
		tion listed, enter the amount paid f					
		omptly and directly delivered to a s			eparate s	egregated fund o	or a
political action com	mittee (PAC). If a	additional space is needed, provide	e information in Part IV	'. I			
(a) Name	•	(b) Address	(c) EIN	(d) Amount paid		(e) Amount of p	
				filing organizatio		ontributions rece promptly and c	
				funds. If none, ent	.er -0	delivered to a se	
						political organi	zation.
						If none, ente	r -0

Political Campaign and Lobbying Activities

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

ation in dea avibad balaw. Attach to Fr 000 57

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

Schedule C (Form 990) 2023

LHA 332041 11-06-23

SCHEDULE C

(Form 990)

OMB No. 1545-0047

Sche		NATIONAL TU ASSOCIATION	BEROUS SCLEI	ROSIS	95-3	018799 Page 2
Pa	t II-A Complete if the org section 501(h)).	anization is exen	npt under section	501(c)(3) and file	ed Form 5768 (ele	ction under
	expenses, and sha	re of excess lobbying e	• •		group member's name	e, address, EIN,
B (Check if the filing organiza	ation checked box A ar	nd "limited control" pro	visions apply.	ſ	
		its on Lobbying Expe ditures" means amou	nditures Ints paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals
1a	Total lobbying expenditures to infl	uence public opinion (grassroots lobbying)		1,345.	
b	Total lobbying expenditures to influence	uence a legislative boo	ly (direct lobbying)		187,396.	
с	Total lobbying expenditures (add li	-	• • • •		188,741.	
d	e				7,128,616.	
е	e Total exempt purpose expenditures (add lines 1c and 1d)				7,317,357.	
f	Lobbying nontaxable amount. Enter				515,868.	
	If the amount on line 1e, column (a) o	or (b) is: The lob	bying nontaxable amo	ount is:		
	not over \$500,000,	20% of	the amount on line 1e.			
	over \$500,000 but not over \$1,000	0,000, \$100,00	0 plus 15% of the exce	ess over \$500,000.		
	over \$1,000,000 but not over \$1,5	00,000, \$175,00	0 plus 10% of the exce	ess over \$1,000,000.		
	over \$1,500,000 but not over \$17,	000,000, \$225,00	0 plus 5% of the exces	s over \$1,500,000.		
	over \$17,000,000,	\$1,000,	000.			
g	Grassroots nontaxable amount (er	nter 25% of line 1f)			128,967.	
h	Subtract line 1g from line 1a. If zer	o or less, enter -0-			0.	
i	Subtract line 1f from line 1c. If zero	o or less, enter -0			0.	
j	If there is an amount other than ze	ro on either line 1h or	line 1i, did the organiza	tion file Form 4720		
	reporting section 4911 tax for this	year?				Yes No
	(Some organizations t	hat made a section 5	eraging Period Under 01(h) election do not l ate instructions for lin	nave to complete all c	of the five columns be	low.
		Lobbying Exper	nditures During 4-Yea	r Averaging Period		
	Calendar year	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) Total

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) Total
2a Lobbying nontaxable amount	423,685.	497,465.	550,968.	515,868.	1,987,986.
 b Lobbying ceiling amount (150% of line 2a, column(e)) 					2,981,979.
c Total lobbying expenditures	123,014.	154,139.	162,771.	188,741.	628,665.
d Grassroots nontaxable amount	105,921.	124,366.	137,742.	128,967.	496,996.
e Grassroots ceiling amount (150% of line 2d, column (e))					745,494.
f Grassroots lobbying expenditures	895.	1,127.	1,395.	1,345.	4,762.

Schedule C (Form 990) 2023

332042 11-06-23

<u></u>	~	-		
Schedule (U	(⊦orm	990)	2023

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

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 e	For each "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description			(b)	
	e lobbying activity.	Yes	No	Amo	ount
1 a	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: Volunteers?				
b	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?				
	unteers?				
	Diverse and a standard standard with the standard fits and a standard standar				
-					
	t III-A Complete if the organization is exempt under section 501(c)(4), section	n 501(c)(5)	, or sec	tion	
	501(c)(6).				
				Yes	No
1	Were substantially all (90% or more) dues received nondeductible by members?		. 1		
2					
3	Did the organization agree to carry over lobbying and political campaign activity expenditures from the	e prior year?	3		
Par	t III-B Complete if the organization is exempt under section 501(c)(4), section				
	501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered '	'No" OR (b	o) Part I	II-A, line	3, is
	answered "Yes."				
1	Dues, assessments and similar amounts from members		. 1		
2	Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political	al			
	expenses for which the section 527(f) tax was paid).				
а	Current year		2a		
b	Carryover from last year		2b		
с	Total		2c		
3					
4	If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the exce				
	does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and po	olitical			
	expenditures next year?		4		
	Taxable amount of lobbying and political expenditures. See instructions		. 5		
Par	t IV Supplemental Information				
Provi	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	list); Part II-A,	lines 1 a	nd 2 (see	

instructions); and Part II-B, line 1. Also, complete this part for any additional information.

Schedule C (Form 990) 2023

332043 11-06-23

SCI	HEDULE D	I		Supr	olement	al Financi	al S	tatement	S		ON	/IB No. 154	5-0047
(Form 990)		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.								2023			
Departe	nent of the Treasury			Part IV, lir		0, 11a, 11b, 11c, Attach to Form 9		le, 11f, 12a, or 1	2b.		Open to Public		
Internal	Revenue Service					90 for instruction		he latest inform	ation.	Inspection			
Nam	e of the organizati	ion				SCLEROSIS	5			Employer		tification 01879	
Par	t I Organiza	atio	ASSOC: ns Mainta			ed Funds or C	ther S	Similar Funds	or Ac				
I UI				-	990, Part IV, li						South		;
						(a) Dono	or advise	ed funds	(b) Funds and	d othe	er accoun	ts
1	Total number at er	nd of	vear							-			
2	Aggregate value o												
3	Aggregate value o	of grai	nts from (du	ring year)									
4	Aggregate value a	t end	d of year										
5	Did the organization					-							
	are the organizatio											Yes	No No
6	Did the organizatio		•		-					•			
	for charitable purp					,				0		~	N
Par	impermissible priv		n Fasem	ents co	malata if tha a	rganization answe	rod "Va		Dort IV	lino 7		Yes	<u>No</u>
1	Purpose(s) of cons								raitiv,				
				•		ation or education		Preservation of	of a histo	rically impor	tant la	and area	
	Protection o						" <u> </u>	Preservation of		, ,			
	Preservation												
2	Complete lines 2a			organizati	on held a qual	ified conservatior	contrib	oution in the form	of a cor	servation ea	aseme	ent on the	last
	day of the tax year	r.	0	U U						Held	at the	End of the	Tax Year
а	Total number of co	onser	rvation ease	ments						2a			
b	Total acreage rest									2b			
с	c Number of conservation easements on a certified historic structure included on line 2a												
d					•	-							
	on a historic struct									2d			
3	Number of conser	vatio	n easements	s modified,	transferred, re	eleased, extinguis	ned, or	terminated by the	e organiz	zation during	the t	ax	
-	year												
4	Number of states		,					the second second second second					
5	Does the organization				• • •		•					Yes	No
6	violations, and enf Staff and voluntee							nd enforcina con			urir:		
Ŭ					ng, nopooting	, nanaling of viole	cione, a		oorvatio		Guin	ig the yet	
7	Amount of expens	ses in	ncurred in mo	onitoring, ir	nspecting, han	dling of violations	, and er	nforcing conserva	ation eas	ements duri	ng th	e year	
				0.		C C		C C			0		
8	Does each conser	vatio	n easement	reported o	n line 2d abov	e satisfy the requ	rements	s of section 170(I	n)(4)(B)(i)				
	and section 170(h))(4)(B	B)(ii)?									Yes	No
9	In Part XIII, describ	be ho	ow the organ	ization rep	orts conservat	ion easements in	its reve	nue and expense	e statem	ent and			
	balance sheet, and	d incl	lude, if applie	cable, the t	text of the foot	note to the organ	ization's	s financial statem	ents tha	t describes f	the		
Par	organization's acc					f Art, Historic			thor S	milor Aoo	oto		
Far				-		-		asures, or O	uner S	milar Ass	els.		
			-			n 990, Part IV, lin		anua atatamant	and halo	noo oboot w	orleo		
Ia	If the organization of art, historical tre										Orks		
	service, provide in		-		-								
h	If the organization									sheet works	of		
	art, historical treas												
	provide the followi					,	, -				,		
	-	-		-						\$			
	(ii) Assets include									•			
2	If the organization	rece	eived or held										
	the following amou												
а	Revenue included	on F	orm 990, Pa	rt VIII, line	1					\$			
	Assets included in									\$			
LHA	For Paperwork R	educ	ction Act No	tice, see t	he Instruction	is for Form 990.				Schee	dule i	D (Form 9	990) 2023
332051	09-28-23					24							
						31							

