Department of the Treasury

Return of Organization Exempt From Income Tax Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

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

Internal Revenue Service Information about Form 990 and its instructions is at www.irs.gov/form990.

A For the 2016 calendar year, or tax year beginning JUL 1, 2016 and ending JUN 30,

and ending JUN 30, 2017

OMB No. 1545-0047 Open to Public Inspection

В	Check if applicable	C Name of organization THE ASSOCIATION FOR FRONTOTEMPORAL	D Employer identifi	cation number
Г	Addres			
F	change Name change		⊣ 41−2	073220
F	lnitial return	Number and street (or P.O. box if mail is not delivered to street address) Room/si		
F	Final return/	290 KING OF PRUSSIA RD 320		514-7221
	termin ated		G Gross receipts \$	4,479,225.
	Ameno		H(a) Is this a group r	
Ē	Applic		for subordinates	
	pendir	SAME AS C ABOVE	H(b) Are all subordinates i	
1	Tax-exe	empt status: X 501(c)(3) 501(c) () ((insert no.) 4947(a)(1) or		list. (see instructions)
		e: WWW.THEAFTD.ORG	H(c) Group exemption	n number
Κ	Form of	organization: X Corporation Trust Association Other Ly	ear of formation: 2002	State of legal domicile: PA
Pi	art I	Summary		
Φ	1	Briefly describe the organization's mission or most significant activities: ${ t PROMOTE}$	AND FUND RESE	ARCH INTO
Activities & Governance		DEVELOPING BETTER DIAGNOSTIC PROCESSES, THER		
ern	2	Check this box 🕨 📖 if the organization discontinued its operations or disposed of m	nore than 25% of its net a	
Š	1	Number of voting members of the governing body (Part VI, line 1a)		16
ø		Number of independent voting members of the governing body (Part VI, line 1b)		16
ies		Total number of individuals employed in calendar year 2016 (Part V, line 2a)		16
ξĬ		Total number of volunteers (estimate if necessary)		228
Ac		Total unrelated business revenue from Part VIII, column (C), line 12		0.
	b	Net unrelated business taxable income from Form 990-T, line 34		
		Contributions and greats (Port VIII line 1b)	Prior Year 8,057,371.	Current Year 4,190,242.
Revenue		Contributions and grants (Part VIII, line 1h) Program service revenue (Part VIII, line 2g)	0,037,371.	0.
ver		Program service revenue (Part VIII, line 2g) Investment income (Part VIII, column (A), lines 3, 4, and 7d)	2,402.	2,732.
Re		Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	123,761.	140,006.
		Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	8,183,534.	4,332,980.
		Grants and similar amounts paid (Part IX, column (A), lines 1-3)	897,107.	3,126,788.
		Benefits paid to or for members (Part IX, column (A), line 4)	0.	0.
S		Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	1,155,342.	1,435,683.
nse	16a	Professional fundraising fees (Part IX, column (A), line 11e)	0.	51,576.
Expenses	b	Total fundraising expenses (Part IX, column (D), line 25) 546,518.		
ш	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	618,800.	1,051,180.
	18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	2,671,249.	5,665,227.
	19	Revenue less expenses. Subtract line 18 from line 12	5,512,285.	-1,332,247.
Net Assets or Ind Balances			Beginning of Current Year	End of Year
Sset	20	Total assets (Part X, line 16)	8,752,417.	8,259,790.
et Ag	21	Total liabilities (Part X, line 26)	434,468.	1,303,075.
	. 22	Net assets or fund balances. Subtract line 21 from line 20	8,317,949.	6,956,715.
	art II	Signature Block		
		lties of perjury, I declare that I have examined this return, including accompanying schedules and sta t, and complete. Declaration of preparer (other than officer) is based on all information of which prep		y knowledge and beller, it is
uuu	, соптес	t, and complete. Declaration of preparer (other than officer) is based on an information of which prep	arer rias arry knowledge.	
Sig	ın	Signature of officer	I Date	
He		PAUL LESTER, TREASURER		
		Type or print name and title		
		Print/Type preparer's name Preparer's signature	Date Check	PTIN
Pai	d	EDWARD FRONCZKOWSKI CPA	if self-employ	ed P01259092
Pre	parer	Firm's name MAILLIE LLP	Firm's EIN	23-1518888
Use	Only	Firm's address 624 WILLOWBROOK LANE		
		WEST CHESTER, PA 19382	Phone no. (6	10)696-4353
Ма	y the IF	RS discuss this return with the preparer shown above? (see instructions)		X Yes No

Form	990 (2016) DEGENERATION	41-20	73220	Page 2
Pai	rt III Statement of Program Service Accomplishments			
	Check if Schedule O contains a response or note to any line in this Part III			X
1	Briefly describe the organization's mission:			
	PROMOTE AND FUND RESEARCH INTO DEVELOPING BETTER DIAGNO			ES,
	THERAPIES, AND CURES FOR FRONTOTEMPORAL DEGENERATION (
	INFORMATION, EDUCATION, SUPPORT AND ADVOCACY TO PERSONS			TTH
	FTD, THEIR FAMILIES AND CAREGIVERS; EDUCATE PHYSICIANS	AND ALI	TED	
2	Did the organization undertake any significant program services during the year which were not listed on the			v
	prior Form 990 or 990-EZ?		Yes	L ∆ No
_	If "Yes," describe these new services on Schedule O.		Yes	▼
3	Did the organization cease conducting, or make significant changes in how it conducts, any program services	?	∟ Yes	L <u>A</u> ∟No
	If "Yes," describe these changes on Schedule O.			
4	Describe the organization's program service accomplishments for each of its three largest program services, a		•	
	Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to other	ners, the total	expenses, a	and
4-	revenue, if any, for each program service reported. (Code:) (Expenses \$3,571,338 • including grants of \$3,039,139 •) (Reverse)			
4a	(Code:) (Expenses \$ 3,5/1,338 including grants of \$ 3,039,139 including grants of \$	nue \$		
	KEDBAKCII			
	EACH YEAR AFTD INVESTS IN THE SCIENCE THAT WILL DRIVE I	TSCOVE	SA VID	
	DEVELOPMENT OF ACCURATE DIAGNOSIS AND THE FIRST THERAPE			D .
	AFTD AWARDED \$2 MILLION IN GRANTS THROUGH THE FTD BIOMA		. 01. 11.	
	INITIATIVE, A FIVE-YEAR PROGRAM TO STIMULATE RESEARCH			
	QUANTIFIABLE, PHYSICAL SIGNS OF FTD'S DEVELOPMENT. WE A		TWO P	ILOT
	GRANTS, TWO DRUG-DISCOVERY GRANTS AND TWO POSTDOCTORAL			
	AFTD LAUNCHED THE FTD DISORDERS REGISTRY, WHICH SURPASS			EAR
	REGISTRANT GOAL IN JUST THREE MONTHS.			
4b	(Code:) (Expenses \$ 493,322 • including grants of \$ 87,649 •) (Reve	enue \$		
	SUPPORT			
	AFTD UNDERSTANDS THE CHALLENGES THAT FTD PRESENTS TO PA	TIENTS	AND T	HEIR
	FAMILIES, AND WORKS HARD TO DEVELOP UNIQUE RESOURCES AN			
	THAT WILL IMPROVE QUALITY OF LIFE FOR THOSE LIVING WITH			
	RESPONDED TO 2,451 HELPLINE CALLS AND EMAILS. WE EXPANI			RK
	OF AFFILIATED SUPPORT GROUPS; AS OF JUNE 30, 2017, THEF			
	AFTD-AFFILIATED SUPPORT GROUP FACILITATORS LEADING GROU			
	DIFFERENT STATES. AFTD AWARDED 180 COMSTOCK TRAVEL AND	RESPIT	E GRAN	TS
	TO FTD CAREGIVERS AND PERSONS DIAGNOSED.			
	010, 220			
4c	(Code:) (Expenses \$ 818,330. including grants of \$) (Reversely 100) (Re	nue \$		
	EDUCATION, AWARENESS AND INFORMATION			
	AFTD COLLABORATES WITH A GROWING NUMBER OF PARTNERS EAC	עבאם	ШΟ	
	EDUCATE HEALTHCARE PROFESSIONALS ABOUT FTD, WITH A GOAL			OTTD
	WAY TOWARD ACCURATE DIAGNOSIS AND EFFECTIVE DISEASE MAN			OOK
	TREATMENT. AFTD PUBLISHED THREE NEW ISSUES OF THE PARTY) D F
	NEWSLETTER FOR HEALTH PROFESSIONALS AND FAMILIES. WE PR			AILL
	EXPERT-LED WEBINARS THROUGH A NEWLY LAUNCHED SERIES. FI			DR EW
	MORE THAN 320 PEOPLE TO THE ANNUAL AFTD EDUCATION CONFI			
	HIGHEST ATTENDANCE FIGURE TO DATE.			
	AWARENESS			
	AWARENESS IS THE KEY TO ACHIEVING OUR MISSION. OUR GOAL	OFA	WORID	
44	Other program services (Describe in Schedule O.)			
→u	(Expenses \$ including grants of \$) (Revenue \$)	
4e	Total program service expenses 4,882,990.		,	
	, i = i =		Form 9	90 (2016
		/ ~ \		,-5.0