^{2023.04030} NATIONAL TUBEROUS SCLEROS 71690.02

	NATIONA	L TUBEROUS	SCLEROSIS						
Sche	dule D (Form 990) 2023 ASSOCIA)18799	<u>) Р</u>	age 2
Par	t III Organizations Maintaining C	ollections of Art	t, Historical Tre	asures, or Oth	er Sin	nilar Asset	s (contir	nued)	
3	Using the organization's acquisition, accession	on, and other records	s, check any of the f	ollowing that make	signific	ant use of its			
	collection items (check all that apply).								
а	Public exhibition	d	Loan or exc	hange program					
b	Scholarly research	е	Other						
с	Preservation for future generations								
4	Provide a description of the organization's co	llections and explain	how they further th	e organization's exe	empt p	urpose in Par	t XIII.		
5	During the year, did the organization solicit o	r receive donations o	of art, historical treas	sures, or other simila	ar asse	ts			
	to be sold to raise funds rather than to be ma						Yes		No
Par	t IV Escrow and Custodial Arrang	gements Complet	te if the organizatior	answered "Yes" or	n Form	990, Part IV,	line 9, or		
	reported an amount on Form 990, Par	t X, line 21.							
1a	Is the organization an agent, trustee, custodi	an, or other intermed	liary for contribution	s or other assets no	ot inclu	ded			_
	on Form 990, Part X?					L	Yes		No
b	If "Yes," explain the arrangement in Part XIII	and complete the foll	lowing table:		_				
					L		Amoun	t –	
с	Beginning balance				L	1c			
d	Additions during the year				L	1d			
е	Distributions during the year				L	1e			
f	Ending balance				L	1f			
2a	Did the organization include an amount on Fe				oility?		Yes		No
b	If "Yes," explain the arrangement in Part XIII.								
Par	Tt V Endowment Funds Complete if	the organization ans	wered "Yes" on For	m 990, Part IV, line	-				
		(a) Current year	(b) Prior year	(c) Two years back	(d)⊺	hree years back	t (e) Four	years	back
1a	Beginning of year balance	5,500,387.	6,711,748.	5,893,521.	•	5,915,805	. 5	,193,	,934.
b	Contributions	141,816.	68,423.	132,476.	•	54,645.		5. 78,962	
с	Net investment earnings, gains, and losses	812,509.	-860,036.	1,053,588.	•	416,431	•	959,	,121.
d	Grants or scholarships								
е	Other expenditures for facilities								
	and programs	572,625.	238,000.	333,813,	•	463,721	•	288,	,356.
f	Administrative expenses	60,900.	181,748.	34,024	•	29,639	•	27,	,856.
g	End of year balance	5,821,187.	5,500,387.	6,711,748		5,893,521	. 5	,915,	,805.
2	Provide the estimated percentage of the curr	ent year end balance	e (line 1g, column (a)) held as:					
а	Board designated or quasi-endowment	83.6060	_%						
b	Permanent endowment 15.7890	%							
с	Term endowment .6050	%							
	The percentages on lines 2a, 2b, and 2c show	uld equal 100%.							
3a	Are there endowment funds not in the posse	ssion of the organiza	tion that are held ar	nd administered for	the		-		
	organization by:							Yes	No
	(i) Unrelated organizations?						3a(i)		X
							a (11)	Х	
b	If "Yes" on line 3a(ii), are the related organiza	tions listed as require	ed on Schedule R?				. 3b	Х	
4	Describe in Part XIII the intended uses of the	organization's endov	wment funds.						
Par	t VI Land, Buildings, and Equipm	ent							
	Complete if the organization answere	d "Yes" on Form 990	, Part IV, line 11a. S	ee Form 990, Part >	K, line 1	0.			
	Description of property	(a) Cost or o	ther (b) Cost	or other (c)	Accum	ulated	(d) Boo	k valu	ie
		basis (investr	nent) basis	(other) c	leprecia	ation			
1a	Land								
b	Buildings								
	Leasehold improvements			9,272.	153	,160.	29	5,1	12.
	Equipment		28	1,726.	183	,877.	9	7,8	49.
	Other		8	0,272.	80	,272.			0.
Total	Add lines 1a through 1e. (Column (d) must e	aual Form 990. Part)	X. line 10c. column	<i>(</i> B))			39:	3,9	61.

Schedule D (Form 990) 2023

ASSOCIATION Schedule D (Form 990) 2023 Part VII Investments - Other Securities Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12. (c) Method of valuation: Cost or end-of-year market value (a) Description of security or category (including name of security) (b) Book value (1) Financial derivatives (2) Closely held equity interests (3) Other (A) (B) (C) (D) (E) (F) (G) (H) Total. (Col. (b) must equal Form 990, Part X, line 12, col. (B)) Part VIII Investments - Program Related. Complete if the organization answered "Yes" on Form 990, Part IV, line 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, line 13, col. (B)) Part IX Other Assets Complete if the organization answered "Yes" on Form 990, Part IV, line 11d. See Form 990, Part X, line 15. (a) Description (b) Book value NET ASSETS OF AFFILIATE 5,821,187. (1) OPERATING LEASE RIGHT-OF-USE ASSET 654,282. (2) 334,624 DUE FROM AFFILIATE (3) (4) (5) (6) (7) (8) (9) 6,810,093. Total. (Column (b) must equal Form 990, Part X, line 15, col. (B)) Part X Other Liabilities Complete if the organization answered "Yes" on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25. (a) Description of liability (b) Book value 1. (1) Federal income taxes 1,084,988 OPERATING LEASE LIABILITY (2)DUE FROM RELATED PARTY 693 (3) (4) (5) (6) (7) (8) (9) 1,085,681. Total. (Column (b) must equal Form 990, Part X, line 25, col. (B)) Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the

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

Schedule D (Form 990) 2023

332053 09-28-23

	NATIONAL TUBEROUS SCLEROSI	S				
Sche	dule D (Form 990) 2023 ASSOCIATION				3018799	Page 4
Par	t XI Reconciliation of Revenue per Audited Financial Stateme	ents With I	Revenue per Re	turn		
	Complete if the organization answered "Yes" on Form 990, Part IV, line 12a	1 .				
1	Total revenue, gains, and other support per audited financial statements			1	10,024,	,868.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:					
а	Net unrealized gains (losses) on investments	. 2a	-6,233.			
b	Donated services and use of facilities	. 2b	14,718.			
с	Recoveries of prior year grants	. 2c				
d	Other (Describe in Part XIII.)	. 2d				
е	Add lines 2a through 2d			2e		,485.
3	Subtract line 2e from line 1			3	10,016,	<u>,383.</u>
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:					
а	Investment expenses not included on Form 990, Part VIII, line 7b	4a				
b	Other (Describe in Part XIII.)	4b				
С	Add lines 4a and 4b			4c		0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I. line 12.)			5	10,016,	,383.
Pa	t XII Reconciliation of Expenses per Audited Financial Statem		Expenses per H	letur	n	
	Complete if the organization answered "Yes" on Form 990, Part IV, line 12a					
1	Total expenses and losses per audited financial statements			1	8,482,	,366.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:					
а	Donated services and use of facilities		14,718.			
b	Prior year adjustments	. 2b				
С	Other losses					
d	Other (Describe in Part XIII.)	. 2d				
е	Add lines 2a through 2d			2e		<u>,718.</u>
3	Subtract line 2e from line 1			3	8,467,	,648.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:					
а	Investment expenses not included on Form 990, Part VIII, line 7b					
b	Other (Describe in Part XIII.)	. 4b				-
с	Add lines 4a and 4b			4c		0.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)			5	8,467,	,648.
Pa	t XIII Supplemental Information					

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

PART V, LINE 4:

THE ALLIANCE'S ENDOWMENTS CONSIST OF TWO FUNDS ESTABLISHED FOR DIFFERENT

PURPOSES. THE ALLIANCE'S ENDOWMENTS INCLUDE ONE TRADITIONAL

DONOR-RESTRICTED ENOWMENT FUND AND ONE BOARD-DESIGNATED ENDOWMENT FUND.

34

THE BOARD-DESIGNATED ENDOWMENT FUND SOLELY CONSISTS OF THE ENDOWMENT

FUND'S UNRESTRICTED NET ASSET BALANCE.

PART XII, LINE 2D - OTHER ADJUSTMENTS:

ROUNDING

PART XII, LINE 4B - OTHER ADJUSTMENTS:

FUNDRAISING EXPENSES INCLUDED ON PART VIII

332054 09-28-23

Schedule D (Form 990) 2023

NATIONAL	TUBEROUS	SCLEROSIS
ASSOCIATI	ION	

Schedule D (Form 990) 2023 ASSOCIATION	95-3018799 Page 5
Schedule D (Form 990) 2023 ASSOCIATION Part XIII Supplemental Information (continued)	
	Schedule D (Form 990) 2023

SCHEDULE F	Statement of Activities Outside the United States							
(Form 990)	Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.							
Dependence of the Turner we	•	5	Attach to Form 990.			Open	to Public	
Department of the Treasury Internal Revenue Service	Go to w	ww.irs.gov/Form	1990 for instructions and the latest i	nformation.		Inspec		
Name of the organization					Employer	identific	cation number	
NATIONAL TUBERC	US SCLER	OSIS				1000	`	
ASSOCIATION	motion on A		aida tha Unitad Stataa		95-301			
		cuvilles Out	side the United States. Compl	ete if the orgar	lization answ	ered "Ye	es" on	
Form 990, Part I 1 For grantmakers. Doe	,	a maintain rocor	ds to substantiate the amount of its gra	onts and other	assistanco			
=	-		the selection criteria used to award the				Yes 🗌 No	
2 For grantmakers. Des United States.	cribe in Part V the	e organization's	procedures for monitoring the use of its	s grants and ot	her assistand	ce outsic	le the	
3 Activities per Region. (1	he following Part	I, line 3 table ca	an be duplicated if additional space is r	eeded.)				
(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, pro- gram services, investments, grants to recipients located in the region)	is a pro describe	vity listed in (gram service e specific typ (s) in the regi	e, e	(f) Total expenditures for and investments in the region	
EUROPE (INCLUDING		<u>_</u>						
ICELAND & GREENLAND)								
- ALBANIA, ANDORRA,			GRANTS TO RECIPIENTS					
AUSTRIA, BELGIUM	3	0	LOCATED IN REGION	RESEARCH GF	ANTS		148,750.	
3 a Subtotal	3	0					148,750.	
b Total from continuation		_					-	
sheets to Part I	0	0					0.	
c Totals (add lines 3a and 3b)	3	0					148,750.	

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

Schedule F (Form 990) 2023

LHA 332071 11-29-23

Schedule F (Form 990) 2023

ASSOCIATION

95-3018799

8799

Part II

t II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV appraisal, other)
		EUROPE (INCLUDING						
		ICELAND &						
		GREENLAND) -	RESEARCH ON TUBEROUS					
		ALBANIA, ANDORRA,	SCLEROSIS COMPLEX	18,750.	WIRE TRANSFER	٥.		
		EUROPE (INCLUDING						
		ICELAND &						
		GREENLAND) -	RESEARCH ON TUBEROUS					
			SCLEROSIS COMPLEX	75,000.	WIRE TRANSFER	٥.		
		MIDDLE EAST AND						
		NORTH AFRICA -						
		ALGERIA, BAHRAIN,						
			RESEARCH	8,500.	WIRE TRANSFER	٥.		
		EUROPE (INCLUDING						
		ICELAND &						
		GREENLAND) -	YOUNG INVESTIGATOR					
		ALBANIA, ANDORRA,	FELLOWSHIP AWARD	27,500.	WIRE TRANSFER	٥.		

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

3 Enter total number of other organizations or entities

Schedule F (Form 990) 2023

0 4

Page **2**

95-3018799

ASSOCIATION Schedule F (Form 990) 2023 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 additional space is needed. **(h)** Method of valuation (book, FMV, appraisal, other) (c) Number of (d) Amount of (e) Manner of (f) Amount of (g) Description of (a) Type of grant or assistance (b) Region recipients cash grant cash disbursement noncash assistance noncash assistance

Schedule F (Form 990) 2023

Page 3

Sched	lule F (Form 990) 2023 ASSOCIATION	95-3018799	Page 4
Part			9
1	Was the organization a U.S. transferor of property to a foreign corporation during the tax year? <i>If</i> "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see the 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 the 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? <i>If</i> "Yes," <i>the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see the Instructions for Form 5471)</i>	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? <i>If</i> "Yes," <i>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 the Instructions for Form 8621)</i>	Yes	X No
5	Did the organization have an ownership interest in a foreign partnership during the tax year? <i>If</i> "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see the 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? <i>If</i> "Yes," <i>the organization may be required to separately file Form 5713, International Boycott Report (see the Instructions for Form 5713; don't file with Form 990)</i>	Yes	X No

Schedule F (Form 990) 2023

332074 11-29-23

ASSOCIATION

Schedule F (Form 990) 2023 Part V | Supplemental Information

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

PART I, LINE 2:

GRANTEE ORGANIZATIONS ARE EXPECTED TO FILE ANNUAL PROGRESS REPORTS TO

OUTLINED GRANT GOALS AND MILESTONES. THESE REPORTS ARE REVIEWED BY A

COMMITTEE OF PEERS. THIS COMMITTEE MAKES DETERMINATIONS BASED ON QUALITY

OF WORK TO GOALS AND IF THE GRANTEE WILL CONTINUE TO RECEIVE FUNDING. A

FINAL WRITTEN AND FINANCIAL REPORT IS REQUIRED OF ALL GRANTEES.

Schedule F (Form 990) 2023

332075 11-29-23

SCHEDULE G	0	MB No. 1545-0047								
(Form 990)		e organization answered "Yes" on organization entered more than \$1				r 19, or if the		2023		
Department of the Treasury			Open to Public							
Internal Revenue Service		o www.irs.gov/Form990 for instruct		and th	ne latest information			Inspection		
Name of the organization	NATIONA ASSOCIA	L TUBEROUS SCLEROS TION	IS			95-3		ntification number 799		
		Complete if the organization answe	red "Y	es" or	n Form 990, Part IV, li	ine 17. Form 99	Э0-ЕZ	filers are not		
· · ·	complete this par									
 a Mail solicitat b Internet and c Phone solicitat d In-person so 2 a Did the organization 	b Internet and email solicitations f Solicitation of government grants c Phone solicitations g Special fundraising events									
compensated at le	-			agreer						
(i) Name and addres or entity (func		(ii) Activity	(iii) fundi have c or cor contrib	Did raiser ustody atrol of utions?	(iv) Gross receipts from activity	(v) Amount p to (or retained fundraiser listed in col.	l by)	(vi) Amount paid to (or retained by) organization		
			Yes	No						
Total		1	1	1						
Total										

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

Schedule G (Form 990) 2023

LHA 332081 09-13-23

		e G (Form 990) 2023 ASSOCIA				3018799 Page 2
Pa	rt II	Fundraising Events. Complete if t of fundraising event contributions and gr	•	-	· · ·	-
		of fundraising event contributions and gr	(a) Event #1	(b) Event #2	(c) Other events	
			WALK-RUN-RID		(0)	(d) Total events
				CURE	8	(add col. (a) through
			(event type)	(event type)	(total number)	col. (c))
Revenue						
eve	1	Gross receipts	789,897.	464,844.	183,399.	1,438,140
۳						
	2	Less: Contributions	789,897.	389,556.		1,179,453
	2	Cross income (line 1 minus line 2)		75,288.	183,399.	258,687
+	3	Gross income (line 1 minus line 2)		75,200.	105,599.	230,007
	4	Cash prizes				
	5	Noncash prizes	44,986.	1,128.	2,478.	48,592
ses						
Direct Expenses	6	Rent/facility costs	6,147.	28,633.	8,699.	43,479
Ш Ш	7	Food and beverages	8,314.	44,988.		53,302
lired	'		0,0110	11,5000		557502
	8	Entertainment	12,797.	2,969.		15,766
		Other direct expenses			2,993.	2,993
	10	Direct expense summary. Add lines 4 throug	h 9 in column (d)			164,132
		Net income summary. Subtract line 10 from				94,555
Pa	rt II	• • • • • • • • • • • • • • • • •	answered "Yes" on Form	1990, Part IV, line 19, or	reported more than	
_		\$15,000 on Form 990-EZ, line 6a.	1	(b) Pull tabs/instant		(d) Total gaming (add
e			(a) Bingo	bingo/progressive bingo	(c) Other gaming	col. (a) through col. (c
Revenue				2go, progressive 2go		
æ	1	Gross revenue				
s	2	Cash prizes				
penses						
	3	Noncash prizes				
Direct Ex		Dent (facility aceta				
ä	4	Rent/facility costs				
	5	Other direct expenses				
	-		Yes %	Yes %	Yes %	
	6	Volunteer labor	No	No	No	
	7	Direct expense summary. Add lines 2 throug	h 5 in column (d)			
	-					
	8	Net gaming income summary. Subtract line	(from line 1, column (d)			
9	Fnt	er the state(s) in which the organization cond	ucts gaming activities.			
		he organization licensed to conduct gaming a				Yes N
		No," explain:				
		re any of the organization's gaming licenses r			/ear?	Yes N
b	lf "`	Yes," explain:				
3208	2 09-	-13-23			Sche	dule G (Form 990) 202
			10			

09560927 712177 71690.00001

		NATIONAL	TUBEROUS S	SCLEROSIS			
-	edule G (Form 990) 2023	ASSOCIAT					age 3
	Does the organization conduct ga					Yes	No
	Is the organization a grantor, bene to administer charitable gaming?				•	Yes	No
	Indicate the percentage of gaming						
	The organization's facility					13a 13b	<u>%</u> %
	An outside facility Enter the name and address of the					130	70
	Name						
	Address						
15a	Does the organization have a cont	tract with a third pa	arty from whom the o	organization receives gaming	revenue?	Yes	No
k	If "Yes," enter the amount of gami of gaming revenue retained by the		ed by the organizatio	n \$	_ and the amount		
C	If "Yes," enter name and address	of the third party:					
	Name						
	Address						
16	Gaming manager information:						
	Name						
	Gaming manager compensation	\$					
	Description of services provided						
	Director/officer	Employee	Inde	pendent contractor			
	Mandatory distributions:	state law to make	charitable distributio	one from the gaming process	le to		
c	Is the organization required under retain the state gaming license?			ons norm the gaming proceed		Yes	No
k	Enter the amount of distributions						
	organization's own exempt activiti						
Ра				uired by Part I, line 2b, colui I information. See instruction		rt III, lines 9, 9b, ⁻	10b,
3320	33 09-13-23		4	3	Scheo	lule G (Form 990) 2023

09560927 712177 71690.00001

NATIONAL	TUBEROUS	SCLEROSIS
ASSOCIATI	ION	

Schedule G	a (Form 990) ASSOCIATION	95-3018799 Page 4
Part IV	(Form 990) ASSOCIATION Supplemental Information (continued)	
		Schedule G (Form 990)

332084 04-01-23

SCHEDULE I	G	arants and Oth	er Assistan	ce to Organ	izations.		OMB No. 1545-0047		
Form 990) Governments, and Individuals in the United States Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.									
Department of the Treasury Internal Revenue Service		Go to www.irs	Attach to Form		ation.		Open to Public Inspection		
Internal Revenue Service Go to www.irs.gov/Form990 for the latest information. Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION Emplo									
Part I General Information on Grants ar							95-3018799		
1 Does the organization maintain records to criteria used to award the grants or assis	tance?								
2 Describe in Part IV the organization's pro									
Part II Grants and Other Assistance to I recipient that received more than \$	-				anization answered "Y	es" on Form 990, Part	IV, line 21, for any		
1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance		
BAYLOR COLLEGE OF MEDICINE PO BOX 301207 DALLAS, TX 70690	74-1613878	501(C)(3)	18,750.	0.			RESEARCH GRANT		
BRIGHAM & WOMEN'S HOSPITAL P.O.B 3149 BOSTON, MA 02241	04-2312909	501(C)(3)	56,250.	0.			RESEARCH GRANT		
UNIVERSITY OF VIRGINIA 1001 n. EMMET ST CHARLOTTESVILLE, VA 22903	54-6001796	501(C)(3)	18,750.	0.			RESEARCH GRANT		
NATIONAL ORGANIZATION FOR RARE DISORDERS - DEPT 5430, PO BOX 4110 - WOBURN, MA 01888	13-3223946	501(C)(3)	125,000.	0.			TSC TRAVEL AND LODGING ASSISTANCE PROGRAM		
UNIVERSITY OF CALIFORNIA 10889 WILSHIRE BLVD, SUITE 700 LOS ANGELES, CA 90095	95-6006143	501(C)(3)	20,000.	0.			RESEARCH GRANT		
COLUMBIA UNIVERSITY IN THE CITY OF NEW YORK - 615 W. 131ST STREET, 6TH FLOOR, MAIL CODE 8725 - NEW	12 5508002	501(0)(2)	75.000	0.			DECEADOR ODANM		
YORK, NY 10027 2 Enter total number of section 501(c)(3) ar	13-5598093 nd government org		75,000. e line 1 table	L	l	I	RESEARCH GRANT 13.		
3 Enter total number of other organizations	listed in the line 1	table	·····	·····	<u></u>	·····	0.		