DEGENERATION Part IV | Checklist of Required Schedules

			Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)?			
	If "Yes," complete Schedule A	1	X	
2	Is the organization required to complete Schedule B, Schedule of Contributors?	2	Х	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	3		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 Revenue Procedure 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? <i>If</i> "Yes," <i>complete Schedule D, Part III</i>	8		х
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for			
	amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services?			
	If "Yes," complete Schedule D, Part IV	9		Х
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent			
	endowments, or quasi-endowments? If "Yes," complete Schedule D, Part V	10		Х
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X			
	as applicable.			
а	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI	11a	х	
b	Did the organization report an amount for investments - other securities in Part X, line 12 that is 5% or more of its total			
	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII	11b		Х
С	Did the organization report an amount for investments - program related in Part X, line 13 that is 5% or more of its total			
	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII	11c		X
d	Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in			
	Part X, line 16? If "Yes," complete Schedule D, Part IX	11d		X
е	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e		Х
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses			.,
	the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X	11f		X
12a	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete		v	
1.	Schedule D, Parts XI and XII	12a	Х	
р	Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	406		х
13	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	12b 13		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a		X
b		174		
	investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000			
	or more? If "Yes," complete Schedule F, Parts I and IV	14b	Х	
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any			
	foreign organization? If "Yes," complete Schedule F, Parts II and IV	15	Х	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to			
	or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV	16		Х
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX,			
	column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I	17	X	
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines			
	1c and 8a? If "Yes," complete Schedule G, Part II	18	X	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes,"			
	complete Schedule G, Part III	19		X

Form **990** (2016)

Page 4

THE ASSOCIATION FOR FRONTOTEMPORAL **DEGENERATION**

Form 990 (2016)

Part IV Checklist of Required Schedules (continued)

			Yes	No
20a	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		X
b	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	Х	
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	Х	<u> </u>
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		37	
	Schedule J	23	Х	<u> </u>
24a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the			
	last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete			х
	Schedule K. If "No", go to line 25a	24a		
	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
C	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c		
d	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit			
	transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I	25a		Х
b	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and			
	that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete			
	Schedule L, Part I	25b		X
26	Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or			
	former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? If "Yes,"			
	complete Schedule L, Part II	26		X
27	Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial			
	contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member			
	of any of these persons? If "Yes," complete Schedule L, Part III	27		X
28	Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV			
	instructions for applicable filing thresholds, conditions, and exceptions):			v
	A current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28a		X
	A family member of a current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV	28b		$\stackrel{\Delta}{\vdash}$
C	An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? If "Yes," complete Schedule L, Part IV	28c		х
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29	Х	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation	23		
00	contributions? If "Yes," complete Schedule M	30		х
31	Did the organization liquidate, terminate, or dissolve and cease operations?			
- •	If "Yes," complete Schedule N, Part I	31		Х
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		Х
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	34	Х	
	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		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	35b		<u> </u>
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization?			77
	If "Yes," complete Schedule R, Part V, line 2	36		X
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization			Х
20	and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI	37		
38	Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19?	38	Х	
	Note. All Form 990 filers are required to complete Schedule O	J 30	-77	

Form **990** (2016)

Form 990 (2016)

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Part V	. ST	atements	Regarding	OTHER	IK5	Fillings and	IAY(ombijance
. a.c.		atomicito	i icgai anig			i iiiiigo aiia	IUA	Joinphance

	Check if Schedule O contains a response or note to any line in this Part V	<u></u>	<u></u>			
					Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable	1a	18			
b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable	1b	0			
С	Did the organization comply with backup withholding rules for reportable payments to vendors and r	eporta	ble gaming			
	(gambling) winnings to prize winners?			1c	X	
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements,		4.0			
	filed for the calendar year ending with or within the year covered by this return	2a	16			
b	If at least one is reported on line 2a, did the organization file all required federal employment tax retu			2b	X	
	Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions	s)				77
	-			3a		X
	If "Yes," has it filed a Form 990-T for this year? If "No," to line 3b, provide an explanation in Schedule			3b		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other		•			v
	financial account in a foreign country (such as a bank account, securities account, or other financial	accou	nt)'?	4a		X
р	If "Yes," enter the name of the foreign country:		+- (FDAD)			
E ~	See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial A		· ·	E-0		Х
	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction.			5a 5b		X
				5c		
	If "Yes," to line 5a or 5b, did the organization file Form 8886-T? Does the organization have annual gross receipts that are normally greater than \$100,000, and did the statement of the statem			50		
ua	any contributions that were not tax deductible as charitable contributions?	-		6a		х
h	If "Yes," did the organization include with every solicitation an express statement that such contributions.			- Ou		
~	were not tax deductible?		-	6b		
7	Organizations that may receive deductible contributions under section 170(c).			-		
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and se	rvices p	rovided to the payor?	7a	х	
	If "Yes," did the organization notify the donor of the value of the goods or services provided?			7b	Х	
	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it w					
	to file Form 8282?	-		7c		Х
d	If "Yes," indicate the number of Forms 8282 filed during the year	7d				
	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit of		t?	7e		Х
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit conti	ract?		7f		Х
g	If the organization received a contribution of qualified intellectual property, did the organization file February	orm 88	99 as required?	7g		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization	ation f	le a Form 1098-C?	7h		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained	by th	е			
	sponsoring organization have excess business holdings at any time during the year?			8		
9	Sponsoring organizations maintaining donor advised funds.					
				9a		
	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?			9b		
	Section 501(c)(7) organizations. Enter:	١				
	Initiation fees and capital contributions included on Part VIII, line 12	10a				
	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b				
	Section 501(c)(12) organizations. Enter: Gross income from morphors or shareholders	11a				
	Gross income from members or shareholders Gross income from other sources (Do not net amounts due or paid to other sources against	ı ıa				
Ŋ	amounts due or received from them.)	11b				
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form		<u> </u>	12a		
	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b		.ea		
	Section 501(c)(29) qualified nonprofit health insurance issuers.					
	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					
	organization is licensed to issue qualified health plans	13b				
С	Enter the amount of reserves on hand	13c				
	Did the averagination was in a grown as wearth for indeed towning a source of wines the tay was 0			14a		Х
	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedul			14b		
				Form	990	(2016)

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Form 990 (2016)

41-2073220

Page 6

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 in Schedule O. See instructions.

	Check if Schedule O contains a response or note to any line in this Part VI				X
Sec	tion A. Governing Body and Management				
				Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year	1a	16		
	If there are material differences in voting rights among members of the governing body, or if the governing				
	body delegated broad authority to an executive committee or similar committee, explain in Schedule O.				
b	Enter the number of voting members included in line 1a, above, who are independent	1b	16		
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationshi	p with any other			
	officer, director, trustee, or key employee?		2	X	
3	Did the organization delegate control over management duties customarily performed by or under th	e direct supervision			
	of officers, directors, or 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 9	990 was filed?	4		X
5	Did the organization become aware during the year of a significant diversion of the organization's ass	sets?	5		X
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 a	opoint one or			
	more members of the governing body?		7a	1	X
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, s				
	persons other than the governing body?		7t)	X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year	ar by the following:			
а	The governing body?		8a		
b	Each committee with authority to act on behalf of the governing body?		8k	, X	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be read	ched at the			
	organization's mailing address? If "Yes," provide the names and addresses in Schedule O		9		X
<u>Sec</u>	tion B. Policies (This Section B requests information about policies not required by the Internal Re	evenue Code.)			
				Yes	
10a	Did the organization have local chapters, branches, or affiliates?		<u>10</u>	а	X
b	If "Yes," did the organization have written policies and procedures governing the activities of such cl				
	and branches to ensure their operations are consistent with the organization's exempt purposes? $\ _{\cdot\cdot\cdot}$				
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing bod	y before filing the forr	n? 11	a X	
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.				
12a	Did the organization have a written conflict of interest policy? If "No," go to line 13		12		
b	Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise		12	b X	1
С	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Y		١		
	in Schedule O how this was done		12		
13	Did the organization have a written whistleblower policy?		13		
14	Did the organization have a written document retention and destruction policy?		14		
15	Did the process for determining compensation of the following persons include a review and approve				
_	persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		45	a X	
a	The organization's CEO, Executive Director, or top management official			-	X
D	Other officers or key employees of the organization If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions).		15		- 25
160	Did the organization invest in, contribute assets to, or participate in a joint venture or similar arranger	ment with a			
iva			16	a	Х
h	taxable entity during the year? If "Yes," did the organization follow a written policy or procedure requiring the organization to evalua		'10		
	in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization of evaluation and take steps to safeguard the organization of evaluation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization of evaluation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization of evaluation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization of evaluation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization of evaluation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization of evaluation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization of evaluation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization of evaluation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization of evaluation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization of evaluation in joint venture arrangement of evaluation				
	exempt status with respect to such arrangements?		16	b	
Sec	tion C. Disclosure			-	-
17	List the states with which a copy of this Form 990 is required to be filed ▶KS, KY, ME, MD, M	A,MI,MN,MS	NH,N	J,NM	I,NY
18	Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-1				
	for public inspection. Indicate how you made these available. Check all that apply.	. (///	• /		
		in Schedule O)			
19	Describe in Schedule O whether (and if so, how) the organization made its governing documents, co	,	, and fin	ancial	
	statements available to the public during the tax year.	. ,			
20	State the name, address, and telephone number of the person who possesses the organization's bo	oks and records:			
	THE ORGANIZATION - 2675147221				
	<u> </u>	A 19087			
63200	SEE SCHEDULE O FOR FULL LIST OF STATES		Fo	rm 990	(2016)

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

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

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

- 1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.
- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
 - List all of the organization's current key employees, if any. See instructions for definition of "key employee."
- List the organization's five current highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

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

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

(A) Name and Title	(B) Average		not c		ition more	than		(D) Reportable	(E) Reportable compensation	(F) Estimated
	hours per week (list any hours for related organizations below line)	stee or director			irecto	Highest compensated hod si employee	tee)	compensation from the organization (W-2/1099-MISC)	from related organizations (W-2/1099-MISC)	amount of other compensation from the organization and related organizations
(1) BONNIE SHEPHERD	6.00							_	_	
SECRETARY/VICE CHAIR		Х		Х				0.	0.	0.
(2) HELEN-ANN COMSTOCK	2.00								_	_
DIRECTOR		Х						0.	0.	0.
(3) DEANNA ANGELLO, MBA	2.00									
DIRECTOR		Х						0.	0.	0.
(4) JOHN WHITMARSH, PH.D	4.00	l								•
DIRECTOR	1000	Х						0.	0.	0.
(5) GAIL ANDERSEN	10.00	١		l						•
CHAIR		Х		Х				0.	0.	0.
(6) STEVE BELLWOAR	2.00	١								
DIRECTOR	4 00	Х						0.	0.	0.
(7) PAUL LESTER	4.00	١		l						
TREASURER	4 00	Х		Х				0.	0.	0.
(8) KATHY MELE	4.00	١								
DIRECTOR	4 00	Х						0.	0.	0.
(9) STEVE FENOGLIO	4.00									•
DIRECTOR/SECRETARY	0.00	Х		Х				0.	0.	0.
(10) RICK CHILDS	2.00	,,								0
DIRECTOR	2 00	Х						0.	0.	0.
(11) MATT HATFIELD	2.00	,,							0	•
DIRECTOR	4 00	Х						0.	0.	0.
(12) BETH WALTER	4.00	x						0.	0.	0.
DIRECTOR (13) DANIEL HEDAYA	2.00	^						0.	0.	0.
, ,	2.00	x						0.	0.	0.
DIRECTOR (14A) WARM WINDOW	2.00	Δ						0.	0.	0.
(14) KACY KUNESH DIRECTOR	4.00	x						0.	0.	0.
(15) BRIAN ROSE	2 00	Δ						0.	0.	<u> </u>
DIRECTOR	2.00	x						0.	0.	0.
(16) MICHAEL STOWELL, PHD	2.00	<u> </u>	\vdash	\vdash	\vdash	\vdash	\vdash	"	0.	<u></u>
DIRECTOR	2.00	X						0.	0.	0.
(17) SUSAN DICKINSON	40.00								0.	<u></u>
CHIEF EXECUTIVE OFFICER	40.00	1		х				142,500.	0.	13,250.
000007 14 14 10					<u> </u>	_		112,300	•	Eorm 990 (2016)

632007 11-11-16

Form **990** (2016)

Part VIII Section A. Officers, Directors, Trus	tees, Key Em	ploy	ees/	, and	d Hi	ighe	st (Compensated Employe	es (continued)				
(A)	(B)	(C)						(D)	(E)		1	(F)	
Name and title	Average	Position (do not check more the					one	Reportable	Reportable			stimate	-
	hours per week			ss per				· ·	compensation			nount	of
	(list any	_						- Trom	from related			other	tion
	hours for	direct				_		the organization	organization (W-2/1099-MIS			pensa om the	
	related	9e Or (stee			ısate		(W-2/1099-MISC)	(** 27 1000 14110	,0,		anizat	
	organizations	Individual trustee or director	Institutional trustee		yee	mbel					_	d relat	
	below	idual	tution	-e	Key employee	est co	ıer				orga	anizati	ons
	line)	Indiv	Insti	Officer	Key e	Highest compensated employee	Former						
(18) BENJAMIN FREEMAN	40.00												
DEVELOPMENT & COMMUNICATIONS DIRECTO						Х		116,304.		0.		4,5	<u> 17.</u>
(19) NADINE TATTON	40.00												
SCIENTIFIC DIRECTOR						X		138,500.		0.	1	5,5	71.
											1		
											<u> </u>		
											1		
											<u> </u>		
		1											
											<u> </u>		
											1		
						_					<u> </u>		
											1		
						_					<u> </u>		
											1		
											<u> </u>		
		-									1		
	<u> </u>						L	397,304.		0.	-	ว ว	20
1b Sub-total								397,304.		0.		3,3	0.
c Total from continuation sheets to Part V								397,304.		0.	3	3,3	
d Total (add lines 1b and 1c)									000 - f			5,5	50.
2 Total number of individuals (including but n	iot ilmited to tr	iose	IIST	eu at	OOV	e) wi	10 r	received more than \$100	,000 of reportab	ie			3
compensation from the organization												Yes	No
3 Did the organization list any former officer,	director or tru	ıcta	o ka	w on	nnlc)VAA	or	highest compensated a	mnlovee on	ľ			110
line 1a? If "Yes," complete Schedule J for s	,		,	,	•	,			. ,		3		Х
4 For any individual listed on line 1a, is the su													
and related organizations greater than \$15			-					•	ino organization		4	х	
5 Did any person listed on line 1a receive or a									idual for services				
rendered to the organization? If "Yes," com											5		Х
Section B. Independent Contractors	,												
Complete this table for your five highest co	mpensated in	depe	ende	ent c	onti	racto	ors :	that received more than	\$100,000 of con	npens	ation	from	
the organization. Report compensation for	= -	-								•			
(A)								(B)	,		(0)	
Name and business	address	N	INC	Ξ				Description of s	ervices	С	ompe	nsatio	n
2 Total number of independent contractors (i		ot li	mite	d to		^	ste	d above) who received n	nore than				
\$100,000 of compensation from the organi	zation >					0					_	000	
											Form	99U (2016)

632008 11-11-16

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION

41-2073220 Page 9 Part VIII Statement of Revenue Check if Schedule O contains a response or note to any line in this Part VIII (B) (C) (**D)** Revenue excluded Unrelated Related or Total revenue from tax under exempt function business sections 512 - 514 revenue revenue Contributions, Gifts, Grants and Other Similar Amounts 1 a Federated campaigns **b** Membership dues 1b 1,812,677. c Fundraising events d Related organizations 1d e Government grants (contributions) f All other contributions, gifts, grants, and $|_{1f}|_{2,377,565}$ similar amounts not included above 51,258 g Noncash contributions included in lines 1a-1f: \$ 4,190,242. h Total. Add lines 1a-1f ... Business Code Program Service Revenue 2 a f All other program service revenue g Total. Add lines 2a-2f. Investment income (including dividends, interest, and 2,783. 2,783. other similar amounts) Income from investment of tax-exempt bond proceeds 5 Royalties (i) Real (ii) Personal 6 a Gross rents **b** Less: rental expenses c Rental income or (loss) **d** Net rental income or (loss) ... 7 a Gross amount from sales of (i) Securities (ii) Other 51,258. assets other than inventory b Less: cost or other basis 51,309 and sales expenses c Gain or (loss) -51. -51. d Net gain or (loss) 8 a Gross income from fundraising events (not Revenue including \$1,812,677. of contributions reported on line 1c). See 80,600. Part IV, line 18 a Other 94,936. **b** Less: direct expenses -14,336. -14,336c Net income or (loss) from fundraising events 9 a Gross income from gaming activities. See Part IV, line 19 a **b** Less: direct expenses **c** Net income or (loss) from gaming activities 10 a Gross sales of inventory, less returns and allowances **b** Less: cost of goods sold **c** Net income or (loss) from sales of inventory Miscellaneous Revenue Business Code 11 a CONTRACT 541700 139,332. 139,332. b BOOKS & DVD SALES 900099 15,010. 15,010. С

632009 11-11-16

-11,553. Form 990 (2016)

154,342.