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

ASSOCIATION Schedule I (Form 990)

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
NIVERSITY OF CALIFORNIA IRVINE							
28 ALDRICH HALL							
RVINE, CA 92697	95-2226406	501(C)(3)	18,750.	0.			RESEARCH GRANT
NIVERSITY OF MARYLAND, BALTIMORE							
O BOX 41428							
ALTIMORE, MD 21203	52-6002033	501(C)(3)	56,250.	0.			RESEARCH GRANT
NIVERSITY OF TEXAS SOUTHWESTERN							
EDICAL CENTER - 5323 HARRY HINES							
LVD - DALLAS, TX 75390	75-6002868	501(C)(3)	56,250.	0.			RESEARCH GRANT
·			,				
NIVERSITY OF TEXAS DALLAS							
00 WEST CAMPBEL ROAD, SP2 27							
ICHARDSON, TX 75080	75-1305566	501(C)(3)	18,750.	0.			RESEARCH GRANT
NIVERSITY OF ALABAMA, BIRMINGHAM							
720 2ND AVE SOUTH, AB990		F01 (7) (2)	01.640				
SIRMINGHAM, AL 32294	63-6005396	501(C)(3)	91,649.	0.			RESEARCH GRANT
NIVERSITY OF NEW ENGLAND							
1 HILLS BEACH RD, ROOM 207							
SIDDEFORD, ME 04005	01-0211810	501(C)(3)	20,000.	0.			RESEARCH GRANT
			,				
OSTON CHILDREN'S HOSPITAL							
O BOX 414413							
OSTON, MA 02241	04-2774441	501(C)(3)	57,409.	0.			RESEARCH GRANT

Schedule I (Form 990)

Schedule I (Form 990) 2023

ASSOCIATION

95-3018799

Page 2

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

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non- cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
Part IV Supplemental Information. Provide the information re		 o 2: Dort III. oolumn	(b): and any other as	 ditional information	

Supplemental information. Provide the information required in Part 1, line 2, Part III, column (b), and

PART I, LINE 2:

THE TSC ALLIANCE HAS FUNDED \$37 MILLION IN RESEARCH ON TSC SINCE 1984.

DIRECTED BY STEVEN L. ROBERDS, PH.D, CHIEF SCIENTIFIC OFFICER, THE TSC

ALLIANCE RESEARCH GRANTS PROGRAM FUNDS RESEARCH FOCUSED ON TSC WITH

PRIORITIES SET BY THE RESEARCHERS TOGETHER WITH THE TSC ALLIANCE.

COLLABORATIONS BETWEEN BASIC AND CLINICAL RESEARCHERS ARE ENCOURAGED AND

FOSTERED, AND THE TSC ALLIANCE IS WORKING TO INCREASE FUNDING FOR RESEARCH

ON TSC. THROUGH THE TSC ALLIANCE RESEARCH GRANTS PROGRAM, APPLICATIONS CAN

BE SUBMITTED FOR POSTDOCTORAL FELLOWSHIPS AND TSC RESEARCH GRANTS.

 Schedule I (Form 990)
 ASSOC

 Part IV
 Supplemental Information

GRANTS ARE REVIEWED IN A THREE-STEP PROCESS:

1. A GRANT REVIEW COMMITTEE COMPOSED OF INDIVIDUALS KNOWLEDGEABLE ABOUT THE CLINICAL AND BASIC COMPONENTS OF TSC AS WELL AS CONSUMERS REVIEW ALL GRANT APPLICATIONS FOR SCIENTIFIC MERITS, RELEVANCY TO THE FUNDING PRIORITIES OF THE ORGANIZATION AND WITH A FOCUS ON UNDERSTANDING THE MECHANISMS OF TSC AND/OR THE DEVELOPMENT OF TREATMENTS AND THERAPIES FOR THE MANIFESTATIONS OF THE DISEASE.

2. THE SCIENCE AND MEDICAL COMMITTEE OF THE BOARD OF DIRECTORS THEN REVIEWS THE GRANT REVIEW COMMITTEE'S CONCLUSIONS AND MAKES FUNDING RECOMMENDATIONS TO THE BOARD OF DIRECTORS.

3. THE BOARD OF DIRECTORS THEN REVIEWS THE RECOMMENDATIONS OF THE SCIENCE AND MEDICAL COMMITTEE AND MAKES FINAL APPROVAL FOR THE FUNDING OF GRANTS.

Schedule I (Form 990)

SC	HEDULE J	Compensation Information	1	OMB No. 1	1545-00	47
(Fo	rm 990)	For certain Officers, Directors, Trustees, Key Employees, and Highest		20	22	
		Compensated Employees		20	ZJ)
Depa	rtment of the Treasury	Complete if the organization answered "Yes" on Form 990, Part IV, line 23. Attach to Form 990.		Open to	Publ	ic
	al Revenue Service		Inspe	ction		
Nan	ne of the organization	NATIONAL TUBEROUS SCLEROSIS	Employer ic			mber
		ASSOCIATION	95-3	01879	9	
Pa	rt I Question	s Regarding Compensation				
					Yes	No
1a	Check the appropri	ate 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 c	harter travel Housing allowance or residence for perso	nal use			
	Travel for com					
		ation and gross-up payments Health or social club dues or initiation fee				
	Discretionary s	spending account Personal services (such as maid, chauffer	ır, chef)			
b	•	on line 1a are checked, did the organization follow a written policy regarding payment or				
-		rovision of all of the expenses described above? If "No," complete Part III to explain		1b		
2		n require substantiation prior to reimbursing or allowing expenses incurred by all directors,				
	trustees, and office	rs, including the CEO/Executive Director, regarding the items checked on line 1a?		2		
•						
3		ny, of the following the organization used to establish the compensation of the organization's				
		ctor. Check all that apply. Do not check any boxes for methods used by a related organization of the OFO (Fuer view Directory but eveloping a part III)	on to			
		ation of the CEO/Executive Director, but explain in Part III.				
	X Compensation					
		ompensation consultant X Compensation survey or study ther organizations X Approval by the board or compensation c				
	X Form 990 of o	ther organizations X Approval by the board or compensation c	ommittee			
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 re					
а	0	e payment or change-of-control payment?		4a		X
b		eive payment from a supplemental nonqualified retirement plan?				X
с		eive payment from an equity-based compensation arrangement?				X
	-	les 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		n Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensatio	n			
	contingent on the re					
а	The organization?			. 5a	Х	
b	Any related organiz	ation?		5b		X
		r 5b, describe in Part III.				
6	For persons listed of	n Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensatio	'n			
	contingent on the n	et earnings of:				
а	The organization?			6a	Х	
		ation?				X
		r 6b, describe in Part III.				
7		n Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments				
		ies 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 th	1e			
	initial contract exce	ption described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III		8		X
9	-	d the organization also follow the rebuttable presumption procedure described in				
	Regulations section			9		
For	Paperwork Reducti	on Act Notice, see the Instructions for Form 990.	Schedu	ule J (Forn	n 990) 2023

LHA 332111 11-06-23

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

Schedule J (Form 990) 2023

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.

	((B) Breakdown of W	/-2 and/or 1099-MIS0 compensation	C and/or 1099-NEC	(C) Retirement and other deferred	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation in column (B)
(A) Name and Title		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation	compensation			reported as deferred on prior Form 990
(1) STEVEN ROBERDS (i	i)	214,711.	22,497.	0.	7,291.	19,272.	263,771.	0.
CHIEF SCIENTIFIC OFFICER		0.	0.	0.	0.	0.	0.	0.
(2) KARI LUTHER ROSBECK (i	i)	201,924.	21,822.	0.	7,012.	22,405.	253,163.	0.
PRESIDENT & CEO (i		2,040.	220.	0.	0.	0.	2,260.	0.
(3) DEAN RAGER-AGUIAR (i	i)	159,369.	18,356.	0.	5,660.	22,431.	205,816.	0.
VICE PRESIDENT, TRANSLATIONAL RESEAR (i	ii)	0.	0.	0.	0.	0.	0.	0.
(4) CYNTHIA ARCURI (i	i)	161,389.	15,600.	0.	5,588.	3,894.	186,471.	0.
CHIEF FINANCIAL OFFICER (i	ii)	8,494.	821.	0.	0.	0.	9,315.	0.
(i	i)							
(ii	ii)							
(i	i)							
(i	ii)							
(i	i) _							
(ii	_							
	i) _							
(ii								
	i)							
(i	-							
	i) _							
(i	_							
	i)							
(ii	_							
	i) _							
(ii	_							
	i) _							
(ii	i)							
	ッ_ ii)							
	i)							
(i								
	i)							
(

Schedule J (Form 990) 2023

Page 2

95-3018799

Schedule J (Form 990) 2023

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, STEVE ROBERDS, CYNTHIA ARCURI, DEAN AGUIAR, JAYE

ISHAM, LISA MOSS, AND ASHLEY POUNDERS ALL HAVE INCENTIVE COMPENSATION EQUAL

TO A PERCENTAGE OF THEIR SALARIES BASED ON KEY PERFORMANCE OBJECTIVES AS

ESTABLISHED BY THEIR COMPENSATION COMMITTEE.

ASSOCIATION

PART I, LINE 6:

KARI LUTHER ROSBECK, STEVE ROBERDS, CYNTHIA ARCURI, DEAN AGUIAR, JAYE

ISHAM, LISA MOSS, AND ASHLEY POUNDERS ALL HAVE INCENTIVE COMPENSATION EQUAL

TO A PERCENTAGE OF THEIR SALARIES BASED ON KEY PERFORMANCE OBJECTIVES AS

ESTABLISHED BY THEIR COMPENSATION COMMITTEE.

Schedule J (Form 990) 2023

SCHEDULE O (Form 990)

Department of the Treasury Internal Revenue Service Name of the organization

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 Form 990-EZ.

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

ZUZ3 Open to Public Inspection Employer identification number 95-3018799

OMB No. 1545-0047

NATIONAL TUBEROUS SCLEROSIS ASSOCIATION

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

TREATMENTS, DRIVING RESEARCH TOWARD A CURE AND EXPANDING ACCESS TO

LIFELONG SUPPORT.

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

RESEARCH GRANTS AND POSTDOCTORAL FELLOWSHIPS, \$5.3 MILLION INTO THE

NATURAL HISTORY DATABASE AND BIOSAMPLE REPOSITORY, \$9.6 MILLION INTO

THE PRECLINICAL CONSORTIUM, AND \$1.6 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

TSCALLIANCE.ORG/GRANTS.