4,332,980.

d All other revenue

Total revenue. See instructions.

e Total. Add lines 11a-11d

154,291.

Part IX | Statement of Functional Expenses Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A). Check if Schedule O contains a response or note to any line in this Part IX (D) (B) (C) Do not include amounts reported on lines 6b. Program service expenses Total expenses Management and general expenses Fundraising 7b, 8b, 9b, and 10b of Part VIII. expenses Grants and other assistance to domestic organizations 2,230,453. 2,230,453. and domestic governments. See Part IV, line 21 Grants and other assistance to domestic individuals. See Part IV, line 22 87,649 87,649 Grants and other assistance to foreign organizations, foreign governments, and foreign 808,686. 808,686. individuals. See Part IV, lines 15 and 16 Benefits paid to or for members Compensation of current officers, directors, 170,720. 34,144. 34,144. 102,432. trustees, and key employees Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) 1,070,078. 833,591. 61,968. 174,519. 7 Other salaries and wages Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions) 3,611. 92,340. 74,048. 14,681. Other employee benefits 9 5,745. 102,545. 80,738. 16,062. Payroll taxes 10 Fees for services (non-employees): 11 a Management Legal Accounting Lobbying 51,576. 51,576. Professional fundraising services. See Part IV, line 17 Investment management fees Other, (If line 11g amount exceeds 10% of line 25, 270,318. 48,914. 10,299. 211,105. column (A) amount, list line 11g expenses on Sch O.) Advertising and promotion 12 97,240. 58,082. 9,499. 29,659. Office expenses 13 14 Information technology 15 Royalties 89,399. 62,579. 13,410. 13,410. 16 Occupancy 50,426. 43,948. 710. 5,768. 17 Travel 18 Payments of travel or entertainment expenses for any federal, state, or local public officials 221,153. 194,099. 26,921 <u>133.</u> Conferences, conventions, and meetings 19 20 Payments to affiliates 21 7,137. 7,137. Depreciation, depletion, and amortization 22 9,953. 6,967. 1,493. 1,493. 23 Other expenses. Itemize expenses not covered 24 above. (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.) INDIRECT EVENT EXPENSES 146,423. 146,423. WEBSITE 55,081. 38,557. 8,262. 8,262. 28,992. POSTAGE 20,044. 1,467. 7,481. 20,140 BANK & CREDIT CARD FEES 20,052. 87. 54,918. 12,556. 30,011. 12,351.

Form 990 (2016)

546,518.

25

4,882,990.

5,665,227.

Check here

e All other expenses

Total functional expenses. Add lines 1 through 24e

Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.

if following SOP 98-2 (ASC 958-720)

235,719.

Form 990 (2016)

Part X | Balance Sheet

Part X	X	Balance Sheet					
		Check if Schedule O contains a response or not	e to an	y line in this Part X			
					(A) Beginning of year		(B) End of year
1	1	Cash - non-interest-bearing			15,141.	1	17,429.
2	2	Savings and temporary cash investments			2,599,329.	2	4,767,883.
3	3	Pledges and grants receivable, net			5,750,000.	3	3,055,000
4		Accounts receivable, net			21,036.	4	9,320
5		Loans and other receivables from current and for					
		trustees, key employees, and highest compensations	ated en	nployees. Complete			
		Part II of Schedule L		5			
6	6	Loans and other receivables from other disquali					
		section 4958(f)(1)), persons described in section	c)(3)(B), and contributing				
		employers and sponsoring organizations of sec					
<u>v</u>		employees' beneficiary organizations (see instr).				6	
Assets	7	Notes and loans receivable, net			7		
₹ 8	3	Inventories for sale or use				8	
9		Prepaid expenses and deferred charges			60,868.	9	81,369
10)a	Land, buildings, and equipment: cost or other					
		basis. Complete Part VI of Schedule D	10a	48,315.			
	b	Less: accumulated depreciation	-	28,789.	20,176.	10c	19,526
11		Investments - publicly traded securities				11	
12	2	Investments - other securities. See Part IV, line			12		
13	3	Investments - program-related. See Part IV, line		279,578.	13	300,591	
14	4	Intangible assets		14			
15	5	Other assets. See Part IV, line 11	6,289.	15	8,672		
16	6	Total assets. Add lines 1 through 15 (must equ	8,752,417.	16	8,259,790		
17	7	Accounts payable and accrued expenses			9,468.	17	38,848
18	3	Grants payable	125,000.	18	1,141,227		
19		Deferred revenue		300,000.	19	123,000	
20	0	Tax-exempt bond liabilities			20		
21		Escrow or custodial account liability. Complete				21	
ဖ္က 22	2	Loans and other payables to current and former					
≝		key employees, highest compensated employee	es, and	disqualified persons.			
Liabilities 52		Complete Part II of Schedule L				22	
⊐ 23	3	Secured mortgages and notes payable to unrela				23	
24	4	Unsecured notes and loans payable to unrelate	d third	parties		24	
25	5	Other liabilities (including federal income tax, pa	yables	to related third			
		parties, and other liabilities not included on lines	17-24)	. Complete Part X of			
		Schedule D				25	
26	6	Total liabilities. Add lines 17 through 25			434,468.	26	1,303,075
		Organizations that follow SFAS 117 (ASC 958), chec	k here 🕨 🐰 and			
es		complete lines 27 through 29, and lines 33 and	d 34.				
ဋ 27	7	Unrestricted net assets		2,196,410.	27	3,070,098	
ਲੂੱ 28	3	Temporarily restricted net assets	6,121,539.	28	3,886,617		
ᅙ 29	9	Permanently restricted net assets		29			
Ē │		Organizations that do not follow SFAS 117 (A	SC 958	B), check here 🕨 📖			
Net Assets or Fund Balances 25 29 30 31 32 32		and complete lines 30 through 34.					
हु 30	0	Capital stock or trust principal, or current funds				30	
8 31	1	Paid-in or capital surplus, or land, building, or ed	quipme	nt fund		31	
<u>5</u> 32		Retained earnings, endowment, accumulated in		 		32	
z 33	3	Total net assets or fund balances			8,317,949.	33	6,956,715
34		Total liabilities and net assets/fund balances			8,752,417.	34	8,259,790.

Form **990** (2016)

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	4,33	2,9	80.				
2	Total expenses (must equal Part IX, column (A), line 25)	2	5,66						
3	Revenue less expenses. Subtract line 2 from line 1	3	-1,33 8,31						
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))								
5	Net unrealized gains (losses) on investments	5	-2	8,9	87.				
6	Donated services and use of facilities	6							
7	Investment expenses	7							
8	Prior period adjustments	8							
9	Other changes in net assets or fund balances (explain in Schedule O)	9			0.				
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33,								
	column (B))	10	6,95	6,7	15.				
Pa	rt XII Financial Statements and Reporting								
	Check if Schedule O contains a response or note to any line in this Part XII				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 in Schedule	Ο.							
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	d 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 separat	e basis,							
	consolidated basis, or both:								
	X Separate basis 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 th	e 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 in Sch								
За	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Si	ngle Audit							
	Act and OMB Circular A-133?	-	3a		Х				
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the requ	ired audit							
	or audits, explain why in Schedule O and describe any steps taken to undergo such audits		3b						
				990	(2016)				

SCHEDULE A

Department of the Treasury

Internal Revenue Service

(Form 990 or 990-EZ)

Public Charity Status and Public Support Complete if the organization is a section 501(c)(3) organization or a section

4947(a)(1) nonexempt charitable trust.

► Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047 **2016**

Open to Public Inspection

Name of the organization THE ASSOCIATION FOR FRONTOTEMPORAL

Employer identification number

_			NERATION					1-20/3220						
Pa	rt I	Reason for Public (Charity Status (All organizations must co	omplete th	is part.) S	ee instructions.							
Γhe	organ	ization is not a private found	lation because it is: (For lines 1 through 12, o	check only	one box.)								
1	Ш	A church, convention of ch	urches, or association	on of churches describe	d in sectio	n 170(b)(1)(A)(i).							
2		A school described in secti	ion 170(b)(1)(A)(ii). (Attach Schedule E (Forn	n 990 or 99	90-EZ).)								
3		A hospital or a cooperative	hospital service orga	anization described in s e	ection 170	(b)(1)(A)(i	ii).							
4		A medical research organiz	ation operated in co	njunction with a hospita	described	d in sectio	n 170(b)(1)(A)(iii). Enter	the hospital's name,						
		city, and state:												
5		An organization operated for	or the benefit of a co	llege or university owne	d or opera	ted by a g	overnmental unit descril	bed in						
		section 170(b)(1)(A)(iv). (C			•	, ,								
6		A federal, state, or local gov	•	nental unit described in	section 17	70(b)(1)(A)	(v).							
	X	An organization that norma	-					I public described in						
•		section 170(b)(1)(A)(vi). (C		artial part of its support	rom a gov	orranio raca	arme or morn and gornoral	i pasiis asserissa iri						
8				(1)(A)(vi) (Complete Par	+ II \									
9	H	 ☐ A community trust described in section 170(b)(1)(A)(vi). (Complete Part II.) ☐ An agricultural research organization described in section 170(b)(1)(A)(ix) operated in conjunction with a land-grant college 												
9														
		or university or a non-land-g	grant college of agric	culture (see instructions)	Enter the	name, cit	y, and state of the collec	je or						
40		university:	II	then 00 1/00/ of its aver										
10		An organization that norma												
		activities related to its exen												
		income and unrelated busin		(less section 511 tax) fr	om busine	sses acqu	ired by the organization	after June 30, 1975.						
		See section 509(a)(2). (Cor												
11		An organization organized a	=	•	•									
12		An organization organized a	·		•									
		more publicly supported or	ganizations describe	ed in section 509(a)(1) o	r section :	509(a)(2).	See section 509(a)(3). (Check the box in						
		lines 12a through 12d that	describes the type o	of supporting organization	n and com	nplete line:	s 12e, 12f, and 12g.							
а		Type I. A supporting orga	anization operated, s	supervised, or controlled	by its sup	ported or	ganization(s), typically by	y giving						
		the supported organization	on(s) the power to re	gularly appoint or elect	a majority	of the dire	ctors or trustees of the	supporting						
		organization. You must o	complete Part IV, Se	ections A and B.										
b	L	Type II. A supporting org	anization supervised	d or controlled in connec	tion with it	s support	ed organization(s), by ha	aving						
		control or management o	f the supporting orga	anization vested in the s	ame perso	ons that co	ontrol or manage the sup	oported						
		organization(s). You mus	t complete Part IV,	Sections A and C.										
С		Type III functionally inte	grated. A supporting	g organization operated	in connec	tion with,	and functionally integrat	ed with,						
		its supported organization	n(s) (see instructions	s). You must complete	Part IV, Se	ections A,	D, and E.							
d		Type III non-functionally	, integrated. A supp	orting organization oper	ated in co	nnection v	vith its supported organ	ization(s)						
		that is not functionally int	egrated. The organiz	zation generally must sa	tisfy a dist	ribution re	quirement and an attent	tiveness						
		requirement (see instruct	ions). You must con	nplete Part IV, Sections	A and D,	and Part	V.							
е		Check this box if the orga	•											
		functionally integrated, or												
f	Ente	er the number of supported o		, , , , , , , , , , , , , , , , , , , ,										
q		ride the following information												
		i) Name of supported	(ii) EIN	(iii) Type of organization	(iv) Is the orga in your governi	nization listed	(v) Amount of monetary	(vi) Amount of other						
		organization		(described on lines 1-10 above (see instructions))	Yes	No	support (see instructions)	support (see instructions)						
				above (see instructions))										
Tot:														

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

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

Sec	ction A. Public Support						
Cale	ndar year (or fiscal year beginning in)	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
1	Gifts, grants, contributions, and	, ,	` ,	Ì		. ,	.,
	membership fees received. (Do not						
	include any "unusual grants.")	1,230,706.	1,544,802.	2,162,391.	2,307,371.	4,190,242.	11,435,512.
2	Tax revenues levied for the organ-	, , ,	, , ,	, , ,	, , -	, , ,	, , ,
_	ization's benefit and either paid to						
	or expended on its behalf						
2	The value of services or facilities						
3	furnished by a governmental unit to						
	the organization without charge						
		1,230,706.	1,544,802.	2,162,391.	2,307,371.	4,190,242.	11,435,512.
	Total. Add lines 1 through 3	1,230,700.	1,344,002.	2,102,391.	2,307,371.	4,130,242.	11,433,312.
5	The portion of total contributions						
	by each person (other than a						
	governmental unit or publicly						
	supported organization) included						
	on line 1 that exceeds 2% of the						
	amount shown on line 11,						
_	column (f)						1,088,803.
	Public support. Subtract line 5 from line 4.						10,346,709.
	ction B. Total Support	1	1				
	ndar year (or fiscal year beginning in)	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
	Amounts from line 4	1,230,706.	1,544,802.	2,162,391.	2,307,371.	4,190,242.	11,435,512.
8	Gross income from interest,						
	dividends, payments received on						
	securities loans, rents, royalties						
	and income from similar sources	2,810.	2,770.	2,637.	2,402.	2,783.	13,402.
9	Net income from unrelated business						
	activities, whether or not the						
	business is regularly carried on						
10	Other income. Do not include gain						
	or loss from the sale of capital						
	assets (Explain in Part VI.)						
11	Total support. Add lines 7 through 10					_	11,448,914.
12	Gross receipts from related activities,	etc. (see instruction	ons)			12	311,209.
13	First five years. If the Form 990 is for	r the organization's	first, second, third	l, fourth, or fifth ta	x year as a sectio	n 501(c)(3)	
	organization, check this box and stor	here					>
Sec	ction C. Computation of Publ	ic Support Pe	rcentage				
14	Public support percentage for 2016 (line 6, column (f) di	vided by line 11, co	olumn (f))		14	90.37 %
15	Public support percentage from 2015	Schedule A, Part	II, line 14			15	91.20 %
16a	33 1/3% support test - 2016. If the	organization did no	t check the box on	line 13, and line 1	14 is 33 1/3% or n	nore, check this bo	
	stop here. The organization qualifies	as a publicly supp	orted organization				►X
b	33 1/3% support test - 2015. If the	organization did no	t check a box on li	ne 13 or 16a, and	line 15 is 33 1/3%	or more, check th	is box
	and stop here. The organization qual	ifies as a publicly s	supported organiza	tion			▶□
17a	10% -facts-and-circumstances tes	t - 2016. If the org	anization did not cl	heck a box on line	13, 16a, or 16b, a	and line 14 is 10%	or more,
	and if the organization meets the "fac	ts-and-circumstan	ces" test, check th	is box and stop h e	ere. Explain in Par	t VI how the organ	ization
	meets the "facts-and-circumstances"	test. The organiza	tion qualifies as a p	oublicly supported	organization		
b	10% -facts-and-circumstances tes	t - 2015. If the org	anization did not cl	heck a box on line	13, 16a, 16b, or	17a, and line 15 is	10% or
	more, and if the organization meets the						
	organization meets the "facts-and-circ	cumstances" test.	The organization q	ualifies as a public	cly supported orga	anization	
18	Private foundation. If the organization						s >
						dule A (Form 990	

3chedule A (Form 990 of 990-LZ) 20 i

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.)

Sec	ction A. Public Support	elow, piease con	ipiete i ait ii.)				
	ndar year (or fiscal year beginning in)	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
	Gifts, grants, contributions, and	,		, ,	, ,		,
	membership fees received. (Do not						
	include any "unusual grants.")						
2	Gross receipts from admissions,						
_	merchandise sold or services per-						
	formed, or facilities furnished in						
	any activity that is related to the organization's tax-exempt purpose						
3	Gross receipts from activities that						
3	are not an unrelated trade or bus-						
1	Tax revenues levied for the organ-						
4	•						
	ization's benefit and either paid to or expended on its behalf						
_							
5	The value of services or facilities						
	furnished by a governmental unit to						
_	the organization without charge						
	Total. Add lines 1 through 5						
7a	Amounts included on lines 1, 2, and						
	3 received from disqualified persons						
b	Amounts included on lines 2 and 3 received from other than disqualified persons that						
	exceed the greater of \$5,000 or 1% of the						
	amount on line 13 for the year						
	Add lines 7a and 7b						
8	Public support. (Subtract line 7c from line 6.)						
	ction B. Total Support						
	ndar year (or fiscal year beginning in) 🖊	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
	Amounts from line 6						
10a	Gross income from interest,						
	dividends, payments received on securities loans, rents, royalties						
	and income from similar sources						
b	Unrelated business taxable income						
	(less section 511 taxes) from businesses						
	acquired after June 30, 1975						
c	Add lines 10a and 10b						
	Net income from unrelated business						
	activities not included in line 10b,						
	whether or not the business is regularly carried on						
12	Other income. Do not include gain						
	or loss from the sale of capital						
13	assets (Explain in Part VI.) Total support. (Add lines 9, 10c, 11, and 12.)						
	First five years. If the Form 990 is for	the organization	's first second this	d fourth or fifth t	av voar as a soct	ion 501(c)(3) organi	zation
'-		ū			•		· •
Sec	etion C. Computation of Publi						
	Public support percentage for 2016 (li			column (f))		15	9/
						16	9/
	Public support percentage from 2015 ction D. Computation of Inves					10	7
	•					17	0.
	Investment income percentage for 20					 	9
	Investment income percentage from 2					18	17 is not
198	33 1/3% support tests - 2016. If the	-					
_	more than 33 1/3%, check this box ar						
b	33 1/3% support tests - 2015. If the	· ·			•	•	
_	line 18 is not more than 33 1/3%, che						
20	Private foundation. If the organization	n did not check a	a box on line 14. 19	a. or 19b. check t	his box and see i	nstructions	▶∟_