IN 2023, THE TSC ALLIANCE HOSTED OUR BIENNIAL INTERNATIONAL TSC

RESEARCH CONFERENCE: FUELING THE FUTURE. FIFTEEN PERCENT OF ATTENDEES

 SELF-IDENTIFIED AS MEMBERS OF GROUPS HISTORICALLY UNDERREPRESENTED IN

 For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.
 Schedule O (Form 990) 2023

LHA 332211 11-14-23

52

Schedule O (Form 990) 2023	Page 2				
Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799				
ASSOCIATION	95-3010799				
BIOMEDICAL RESEARCH. THE CONFERENCE FEATURED AN EARLY CARE	ER RESEARCH				
SYMPOSIUM, A KEYNOTE SPEECH FROM DR. MARTINA BEBIN, 30 ORA	L				
PRESENTATIONS, 59 POSTERS, A TSC INTERNATIONAL WORKSHOP, A	ND A COMBINED				
CLOSING SESSION WITH TSC & LAM REGIONAL CONFERENCE PARTICI	PANTS. THE				
CONFERENCE ALSO FEATURED FOUR BREAKOUT WORKING GROUP SESSI	ONS				
(TRANSITION FROM PEDIATRIC TO ADULT, NEURODEVELOPMENT AND	EARLY				
INTERVENTION, CELLULAR ENERGETICS AND METABOLISM, AND BIG	DATA AND				
SINGLE CELL APPROACHES/ANALYSIS) TO ALLOW TIME FOR ATTENDEES TO MEET					
WITH OTHERS IN THEIR FIELD AND WORK TOWARD SOLUTIONS FOR C	URRENT ISSUES				
IN THEIR AREA.					

IMPLEMENTED IN 2006, THE TSC NATURAL HISTORY DATABASE (NHD) CAPTURES CLINICAL DATA TO DOCUMENT THE IMPACT OF THE DISEASE ON A PERSON'S HEALTH OVER HIS/HER 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 2023, 2,678 PEOPLE WITH TSC WERE ENROLLED IN THE PROJECT FROM AMONG 22 TSC CLINIC 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

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 10 YEARS OR MORE. THE TSC ALLIANCE'S Schedule O (Form 990) 2023 332212 11-14-23 53

09560927 712177 71690.00001

Schedule O (Form 990) 2023	Page 2
Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
SCIENCE AND MEDICAL COMMITTEE IDENTIFIED THIS AS A GAP THA	AT CAN ONLY BE
FILLED EFFECTIVELY WITH LEADERSHIP OF THE TSC ALLIANCE, GU	JIDED BY A
STEERING COMMITTEE OF CLINICIANS AND RESEARCHERS. HIGH-QUA	ALITY
BIOSAMPLES SUCH AS BLOOD, DNA, AND TISSUES LINKED TO DETAI	ILED CLINICAL
DATA ARE CRITICAL FOR RESEARCHERS TO UNDERSTAND WHY TSC IS	S SO DIFFERENT
FROM PERSON TO PERSON. SAMPLES IN THE REPOSITORY ARE LINKE	ED TO DETAILED
CLINICAL DATA IN OUR EXISTING TSC NATURAL HISTORY DATABASE	E 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. AS OF DECEMBER 31, 2023, THE	TSC BIOSAMPLE
REPOSITORY HAS ACQUIRED 2,654 BIOSAMPLES: 1012 BLOOD SAMPI	LES FROM
INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 452 BUCCAL SAMPI	LES FROM
INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 197 TISSUE SAMPI	LES FROM
INDIVIDUALS WITH TSC ENROLLED IN THE NHD, 591 BLOOD SAMPLE	ES FROM THE
TSC CLINICAL RESEARCH CONSORTIUM COLLABORATIVE PROJECTS, 3	389 DNA
SAMPLES FROM THE TSC AUTISM CENTER OF EXCELLENCE NETWORK A	AUTISM
BIOMARKER STUDY, AND 10 CONTROL SAMPLES.	
THE ADAMTESTAN CONTINUES TO CROW THE REACTION	

THE ORGANIZATION CONTINUES 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. SINCE THE INCEPTION OF OUR MOBILE PHLEBOTOMY INITIATIVE, WE HAVE ACQUIRED 473 BLOOD SAMPLES VIA MOBILE PHLEBOTOMY. TO ENCOURAGE AND ENABLE MORE RESEARCHERS TO UTILIZE BIOSAMPLES, THE TSC ALLIANCE AWARDED Schedule O (Form 990) 2023 332212 11-14-23 54

Schedule O (Form 990) 2023	Page 2	
Name of the organization N	Employer identification number 95-3018799	
THREE SEED GRAN	TS IN 2023, TOTALING \$60,000, TO LABS THAT	SUBMITTED

MERITORIOUS AND INNOVATIVE IDEAS FOR RESEARCH ON TSC BIOSAMPLES.

THE TSC ALLIANCE'S WHOLE-GENOME SEQUENCING (WGS) INITIATIVE USING DNA FROM BLOOD SAMPLES IN OUR BIOSAMPLE REPOSITORY SEQUENCED AN ADDITIONAL 72 SAMPLES IN 2023, TOTALING 115 SAMPLES SINCE INCEPTION. THIS INITIATIVE SUPPORTS CLINICAL VALIDATION OF VARIANTS FOUND VIA WGS IN EITHER THE TSC1 OR TSC2 GENE, AND GENETIC RESULTS ARE OFFERED BACK TO PARTICIPANTS ALONG WITH A GENETIC COUNSELING SESSION FREE OF CHARGE TO THE FAMILY TO HELP THEM BETTER UNDERSTAND THEIR UNIQUE TSC DIAGNOSIS AND PROVIDE VALUABLE INFORMATION FOR FUTURE DECISION MAKING SUCH AS FAMILY PLANNING.

IN DECEMBER 2021, THE TSC ALLIANCE ADDED THE TSC SELF-REPORT PORTAL TO THE TSC NATURAL HISTORY DATABASE. THIS PORTAL PERMITS THE COLLECTION OF PATIENT-REPORTED OUTCOMES ON HOW TSC AFFECTS INDIVIDUALS AND FAMILIES, WHICH WILL COMPLEMENT MEDICAL DATA IN THE NATURAL HISTORY DATABASE. THE PURPOSE OF THIS INITIATIVE IS TO HELP THE TSC ALLIANCE AND TSC RESEARCHERS BETTER UNDERSTAND THE PERSPECTIVE OF THOSE AFFECTED BY TSC TO DEVELOP TOOLS TO MEASURE IMPROVEMENT IN AREAS MOST IMPORTANT TO THE TSC COMMUNITY. EVENTUALLY, THESE MEASUREMENTS CAN BE USED TO IDENTIFY ENDPOINTS FOR CLINICAL TRIALS AND EVIDENCE-BASED GUIDELINES FOR TREATMENT.

ONE OF THE MOST IMPACTFUL ASPECTS OF TSC ON THE QUALITY OF LIFE FOR PEOPLE LIVING WITH TSC IS TSC-ASSOCIATED NEUROPSYCHIATRIC DISORDERS (TAND). THEREFORE, THE TSC ALLIANCE'S FIRST USE OF THE PORTAL IS THROUGH COLLABORATION WITH THE TANDEM PROJECT (EMPOWERING FAMILIES 332212 11-14-23 Schedule O (Form 990) 2023 55 2023.04030 NATIONAL TUBEROUS SCLEROS 71690.02

Schedule O (Form 990) 2023	Page 2
Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
THROUGH TECHNOLOGY: A MOBILE-HEALTH PROJECT TO REDUCE THE	TAND
IDENTIFICATION AND TREATMENT GAP) BY ALLOWING THE COMMUNIT	Y TO COMPLETE
THE SELF-QUANTIFIED TAND CHECKLIST (TAND-SQ). AT THE END C	F 2023, 105
INDIVIDUALS WERE ENROLLED THROUGH THE SELF-REPORT PORTAL.	

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 TAND. IN 2022, THE TSC ALLIANCE ENTERED INTO A PARTNERSHIP WITH THE LAM FOUNDATION TO ADD LAM MOUSE MODELS TO THE PRECLINICAL CONSORTIUM. 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 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 F L7-CRE-TSC2 MICE ON BEHALF OF THE PRECLINICAL CONSORTIUM. 332212 11-14-23 Schedule O (Form 990) 2023

09560927 712177 71690.00001

56

95-3018799

FORM 990, PART III, LINE 4A, DESCRIPTION OF PROGRAM SERVICE:
THE PRECLINICAL CONSORTIUM INVITES COMPOUND NOMINATIONS FROM ACADEMIC
AND INDUSTRY RESEARCHERS 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. A MEMBERS
MEETING IS HELD ANNUALLY 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. IN 2023, TWO NEW INDUSTRY MEMBERS JOINED THE CONSORTIUM
WITH A TOTAL OF 9 ACTIVE INDUSTRY MEMBERS AT THE END OF THE YEAR. THE
CONSORTIUM HAS HAD 22 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% OVERHEAD PAID BY THE COMPANY,
WHICH IS A SOURCE OF REVENUE FOR THE TSC ALLIANCE. THE CONSORTIUM
TESTED 17 UNIQUE COMPOUNDS IN 2023, RAISING THE TOTAL TESTED TO 82
SINCE 2016. MANY COMPOUNDS WILL ENTER PRECLINICAL TESTING, THOUGH ONLY
SOME WILL ADVANCE TO CLINICAL TESTING DUE TO LACK OF EFFICACY AND
SAFETY.