632023 09-21-16

THE ASSOCIATION FOR FRONTOTEMPORAL

Schedule A (Form 990 or 990-EZ) 2016 DEGENERATION

Part IV | Supporting Organizations

(Complete only if you checked a box in line 12 on Part I. If you checked 12a of Part I, complete Sections A and B. If you checked 12b of Part I, complete Sections A and C. If you checked 12c of Part I, complete Sections A, D, and E. If you checked 12d of 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 (b) and (c) 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 12a or 12b in Part I, answer (b) and (c) 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 (b) and (c) 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 (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).
- 8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).
- 9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in **Part VI.**
- **b** Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in **Part VI.**
- c Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI.
- 10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer 10b below.
 - **b** Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)

		Yes	No
	1		
	•		
	2		
	3a		
	Ja		
	3b		
	3с		
	4a		
	4b		
	4c		
	5a		
	- Cu		
	5b		
	5c		
	6		
	_		
	7		
	c		
	8		
	9a		
	9b		
	9с		
	10a		
	10b		
m 9	90 or 99	90-EZ)	2016

632024 09-21-16

Par	t IV Supporting Organizations _(continued)			
			Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?			
а	A person who directly or indirectly controls, either alone or together with persons described in (b) and (c)			
		11a		
b		11b		
	· · · · · · · · · · · · · · · · · · ·	11c		
	tion B. Type I Supporting Organizations		'	
			Yes	No
1	Did the directors, trustees, or membership of one or more supported organizations have the power to			
	regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the			
	tax year? If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or			
	controlled the organization's activities. If the organization had more than one supported organization,			
	describe how the powers to appoint and/or remove directors or trustees were allocated among the supported			
	organizations and what conditions or restrictions, if any, applied to such powers during the tax year.	1		
2	Did the organization operate for the benefit of any supported organization other than the supported			
	organization(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,			
	supervised, or controlled the supporting organization.	2		
Sect	tion C. Type II Supporting Organizations		'	
			Yes	No
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			
	the supported organization(s).	1		
Sect	tion 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 in (2), 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		
<u>Sect</u>	tion 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 yea(see instructions).			
а	The organization satisfied the Activities Test. Complete line 2 below.			
b	The organization is the parent of each of its supported organizations. Complete line 3 below.			
С	The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instruc	ctions) T		
2	Activities Test. Answer (a) and (b) below.		Yes	No
а	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			
	· · · · · · · · · · · · · · · · · · ·	2a		
b	Did the activities described in (a) 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			
_	· · · · · · · · · · · · · · · · · · ·	2b		
3	Parent of Supported Organizations. <i>Answer (a) and (b) below.</i>			
а	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or			
	· · · · · · · · · · · · · · · · · · ·	3a		
b	Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each	01		
	of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.	3b	[

632025 09-21-16

Distributable Amount. Subtract line 5 from line 4, unless subject to

emergency temporary reduction (see instructions)

instructions).

Schedule A (Form 990 or 990-EZ) 2016 DEGENERATION Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI.) See instructions. All other Type III non-functionally integrated supporting organizations must complete Sections A through E. (B) Current Year Section A - Adjusted Net Income (A) Prior Year (optional) Net short-term capital gain 1 Recoveries of prior-year distributions 2 2 Other gross income (see instructions) 3 4 Add lines 1 through 3 5 5 Depreciation and depletion Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions) 6 7 Other expenses (see instructions) Adjusted Net Income (subtract lines 5, 6, and 7 from line 4) 8 (B) Current Year Section B - Minimum Asset Amount (A) Prior Year (optional) 1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): a Average monthly value of securities 1a **b** Average monthly cash balances 1b c Fair market value of other non-exempt-use assets 1c d Total (add lines 1a, 1b, and 1c) 1d e Discount claimed for blockage or other factors (explain in detail in Part VI): Acquisition indebtedness applicable to non-exempt-use assets 2 Subtract line 2 from line 1d 3 Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, 4 see instructions) 5 5 Net value of non-exempt-use assets (subtract line 4 from line 3) Multiply line 5 by .035 6 6 Recoveries of prior-year distributions 7 7 8 Minimum Asset Amount (add line 7 to line 6) Section C - Distributable Amount Current Year Adjusted net income for prior year (from Section A, line 8, Column A) 1 1 Enter 85% of line 1 2 3 Minimum asset amount for prior year (from Section B, line 8, Column A) 3 Enter greater of line 2 or line 3 4 5 5 Income tax imposed in prior year

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

Schedule A (Form 990 or 990-EZ) 2016

6

Par	t V	Type III Non-Functionally Integrated 509	(a)(3) Supporting Orga	anizations _(continued)				
Secti	on D -	Distributions		,	Current Year			
1	Amou	nts paid to supported organizations to accomplish exe	mpt purposes					
2								
	organi	izations, in excess of income from activity						
3		nistrative expenses paid to accomplish exempt purpose	ns					
4	Amou	nts paid to acquire exempt-use assets						
5	Qualif	ied set-aside amounts (prior IRS approval required)						
6	Other	distributions (describe in Part VI). See instructions						
7	Total	annual distributions. Add lines 1 through 6						
8		outions to attentive supported organizations to which the	ne organization is responsive	e				
		de details in Part VI). See instructions	3					
9	(1	outable amount for 2016 from Section C, line 6						
		amount divided by Line 9 amount						
	2,110 0	amount arriada by Emo o amount	(i)	(ii)	(iii)			
			Excess Distributions	Underdistributions	Distributable			
Secti	on E -	Distribution Allocations (see instructions)	Excess Distributions	Pre-2016	Amount for 2016			
1	Dietrih	outable amount for 2016 from Section C, line 6						
		rdistributions, if any, for years prior to 2016 (reason-						
_		ause required- explain in Part VI). See instructions						
3		s distributions carryover, if any, to 2016:						
	EXCES	s distributions carryover, if any, to 2016.						
<u>a</u> b								
	From	2012						
	From							
	From							
		of lines 3a through e						
	• • •	ed to underdistributions of prior years						
		ed to 2016 distributable amount						
<u> </u>		over from 2011 not applied (see instructions)						
j		inder. Subtract lines 3g, 3h, and 3i from 3f.						
4		outions for 2016 from Section D,						
	line 7:	·						
	• • •	ed to underdistributions of prior years						
		ed to 2016 distributable amount						
		inder. Subtract lines 4a and 4b from 4						
5		ining underdistributions for years prior to 2016, if						
	-	Subtract lines 3g and 4a from line 2. For result greater						
		ero, explain in Part VI. See instructions						
6		ining underdistributions for 2016. Subtract lines 3h						
	and 4	b from line 1. For result greater than zero, explain in						
		1. See instructions						
7	Exces	ss distributions carryover to 2017. Add lines 3j						
	and 4	С						
8	Break	down of line 7:						
а								
b	Exces	s from 2013						
С	Exces	s from 2014						
d	Exces	s from 2015						
е	Exces	s from 2016						

Schedule A (Form 990 or 990-EZ) 2016

THE ASSOCIATION FOR FRONTOTEMPORAL

Schedule A	(Form 990 or 990-EZ) 2016 DEGENERATION	41-2073220 Page 8
Part VI	Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, line line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a, and 3b; Part V, line 1; Pa Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any addi (See instructions.)	a or 17b; Part III, line 12; es 1 and 2; Part IV, Section C, rt V, Section B, line 1e; Part V,

SCHEDULE C

(Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service

Political Campaign and Lobbying Activities

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

Complete if the organization is described below. Attach to Form 990 or Form 990-EZ.
Information about Schedule C (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

2016

Open to Public Inspection

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

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

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

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

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

Tax) (see separate instructions), then				
•	Section 501(c)(4), (5), or (6) organiza	ations: Complete Part III.			
Nan	ne of organization THE ASS	SOCIATION FOR FROM	NTOTEMPORAL	Empl	oyer identification number
	DEGENEF	RATION			41-2073220
Pa	art I-A Complete if the or	ganization is exempt unde	er section 501(c) o	or is a section 527 o	rganization.
2	Provide a description of the organi Political campaign activity expendi Volunteer hours for political campa	tures		 ►\$	
		ganization is exempt unde			
1	Enter the amount of any excise tax	incurred by the organization unde	er section 4955	▶\$	
2	Enter the amount of any excise tax	incurred by organization manage	rs under section 4955	\$	
3	If the organization incurred a section	on 4955 tax, did it file Form 4720 f	or this year?		Yes No
4a	Was a correction made?				Yes No
	If "Yes," describe in Part IV.				
Pa	art I-C Complete if the or	ganization is exempt unde	er section 501(c),	except section 501(c)(3).
	Enter the amount directly expende Enter the amount of the filing organ	nization's funds contributed to oth	er organizations for se	ction 527	
_	exempt function activities			▶\$	
3	Total exempt function expenditure		,	> 0	
	line 17b				
	Did the filing organization file Form				
5	Enter the names, addresses and e				
	made payments. For each organization contributions received that were p	•			•
	political action committee (PAC). If			•	ite segregated fund of a
	• • • • • • • • • • • • • • • • • • • •	· · · · · · · · · · · · · · · · · · ·	1		
	(a) Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds. If none, enter -0	(e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0

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

Schedule C (Form 990 or 990-EZ) 2016

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	100.00	- 1.						
P	art II-	Α	Complete if the org	ganization is exe	mpt under sectio	n 501(c)(3) and fil	ed Form 5768 (el	ection under
			section 501(h)).					
A	Check		if the filing organiza	ation belongs to an affi	liated group (and list in	Part IV each affiliated	group member's nam	e, address, EIN,
			expenses, and sha	re of excess lobbying	expenditures).			
В	Check	\blacktriangleright	if the filing organiza	ation checked box A a	nd "limited control" pro	visions apply.		
				its on Lobbying Expe ditures" means amou	nditures unts paid or incurred.		(a) Filing organization's totals	(b) Affiliated group totals
1	a Tota	al lob	bying expenditures to inf	uence public opinion (grass roots lobbying)			
	b Tota	al lob	bying expenditures to inf	uence a legislative bo	dy (direct lobbying)		2,850.	
	c Tota	al lob	bying expenditures (add	lines 1a and 1b)			2,850.	
			kempt purpose expenditu				5,464,378.	
	e Tota	al ex	empt purpose expenditure				5,467,228.	
			g nontaxable amount. Ent				423,361.	
			ount on line 1e, column (a)		bying nontaxable am			
			r \$500,000		the amount on line 1e.			
	Ove	r \$5	00,000 but not over \$1,00	0,000 \$100,00	00 plus 15% of the exc	ess over \$500,000.		
	Ove	r \$1	,000,000 but not over \$1,5		00 plus 10% of the exc			
	Ove	r \$1	,500,000 but not over \$17		00 plus 5% of the exce			
	Ove	r \$1	7,000,000	\$1,000,	000.			
				<u> </u>				
	g Gra	ssro	ots nontaxable amount (e	nter 25% of line 1f)			105,840.	
	h Sub	trac	t line 1g from line 1a. If ze	ro or less, enter -0-			0.	
	i Sub	trac	t line 1f from line 1c. If zer	o or less, enter -0			0.	
			s an amount other than ze					
	rep	ortin	g section 4911 tax for this	year?			[Yes No
			(Some organizations t	hat made a section 5	eraging Period Under 01(h) election do not ate instructions for li	have to complete all	of the five columns b	elow.
				Lobbying Expe	nditures During 4-Yea	r Averaging Period		
		(Calendar vear	(-) 0040	(1-) 004.4	(-) 004E	(-1) 0040	(-) T-4-1

Labbuing Europalitures During A Very Averaging Devied										
	Lobbying Expenditures During 4-Year Averaging Period									
Calendar year (or fiscal year beginning in)	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) Total					
2a Lobbying nontaxable amount	212,792.	248,012.	283,730.	423,361.	1,167,895.					
b Lobbying ceiling amount (150% of line 2a, column(e))					1,751,843.					
c Total lobbying expenditures	1,500.	1,150.	3,350.	2,850.	8,850.					
d Grassroots nontaxable amount	53,198.	62,003.	70,933.	105,840.	291,974.					
e Grassroots ceiling amount (150% of line 2d, column (e))					437,961.					
f Grassroots lobbying expenditures										

Schedule C (Form 990 or 990-EZ) 2016

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	ach "Yes," response on lines 1a through 1i below, provide in Part IV a detailed description	(a)		(b	o)
	e lobbying activity.	Yes	No	Amo	ount
1	During the year, did the filing organization attempt to influence foreign, national, state or				
	local legislation, including any attempt to influence public opinion on a legislative matter				
	or referendum, through the use of:				
а	Volunteers?				
	Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?				
С	Media advertisements?				
	Mailings to members, legislators, or the public?				
	Publications, or published or broadcast statements?				
	Grants to other organizations for lobbying purposes?				
	Direct contact with legislators, their staffs, government officials, or a legislative body?				
	Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?				
	Other activities?				
	Total. Add lines 1c through 1i				
	Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?				
	If "Yes," enter the amount of any tax incurred under section 4912				
	If "Yes," enter the amount of any tax incurred by organization managers under section 4912				
	If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?t III-A Complete if the organization is exempt under section 501(c)(4), section	n 501/c\/	5) or se	ction	
ı aı	501(c)(6).	311 30 1 (C)(C	<i>)</i> , 01 30		
				Yes	No
1	Were substantially all (90% or more) dues received nondeductible by members?				
2	Did the organization make only in-house lobbying expenditures of \$2,000 or less?				
3	Did the organization agree to carry over lobbying and political campaign activity expenditures from the till-B Complete if the organization is exempt under section 501(c)(4), section 5				
1	501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered answered "Yes." Dues, assessments and similar amounts from members	-		t III-A, lir	ne 3, is
2	Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenditures)				
_	expenses for which the section 527(f) tax was paid).		0-		
	Current year				
	Carryover from last year				
c	Total Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues				
3	If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the exc				
4	does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and				
	expenditure next year?		4		
5	Taxable amount of lobbying and political expenditures (see instructions)				
Par			•		
	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	A. lines 1	and 2 (see	
	uctions); and Part II-B, line 1. Also, complete this part for any additional information.	,,	,	•	
	,, , , , , , , , , , , , , , , , , , , ,				

SCHEDULE D (Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

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

Attach to Form 990.

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

Open to Public Inspection

OMB No. 1545-0047

Name of the organization

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION

Employer identification number 41-2073220

Pai	t I Organizations Maintaining Donor Advise	d Funds or Other Similar Funds o	r Accounts. Complete if the
	organization answered "Yes" on Form 990, Part IV, lin	e 6.	
		(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year		
2	Aggregate value of contributions to (during year)		
3	Aggregate value of grants from (during year)		
4	Aggregate value at end of year		
5	Did the organization inform all donors and donor advisors in	writing that the assets held in donor advised	funds
	are the organization's property, subject to the organization's	exclusive legal control?	Yes No
6	Did the organization inform all grantees, donors, and donor a	dvisors in writing that grant funds can be us	ed only
	for charitable purposes and not for the benefit of the donor of	r donor advisor, or for any other purpose co	nferring
Pai	t II Conservation Easements. Complete if the org	ganization answered "Yes" on Form 990, Par	t IV, line 7.
1	Purpose(s) of conservation easements held by the organizati	on (check all that apply).	
	Preservation of land for public use (e.g., recreation or e	education) Preservation of a historic	cally important land area
	Protection of natural habitat	Preservation of a certifie	d historic structure
	Preservation of open space		
2	Complete lines 2a through 2d if the organization held a qualif	ied conservation contribution in the form of	
	day of the tax year.		Held at the End of the Tax Year
а	Total number of conservation easements		2a
	•		
	Number of conservation easements on a certified historic str		
d	Number of conservation easements included in (c) acquired a		l I
	listed in the National Register		
3	Number of conservation easements modified, transferred, rel	eased, extinguished, or terminated by the or	ganization during the tax
	year ▶		
4	Number of states where property subject to conservation eas		
5	Does the organization have a written policy regarding the per		
_	violations, and enforcement of the conservation easements it		
6	Staff and volunteer hours devoted to monitoring, inspecting,	handling of violations, and enforcing conser	vation easements during the year
-			
7	Amount of expenses incurred in monitoring, inspecting, hand	iling of violations, and enforcing conservation	n easements during the year
•	▶ \$ Does each conservation easement reported on line 2(d) above		(4)(D)()
8		•	
9	and section 170(h)(4)(B)(ii)?		
9	include, if applicable, the text of the footnote to the organization		
	conservation easements.	tion's illiancial statements that describes the	organization's accounting to
Pai	t III Organizations Maintaining Collections of	f Art. Historical Treasures. or Oth	er Similar Assets.
	Complete if the organization answered "Yes" on Form	-	
	If the organization elected, as permitted under SFAS 116 (AS		nt and balance sheet works of art
	historical treasures, or other similar assets held for public exh		
	the text of the footnote to its financial statements that descri		
b	If the organization elected, as permitted under SFAS 116 (AS		nd balance sheet works of art. historical
	treasures, or other similar assets held for public exhibition, ed		
	relating to these items:	,	71
	(i) Revenue included on Form 990, Part VIII, line 1		> \$
	(ii) Assets included in Form 990, Part X		· · · · · · · · · · · · · · · · · · ·
2	If the organization received or held works of art, historical treatments		
	the following amounts required to be reported under SFAS 1	-	•
а	Revenue included on Form 990, Part VIII, line 1		> \$
	Assets included in Form 990, Part X		
	For Paperwork Reduction Act Notice, see the Instructions		Schedule D (Form 990) 2016