57

332212 11-14-23

Schedule O (Form 990) 2023 Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Page 2 Employer identification number 95-3018799
IN 2012, THE TSC ALLIANCE HELPED CREATE THE TSC CLINICAL R	ESEARCH
CONSORTIUM IN PARTNERSHIP WITH INVESTIGATORS RUNNING CLINI	CAL STUDIES
TO ENSURE CLINICAL RESEARCH IN TSC IS AS EFFICIENT AND EFF	ECTIVE AS
POSSIBLE. SINCE THEN, TSC CLINICAL RESEARCH CONSORTIUM INV	ESTIGATORS
HAVE BEEN AWARDED MORE THAN \$40 MILLION BY THE NATIONAL IN	ISTITUTES OF
HEALTH (NIH) AND FOOD AND DRUG ADMINISTRATION (FDA) THROUG	H COMPETITIVE
GRANT PROCESSES. TSC ALLIANCE PERSONNEL SERVE ON THE LEADE	RSHIP TEAM
FOR THE CONSORTIUM, ACTIVELY TRACK ENROLLMENT, AND RAISE C	COMMUNITY
AWARENESS TO HELP IDENTIFY POTENTIAL PARTICIPANTS FOR CLIN	IICAL 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 TSCWAS THE FIRST PREVENTA	TIVE TRIAL IN
THE UNITED STATES FOR ANY FORM OF EPILEPSY. INITIAL RESULT	'S FROM THE
STUDY WERE REPORTED THIS YEAR. IN THE PREVENT TRIAL, INFAN	ITS WITH TSC
RECEIVED REGULAR EEG MONITORING AND THOSE WHO DEVELOPED EE	G
ABNORMALITIES WERE PLACED ON EITHER VIGABATRIN (SUPPLIED B	Y LUNDBECK)
OR A PLACEBO. ANY INFANT WHO SUBSEQUENTLY DEVELOPED CLINIC	AL SEIZURES
WAS IMMEDIATELY PLACED ON STANDARD TREATMENT. RESULTS OF T	HE STUDY
SHOWED THAT PREVENTATIVE TREATMENT WITH VIGABATRIN BEGINNI	NG WHEN EEG
BIOMARKER CHANGES WERE OBSERVED DELAYED THE ONSET AND LOWE	RED THE
OVERALL OCCURRENCE OF INFANTILE SPASMS IN INFANTS WITH TSC	. HOWEVER,
THERE WAS NO SIGNIFICANT DIFFERENCE BETWEEN THE TREATMENT	GROUP AND THE
PLACEBO GROUP IN TERMS OF DRUG-RESISTANT EPILEPSY, FOCAL S	EIZURES, OR
COGNITIVE AND BEHAVIORAL OUTCOMES AT TWO YEARS OF AGE. IN	THIS TRIAL,
THE BIGGEST PREDICTOR OF POORER DEVELOPMENTAL OUTCOMES WAS	THE AGE AT
WHICH THE EEG BIOMARKER CHANGES OCCURRED: THOSE INFANTS WH	IOSE EEG
CHANGES OCCURRED PRIOR TO SEVEN MONTHS OF AGE HAD, ON AVER	AGE, LOWER
COGNITIVE AND BEHAVIORAL SCORES THAN THOSE WHOSE EEG CHANG	
332212 11-14-23 58	Schedule O (Form 990) 2023

09560927 712177 71690.00001

Schedule O (Form 990) 2023	Page 2
Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
LATER, REGARDLESS OF TREATMENT VIA VIGABATRIN VERSUS PLACE	BO. THIS
SUGGESTS THAT RAPID DIAGNOSIS OF TSC IN INFANTS, PRIOR TO	HAVING ANY
SEIZURES, FOLLOWED BY A CLOSE MONITORING AND RAPID INITIAT	ION OF
TREATMENT WHEN SEIZURES BEGIN IS CRITICAL FOR ENSURING THE	BEST
OUTCOMES POSSIBLE. MORE DETAILS ABOUT THIS STUDY ARE ONLI	NE AT
WWW.CLINICALTRIALS.GOV/CT2/SHOW/NCT02849457.	

IMMEDIATELY AFTER THE PREVENT TRIAL ENROLLMENT COMPLETED, A SIMILAR CLINICAL TRIAL BEGAN ENROLLING NEWBORNS WITH TSC BEFORE THE ONSET OF SEIZURES TO TEST THE EFFECTS OF SIROLIMUS ON PREVENTING OR DELAYING SEIZURE ONSET. THE STOPPING TSC ONSET AND PROGRESSION 2 (STOP-2) TRIAL ENROLLED FIVE INFANTS AT CINCINNATI CHILDREN'S HOSPITAL MEDICAL CENTER AS AN INITIAL SAFETY STUDY. THE SECOND STAGE OF THE TRIAL IS NOW CALLED "SIROLIMUS TSC EPILEPSY PREVENTION STUDY (TSC-STEPS)" AND THE TSC ALLIANCE HAS CONTRIBUTED \$200,000 TO ENABLE THE TRIAL TO BE EXPANDED TO ADDITIONAL SITES ACROSS THE COUNTRY. THE 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 IN 2019 FOR A SECOND 5-YEAR FUNDING PERIOD. THE TSC ALLIANCE FUNDS A PORTION OF CLINICAL RESEARCH COORDINATORS' SALARIES AT 5 SITES. IN 2021, THE TSC ALLIANCE AWARDED A Schedule O (Form 990) 2023 332212 11-14-23 59

09560927 712177 71690.00001

Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
TWO-YEAR CLINICAL RESEARCH TSC-DSC FELLOWSHIP TO FELIX CHA	N, PHD, AT
BROWN UNIVERSITY WHO MOVED IN 2022 TO ASTON UNIVERSITY IN	BIRMINGHAM,
ENGLAND.	

FORM 990, PART III, LINE 4B, DESCRIPTION OF PROGRAM SERVICE: SUPPORT SERVICES IS DEDICATED TO SUPPORTING INDIVIDUALS AND FAMILIES AFFECTED BY TSC THROUGH OUTREACH PROGRAMS, SUPPORT SERVICES, IMPROVED MEDICAL ACCESS, AND EDUCATIONAL RESOURCES.

IN 2023, THE TSC ALLIANCE IMPLEMENTED A NEW COMMUNITY SUPPORT MODEL THAT PUTS THE TSC COMMUNITY CENTER FOCUSING ON LOCAL RESOURCES, SUPPORT SERVICES, AND ACCESS TO MEDICAL CARE IN CONJUNCTION WITH ENERGIZING THE CURRENT AND FUTURE VOLUNTEER LEADERS TO PROPEL THE TSC ALLIANCE TO THE NEXT LEVEL. THIS MODEL UNITED 36 COMMUNITY ALLIANCES AND ORGANIZED THEM INTO 15 COMMUNITY REGIONS, LED BY MORE THAN 150 DEDICATED LEADERS THROUGHOUT THE UNITED STATES.

THE COMMUNITY PROGRAMS TEAM INVESTED MORE THAN 900 TRAINING HOURS TO OUR LEADERS, TO ENSURE THEY WERE WELL EQUIPPED TO SUPPORT AND EMPOWER THE TSC COMMUNITY. AS A RESULT, WE PROVIDED 4,278 PEER-TO-PEER SUPPORT ENGAGEMENTS AND FACILITATED 50 SCHOOL MEETINGS, WHICH INVOLVED TSC 101 TRAINING AND IEP CONSULTATIONS. IN ADDITION, TWO "ASK AN ADVOCATE" WEBINARS ATTRACTED 94 REGISTRANTS.

THE COMMUNITY PROGRAMS TEAM COLLABORATED WITH KEY STAFF TO HOST SEVEN RESEARCH AND CORPORATE PARTNER WEBINARS. THESE WEBINARS ATTRACTED 312 LIVE ATTENDEES AND GARNERED 832 RECORDED VIEWS, WITH 801 LANDING PAGE 332212 11-14-23 Schedule O (Form 990) 2023 60

09560927 712177 71690.00001

VIEWS AS OF DECEMBER 31, 2023.

THE TSC ALLIANCE ALSO PARTNERED WITH THE LAM FOUNDATION TO CO-HOST FOUR

EDUCATIONAL CONFERENCE SERIES HELD IN SEATTLE, WA; DENVER, CO;

BIRMINGHAM, AL; WASHINGTON, DC. THESE CONFERENCES ATTRACTED 350-PLUS PARTICIPANTS.

THE TSC ALLIANCE'S TSC NAVIGATOR IS AN EASY-TO-USE, INTERACTIVE ONLINE TOOL TO HELP GUIDE INDIVIDUALS AND FAMILIES THROUGH THE COMPLEXITIES OF TSC ACROSS THE LIFESPAN, PROACTIVELY MANAGE THEIR CARE, AND LIVE THEIR FULLEST LIVES. USERS CAN ACCESS INFORMATION BASED ON THE AGE OF ONE'S DIAGNOSIS, SUCH AS PRENATAL, CHILDHOOD, OR ADULT, TO HELP DETERMINE WHICH STEPS WILL HELP EMPOWER THEM THROUGHOUT THEIR INDIVIDUAL JOURNEYS. IN 2023, THE TOOL HAD 2,379 USERS. EIGHT INDIVIDUALS OR FAMILIES WERE ALSO SUPPORTED FOR MEDICATION ACCESS ISSUES VIA OUR TSC NAVIGATOR PROGRAM DURING 2023, DOWN FROM 55 IN 2022, CONSISTENT WITH THE GOAL OF PROACTIVELY HELPING PEOPLE AVOID MEDICATION ACCESS ISSUES.

FORM 990, PART III, LINE 4C, DESCRIPTION OF PROGRAM SERVICE: PUBLIC HEALTH EDUCATION INCREASES AWARENESS OF TSC THROUGHOUT THE GENERAL PUBLIC TO BROADEN THE SCOPE OF SUPPORT AND UNDERSTANDING BEYOND TSC INDIVIDUALS AND THEIR FAMILIES; THESE EFFORTS ALSO WORK TO HELP REACH THE UNDIAGNOSED AND NEWLY DIAGNOSED.

DURING 2023, THE TSC ALLIANCE PRODUCED TWO ISSUES OF ITS NATIONAL

MAGAZINE, PERSPECTIVE, WHICH IS MAILED TO APPROXIMATELY 18,500

CONSTITUENTS AS WELL AS POSTED ON THE WEBSITE. THE TSC ALLIANCE'S
332212 11-14-23
Schedule O (Form 990) 2023
61

09560927 712177 71690.00001

Schedule O (Form 990) 2023	Page 2			
Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799			
PODCAST SERIES, CALLED TSC NOW, PRODUCED EIGHT EPISODES WI	TH 2,180			
TOTAL LISTENS. FIVE ISSUES OF THE ELECTRONIC TSC MATTERS NEWSLETTER				
WERE DISTRIBUTED TO 17,514 RECIPIENTS. THE TSC ALLIANCE'S	WEBSITE			
INCREASES AWARENESS AND PROVIDES EXTENSIVE EDUCATION THROUGH A MONTHLY				
AVERAGE OF 26,916 PAGE VIEWS.				

THE TSC ALLIANCE ALSO RELIES HEAVILY ON SOCIAL MEDIA TO EDUCATE CONSTITUENTS AND PROMOTE NEW RESOURCES AND EVENTS. ITS PRIVATE FACEBOOK TSC DISCUSSION GROUP BOASTS MORE THAN 10,800 MEMBERS FROM AROUND THE WORLD, WHILE ITS TWITTER ACCOUNT HAS 2,684 FOLLOWERS AND INSTAGRAM HAS 3,432 FOLLOWERS.

TO INCREASE PUBLIC AWARENESS, THE TSC ALLIANCE PARTICIPATED IN THE 11TH ANNUAL TSC GLOBAL AWARENESS DAY ON MAY 15 AS WELL AS TSC AWARENESS MONTH THROUGHOUT MAY. THE TSC ALLIANCE ALSO HEAVILY PROMOTED INFANTILE SPASMS AWARENESS WEEK (DECEMBER 1 TO 7). THESE AWARENESS CAMPAIGNS ALONG WITH THE ORGANIZATION'S VARIOUS NEWS RELEASES AND SOCIAL MEDIA OUTREACH EFFORTS CULMINATED IN MORE THAN 812 MILLION CUMULATIVE IMPRESSIONS AND ENGAGEMENTS.

FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES: GOVERNMENT RELATIONS EFFORTS FOCUS ON INCREASING FEDERAL AND STATE APPROPRIATIONS FOR TSC RESEARCH, RAISING AWARENESS, AND COLLABORATING WITH GOVERNMENT PARTNERS TO DRIVE TSC RESEARCH FORWARD AND IMPROVE CLINICAL CARE AND TREATMENT OPTIONS FOR INDIVIDUALS WITH TSC.

	ON	THE	STATE	LEVEL,	THE	TSC	ALLIANCE	ADVOCATE	D FOR	STATE	FUNDING	FOR		
	332212	2 11-14-2	3								Sche	dule O (Form	990) 2023	
								62						
09	5609	927 '	712177	71690.	00001		20	23.04030	NATIO	NAL TU	BEROUS	SCLEROS	71690	.02

Schedule O (Form 990) 2023 Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Page 2 Employer identification number 95-3018799
TSC CENTERS IN ALABAMA, MISSOURI, AND MARYLAND, RESULTING	IN AT LEAST
\$1.25 MILLION IN STATE APPROPRIATIONS. THE ANNUAL TSC ALL	IANCE MARCH
ON CAPITOL HILL TO ADVOCATE FOR FEDERAL FUNDING FOR THE TU	IBEROUS
SCLEROSIS COMPLEX RESEARCH PROGRAM (TSCRP) AT THE DEPARTME	INT OF
DEFENSE'S (DOD) CONGRESSIONALLY DIRECTED MEDICAL RESEARCH	PROGRAM
(CDMRP) TOOK PLACE IN EARLY MARCH 2023. ADVOCATES MET WITH	MORE THAN
322 CONGRESSIONAL OFFICES VIRTUALLY AND IN PERSON TO ASK F	'OR \$10
MILLION IN FUNDING FOR THE TSCRP. THE HOUSE TSCRP DEAR COL	LEAGUE LETTER
SPONSORED BY REPRESENTATIVES FITZPATRICK (R-PA) AND RASKIN	I (D-MD)
CLOSED WITH 191SIGNERS. THE SENATE LETTER SPONSORED BY SEN	IATORS CRAMER
(R-ND) AND HEINRICH (D-NM) CLOSED WITH 41 SIGNERS.	
TOTAL FUNDING FOR THE TSCRP HAS BEEN \$113 MILLION SINCE 20	02, INCLUDING
A \$10 MILLION APPROPRIATION FOR FY234. RESEARCH PERFORMED	THROUGH THIS
PROGRAM HAS RECENTLY LED TO ADDITIONAL CLINICAL TRIALS INC	LUDING
DETERMINING IF IMATINIB, A DRUG FDA-APPROVED FOR CANCER, C	AN SAFELY
IMPROVE LEVELS OF VEGF-D, A BIOMARKER OF LYMPHANGIOLEIOMYC	MATOSIS
(LAM), A LIFE-THREATENING LUNG MANIFESTATION OF TSC, FUNDE	D IN FY2013;
TWO TSCRP AWARDS IN FY2012 AND FY2015 THAT ENABLED GENERAT	ION OF A
POTENTIAL APPROACH FOR GENE THERAPY OF TSC, WHICH HAS SHOW	N PROMISING
RESULTS IN A MOUSE MODEL OF TSC TUMORS IN THE BRAIN; A MUL	TI-SITE
CLINICAL TRIAL TESTING THE EFFICACY OF AN EXPERIMENTAL TOP	ICAL
RAPAMYCIN CREAM TO TREAT THE DISFIGURING FACIAL TUMORS, CA	LLED FACIAL
ANGIOFIBROMAS, CAUSED BY TSC FUNDED IN FY2010 THAT LED THE	THIRD
FDA-APPROVED DRUG TO TREAT TSC IN APRIL 2022; AND A CLINIC	AL RESEARCH
NETWORK THAT 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	
³³²²¹² 11-14-23 63	Schedule O (Form 990) 2023

^{2023.04030} NATIONAL TUBEROUS SCLEROS 71690.02

Schedule O (Form 990) 2023	Page 2
Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
RESEARCH AWARD TO DEFINE EARLY AUTISM PREDICTORS IN TSC AN	D 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 CHIL	DREN WITH
AUTISM. THE TSCRP HAS ALSO FUNDED RESEARCH TO DEVELOP ANIM	AL MODELS OF
TSC THAT HAVE SEIZURES, ENABLING A BETTER UNDERSTANDING OF	THE ETIOLOGY
OF TSC. BASED ON DATA FROM TSCRP-FUNDED ANIMAL MODELS OF T	SC THAT HAVE
SEIZURES AND SHARE PATHOLOGY RELATED TO THAT OF TRAUMATIC	BRAIN INJURY,
AN INDUSTRY-SPONSORED CLINICAL TRIAL DEMONSTRATED THE EFFE	CTIVENESS THE
MTOR INHIBITOR, EVEROLIMUS, AT TREATING EPILEPSY IN MANY I	NDIVIDUALS
WITH TSC. NONE OF THIS PROGRESS WOULD HAVE BEEN POSSIBLE W	ITHOUT THE
CRITICAL SUPPORT PROVIDED THROUGH THE TSCRP.	

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 AFFECTED BY TSC AND RAISE REVENUE AND AWARENESS WHILE SUPPORTING THE MISSION OF THE ORGANIZATION. THE TSC ALLIANCE HAS SIX GLOBAL PARTNERSHIPS, INCLUDING TSC ALLIANCE OF ISRAEL, TS CANADA ST, TSC ALLIANCE OF MEXICO, TSC ALLIANCE FOUNDATION (IN THAILAND), HUNGARIAN FOUNDATION FOR TUBEROUS SCLEROSIS, AND TSC ALLIANCE OF INDIA. THE TSC ALLIANCE RECOGNIZES 13 TSC CLINICS IN GLOBAL ALLIANCE COUNTRIES.

PROFESSIONAL EDUCATION EXPANDS PROGRAMS TO TARGET RESEARCHERS AND

 HEALTHCARE PROVIDERS CARING FOR INDIVIDUALS WITH TSC, MEDICAL STUDENTS,

 332212 11-14-23

 Schedule O (Form 990) 2023

 64

Schedule O (Form 990) 2023 Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Page 2 Employer identification number 95-3018799
GENETIC COUNSELORS AND EDUCATORS TO MINIMIZE THE CONSEQUEN	•
IGNORANCE AND MISINFORMATION. THE TSC ALLIANCE EXHIBITED A	T THE
AMERICAN EPILEPSY SOCIETY ANNUAL MEETING. STAFF MEMBERS AN	ID A VOLUNTEER
SHARED EDUCATIONAL MATERIALS WITH ATTENDEES WHO VISITED TH	E BOOTH.
STAFF ALSO PARTICIPATED IN THE TSC SPECIAL INTEREST GROUP	SESSION, AND
THE TSC ALLIANCE HOSTED MORE THAN 100 PEOPLE AT A RECEPTIO	N WITH
PRESENTATIONS BY PARENTS OF A CHILD WITH TSC AND BY DR. AN	GELIQUE
BORDEY, WHO DESCRIBED HOW TSC ALLIANCE HAS IMPACTED HER RE	SEARCH.
THE TSC ALLIANCE PARTICIPATED IN OR PRESENTED AT 26 PROFES	SIONAL
MEETINGS IN 2023 INCLUDING PRETOLA COURSE, RESEARCH AMERIC	A ANNUAL
ADVOCACY AWARDS, WOMEN AT BRIDGE LEADERSHIP SPEAKING SERIE	S, INSITRO
TOWN HALL, RARE DISEASE INNOVATION AND PARTNERING SUMMIT,	ANYA'S
ACCELERATOR WORKSHOP, NORD, TSC ALLIANCE MEXICO BRIEFING,	EAN
CONGRESSIONAL BRIEFING, ATS ANNUAL MEETING, INTERAGENCY CO	LLABORATIVE
TO ADVANCE RESEARCH IN EPILEPSY (ICARE), RARE DISEASES INT	ERNATIONAL
WORLD HEALTH ASSEMBLY, UCP ANNUAL CONFERENCE, MARINUS TOWN	HALL, TANDEM
MINI SYMPOSIUM, ETSC WORKSHOP, NINDS NONPROFIT FORUM, CRIS	IS
INTERVENTION TRAINING INTERNATIONAL, TSCI WORKSHOP, TSC RE	PRODUCTIVE &
PERINATAL TASK FORCE MEETING, LGS MEETING, GLOBAL GENES RA	RE SUMMIT,
PCORI ANNUAL MEETING, APERTURA TOWN HALL, RDCRN FALL MEETI	NG, AES, AND
EAN BRIEFING.	
EXPENSES \$ 287,855. INCLUDING GRANTS OF \$ 0. REVENUE \$	0.
FORM 990, PART VI, SECTION A, LINE 6:	
MEMBERSHIP IN THE CORPORATION IS AVAILABLE TO ANY PERSON W	HO SUBSCRIBES TO
THE PURPOSES AND OBJECTIVES OF THE CORPORATION, WITHOUT RE	GARD TO RACE,
RELIGION, GENDER, SEXUAL ORIENTATION, AGE, COLOR, NATIONAL	ORIGIN, OR Schedule O (Form 990) 2023
65 560927 712177 71690 00001 2023 04030 אמידסאסן, דינופו	FROME SCLEROS 71690

09560927 712177 71690.00001

Schedule O (Form 990) 2023	Page 2
Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
MENTAL OR PHYSICAL HANDICAP OR DISABILITY. THERE IS NO LI	MIT TO THE NUMBER
OF MEMBERS IN THE CORPORATION. 1) THERE MAY BE ONE OR MOR	E CLASSES OF
MEMBERSHIP AS DETERMINED BY THE BOARD. 2) MEMBERSHIP IS N	OT 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 MEMBERSHIP PROGRAM ALLOWS INDIVIDUALS TO STATE THEIR INTENT TO BE A MEMBER FOR THE PURPOSE OF GOVERNANCE. THERE WERE NO LEVELS TO MEMBERSHIP IN 2021. ANYONE 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 DIRECTORS' AUDIT COMMITTEE. RECOMMENDATIONS ARE MADE BY THE COMMITTEE MEMBERS FOR ANY CHANGES/EDITS/ADDITIONS. AFTER THOSE HAVE BEEN INCORPORATED, THE AUDIT 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 332212 11-14-23 66

09560927 712177 71690.00001

Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
NOTICE OF A POTENTIAL CONFLICT OF INTEREST AND RECUSE HIMS	SELF OR HERSELF
FROM ANY DISCUSSIONS AND VOTES IN CONNECTION WITH THE ISSU	JE 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 2023: BOARD MEMBER MUSTAFA SAHIN, PH.D., M.D., IS EMPLOYED AT BOSTON CHILDREN'S HOSPITAL, WHICH RECEIVED \$57,409 IN GRANTS AND \$6,300 IN FEES FOR SERVICES 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 \$3,420 IN FEES FOR SERVICES FOR PARTICIPATION IN THE TSC NATURAL HISTORY DATABASE.

BOARD MEMBER JESSICA KREFTING, RN, IS EMPLOYED AT UNIVERSITY OF ALABAMA AT BIRMINGHAM, WHICH RECEIVED \$91,649 IN GRANTS AND \$9,010 IN FEES FOR SERVICES FOR PARTICIPATION IN THE TSC NATURAL HISTORY DATABASE.

BOARD MEMBER AND IMMEDIATE PAST CHAIR PETER CRINO, MD, PHD, IS CHAIR OF THE DEPARTMENT OF NEUROLOGY AT THE UNIVERSITY OF MD, WHICH RECIEVED \$56,250 OF GRANT PAYMENTS."

FORM 990, PART VI, SECTION B, LINE 15:

"THE COMPENSATION COMMITTEE REVIEWS AND APPROVES THE SALARIES OF THE

PRESIDENT/CEO, CHIEF SCIENTIFIC OFFICER, CFO, AND ANY EMPLOYEE APPEARING 332212 11-14-23

67

Schedule O (Form 990) 2023	Page 2
Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION	Employer identification number 95-3018799
ON THE FORM 990, IN ACCORDANCE WITH THE TSC ALLIANCE BYLAW	S. SUCH REVIEW
AND APPROVAL OCCURS INITIALLY UPON HIRING, UPON ANNUAL REV	IEWS, AND
WHENEVER MODIFIED.	
THE ORGANIZATION'S EXECUTIVE REMUNERATION HAS BEEN STRUCTU	RED TO ENSURE
THAT IT:	
IS REASONABLE; PROVIDES A COMPETITIVE COMPENSATION PROGRAM	TO RETAIN,
ATTRACT AND REWARD KEY EMPLOYEES AND ACHIEVES CLEAR ALIGNM	ENT BETWEEN TOTAL
REMUNERATION AND DELIVERED BUSINESS AND PERSONAL PERFORMAN	CE 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.

FORM 990, PART XII, LINE 2C:

THIS PROCESS HAS NOT CHANGED FROM THE PRIOR YEAR.

332212 11-14-23

Name of the organization NATIONAL TUBEROUS SCLEROSIS ASSOCIATION Page 2 Employer identification number 95-3018799

FORM 990 AMENDED RETURN

THE FORM 990 WAS AMENDED TO INCLUDE THE JOINT COST ALLOCATION THAT WAS

INADVERTENTLY LEFT OFF OF PART IX LINE 26.

Schedule O (Form 990) 2023

332212 11-14-23

SCHEDULE R		Related Organizations	and Unrelated Pa	rtnerships				OMB No. 1545	5-0047
(Form 990)	Comp	lete if the organization answered "Y	es" on Form 990, Part IV, li	ne 33, 34, 35b, 36,	or 37.			202	3
Department of the Treasury Internal Revenue Service		Aπac Go to www.irs.gov/Form990 for	h to Form 990.	tinformation				Open to Po Inspecti	
Name of the organizat	tion NATIONAL TUBE ASSOCIATION	ROUS SCLEROSIS					oyeridenti 5-3018	ication nu	
Part I Identificat		ete if the organization answered "Yes"	on Form 990, Part IV, line 3	3.					
	(a)	(b)	(c)	(d)	(e)			(f)	
	dress, and EIN (if applicable) f disregarded entity	Primary activity	Legal domicile (state o foreign country)	or Total inco	Total income End-of-yea			irect controlling entity	
		_							
		_							
		-							
Part II Identificat organizatio	tion of Related Tax-Exempt Organiz	cations. Complete if the organization a	answered "Yes" on Form 990), Part IV, line 34, b	ecause it had one	or more rel	ated tax-ex	empt	
	(a) ne, address, and EIN related organization	(b) Primary activity	(c) Legal domicile (state or foreign country)	(d) (e) Exempt Code section status (if section		Direct of	(f) controlling ntity	ent	rolled ity?
TSC ALLIANCE END	OWMENT FUND, INC				501(c)(3))			Yes	No
52-1926919, 8737	COLESVILLE ROAD, NO. 400,	SUPPORT THE MISSION OF THE							
SILVER SPRING, MI	D 20910	TSC ALLIANCE	MARYLAND	501(C)(3)	LINE 12B, II	N/A			X
		-							
		-							
For Paperwork Redu	ction Act Notice, see the Instructio	ns for Form 990.				<u> </u> :	Schedule F	 R (Form 99) 2023

Schedule R (Form 990) 2023 ASSOCIATION

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

		,							T		
(a)	(b)	(c)	(d)	(e)	(f)	(g)	(I	h)	(i)	(j)	(k)
Name, address, and EIN of related organization	Primary activity	Legal domicile (state or foreign	Direct controlling entity	Predominant income (related, unrelated, excluded from tax under sections 512-514)	Share of total income	Share of end-of-year assets		ortionate itions?	Code V-UBI amount in box 20 of Schedule	Genera managi partne	or Percentage ownership
		country)		sections 512-514)			Yes	No	K-1 (Form 1065)	Yes N	0
	-										
	-										
											+
	-										
	-										
	-										
	1										
	4										

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

(a) Name, address, and EIN of related organization	(b) Primary activity	(c) Legal domicile (state or foreign	(d) Direct controlling entity	(e) Type of entity (C corp, S corp, or trust)	Type of entity (C corp, S corp,		(f) Share of total income	(g) Share of end-of-year assets	(h) Percentage ownership	512(b contr	i) b)(13) rolled iity?			
		country)				400010		Yes	No					

ASSOCIATION Schedule R (Form 990) 2023

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

Not	e: Complete line 1 if any entity is listed in Parts II, III, or IV of this schedule.		Yes	No
1	During the tax year, did the organization engage in any of the following transactions with one or more related organizations listed in Parts II-IV?			
а	Receipt of (i) interest, (ii) annuities, (iii) royalties, or (iv) rent from a controlled entity	1a		Х
	Gift, grant, or capital contribution to related organization(s)	1b		Х
	Gift, grant, or capital contribution from related organization(s)	1c	X	
	Loans or loan guarantees to or for related organization(s)	1d		Х
	Loans or loan guarantees by related organization(s)	1e		X
f	Dividends from related organization(s)	1f		X
g		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
k	Lease of facilities, equipment, or other assets from related organization(s)	1k		Х
- 1	Performance of services or membership or fundraising solicitations for related organization(s)	11		X
m	Performance of services or membership or fundraising solicitations by related organization(s)	1m		X
n	Sharing of facilities, equipment, mailing lists, or other assets with related organization(s)	1n	X	
0	Sharing of paid employees with related organization(s)	10	X	
р	Reimbursement paid to related organization(s) for expenses	1p		Х
	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		Х
2	If the answer to any of the above is "Yes," see the instructions for information on who must complete this line, including covered relationships and transaction thresholds.			

(a) Name of related organization	(b) Transaction type (a-s)	(c) Amount involved	(d) Method of determining amount involved
(1) TSC ALLIANCE ENDOWMENT FUND, INC.	С	572,625.	ACTUAL CASH RECEIVED
<u>(2)</u>			
(3)			
(4)			
(5)			
(6)			
7.0	1		1

Schedule R (Form 990) 2023 ASSOCIATION

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)	(d) Predominant income (related, unrelated, excluded from tax under sections 512-514)	(e) Are all partners s 501(c)(3 orgs.? Yes N	(g) Share of end-of-year assets	(r Disprotion allocat Yes) opor- ate ions? No	(i) Code V-UBI amount in box 20 of Schedule K-1 (Form 1065)	(j) General of managin partner? Yes No	(k) Percentage ownership

Schedule R (Form 990) 2023

NATIONAL	TUBEROUS	SCLEROSIS
ASSOCIATI	ION	

Schedule R (Form 990) 2023

Part VII Supplemental Information

Provide additional information for responses to questions on Schedule R. See instructions.

Schedule R (Form 990) 2023

332165 09-28-23