	t III Organizations Maintaining C	ollections of A	rt, His	torical Tr	easures,	or Othe	r Similar A	ssets(continue	ed)
3	Using the organization's acquisition, accession	on, and other record	ds, chec	k any of the	following tha	at are a siç	gnificant use o	f its collection it	ems
	(check all that apply):								
а	Public exhibition	d		Loan or exc	hange progr	ams			
b	Scholarly research	е							
С	Preservation for future generations			-					
4	Provide a description of the organization's co	llections and explain	n how th	nev further t	he organizat	ion's exen	npt purpose in	Part XIII.	
5	During the year, did the organization solicit or								
	to be sold to raise funds rather than to be ma							Yes	O No
Pai	t IV Escrow and Custodial Arrang							t IV, line 9, or	
	reported an amount on Form 990, Par	t X, line 21.		_					
1a	Is the organization an agent, trustee, custodia	an or other intermed	diary for	contribution	ns or other as	sets not i	included		
	on Form 990, Part X?							Yes	O No
b	If "Yes," explain the arrangement in Part XIII a								
								Amount	
С	Beginning balance						. 1c		
	Additions during the year								
	Distributions during the year								
f	Ending balance								
2a	Did the organization include an amount on Fo							Yes	No
b	If "Yes," explain the arrangement in Part XIII.	Check here if the ex	xplanatio	on has been	provided on	Part XIII			
Pai	T V Endowment Funds. Complete if	the organization an	swered	"Yes" on Fo	orm 990, Par	t IV, line 1	0.		
		(a) Current year	(b) F	rior year	(c) Two yea	rs back (d) Three years b	ack (e) Four ye	ars back
1a	Beginning of year balance								
b	Contributions								
С	Net investment earnings, gains, and losses								
d	Grants or scholarships								
е	Other expenditures for facilities								
	and programs								
f	Administrative expenses								
g	End of year balance								
2	Provide the estimated percentage of the curre	ent year end balanc	e (line 1	g, column (a	a)) held as:				
а	Board designated or quasi-endowment		_%						
b	Permanent endowment >	%							
С	Temporarily restricted endowment	%							
	The percentages on lines 2a, 2b, and 2c should	uld equal 100%.							
3a	Are there endowment funds not in the posses	ssion of the organiza	ation tha	at are held a	and administe	ered for th	e organization	·	
	by:							Y	es No
	(i) unrelated organizations							3a(i)	
	(ii) related organizations							3a(ii)	
b	If "Yes" on line 3a(ii), are the related organizate	tions listed as requir	red on S	Schedule R?				3b	
4	Describe in Part XIII the intended uses of the		owment	funds.					
Pai	t VI Land, Buildings, and Equipm								
	Complete if the organization answered	d "Yes" on Form 990	0, Part I	/, line 11a. S	See Form 990	D, Part X, I	ine 10.		
	Description of property	(a) Cost or o			or other		cumulated	(d) Book v	alue
		basis (investr	ment)	basis	(other)	dep	reciation		
	Land								
	Buildings								
С	Leasehold improvements				0 04 5		00 500		
d	Equipment			4	8,315.		28,789.	19,	526.
	Other								<u> </u>
Tota	. Add lines 1a through 1e. (Column (d) must ed	gual Form 990, Part	X, colur	nn (B), line 1	10c.)			19,	526.

Schedule D (Form 990) 2016

		11b. See Form 990, Part X, line 12.	
(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost o	r end-of-year market valu
) Financial derivatives			
Closely-held equity interests			
Other			
(A)			
(B)			
(C)			
(D)			
(E)			
(F)			
(G)			
` /			
(H)			
al. (Col. (b) must equal Form 990, Part X, col. (B) line 12.)			
art VIII Investments - Program Related.			
Complete if the organization answered "Yes"			
(a) Description of investment	(b) Book value	(c) Method of valuation: Cost o	r end-of-year market valu
(1)			
(2)			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
otal. (Col. (b) must equal Form 990, Part X, col. (B) line 13.)			
Part IX Other Assets.			
Complete if the organization answered "Yes" of		11d. See Form 990, Part X, line 15.	
(a) [Description		(b) Book value
(1)			
(2)			
(3)			
(4)			
(4)			
(5)			
(5) (6)			
(5) (6) (7)			
(5) (6) (7) (8)			
(5) (6) (7) (8) (9)			
(5) (6) (7) (8) (9) ttal. (Column (b) must equal Form 990, Part X, col. (B) line	· 15.)		. ▶
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line Part X Other Liabilities.			. >
(5) (6) (7) (8) (9) Intal. (Column (b) must equal Form 990, Part X, col. (B) line Part X Other Liabilities. Complete if the organization answered "Yes" (. ▶ ne 25.
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line eart X Other Liabilities.		11e or 11f. See Form 990, Part X, lir (b) Book value	. ▶ ne 25.
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line art X Other Liabilities. Complete if the organization answered "Yes" (. ▶ ne 25.
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line art X Other Liabilities. Complete if the organization answered "Yes" (a) Description of liability (1) Federal income taxes			. ▶ ne 25.
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line art X Other Liabilities. Complete if the organization answered "Yes" (a) Description of liability (1) Federal income taxes (2)			. ▶ ne 25.
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line art X Other Liabilities. Complete if the organization answered "Yes" (a) Description of liability (1) Federal income taxes (2) (3)			. ▶ ne 25.
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line art X Other Liabilities. Complete if the organization answered "Yes" (a) Description of liability (1) Federal income taxes (2) (3) (4)			. ▶ ne 25.
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line art X Other Liabilities. Complete if the organization answered "Yes" (a) Description of liability (1) Federal income taxes (2) (3) (4) (5)			. ▶ ne 25.
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line art X Other Liabilities. Complete if the organization answered "Yes" (a) Description of liability (1) Federal income taxes (2) (3) (4) (5) (6)			. ▶ ne 25.
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line art X Other Liabilities. Complete if the organization answered "Yes" (a) Description of liability (1) Federal income taxes (2) (3) (4) (5) (6) (7)			. ▶ ne 25.
(5) (6) (7) (8) (9) Ital. (Column (b) must equal Form 990, Part X, col. (B) line Part X Other Liabilities. Complete if the organization answered "Yes" (a) Description of liability (1) Federal income taxes (2) (3) (4) (5)			. ▶ ne 25.
(5) (6) (7) (8) (9) tal. (Column (b) must equal Form 990, Part X, col. (B) line art X Other Liabilities. Complete if the organization answered "Yes" (a) Description of liability (1) Federal income taxes (2) (3) (4) (5) (6) (7)			. ▶ ne 25.

632053 08-29-16

Schedule D (Form 990) 2016

Part	Reconciliation of Revenue per Audited Financial S		Revenue per R	leturn	l .
	Complete if the organization answered "Yes" on Form 990, Part IV	, line 12a.			
1	Total revenue, gains, and other support per audited financial statements			1	4,134,981.
	Amounts included on line 1 but not on Form 990, Part VIII, line 12:				
	Net unrealized gains (losses) on investments				
	Donated services and use of facilities				
	Recoveries of prior year grants				
d	Other (Describe in Part XIII.)	2d			•
	Add lines 2a through 2d			2e	0.
3	Subtract line 2e from line 1			3	4,134,981.
	Amounts included on Form 990, Part VIII, line 12, but not on line 1:	1 1			
	Investment expenses not included on Form 990, Part VIII, line 7b		100.000		
	Other (Describe in Part XIII.)	4b	197,999.		105 000
	Add lines 4a and 4b			4c	197,999.
	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line			5	4,332,980.
Par	Reconciliation of Expenses per Audited Financial		n Expenses per	Retu	rn.
	Complete if the organization answered "Yes" on Form 990, Part IV				F 467 000
	Total expenses and losses per audited financial statements			1	5,467,228.
	Amounts included on line 1 but not on Form 990, Part IX, line 25:	1 1			
	Donated services and use of facilities			-	
	Prior year adjustments			-	
	Other losses			-	
	Other (Describe in Part XIII.)				0
	Add lines 2a through 2d			2e	0. 5,467,228.
	Subtract line 2e from line 1			3	5,407,228.
	Amounts included on Form 990, Part IX, line 25, but not on line 1:	1.1			
	Investment expenses not included on Form 990, Part VIII, line 7b		197,999.	-	
	Other (Describe in Part XIII.)	4b	197,999.	1	107 000
	Add lines 4a and 4b			4c	197,999. 5,665,227.
	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line XIII Supplemental Information.	e 18.)		5	5,005,441.
	le the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide			4; Part	X, line 2; Part XI,
PAR	T XI, LINE 4B - OTHER ADJUSTMENTS:				
IND	IRECT EVENTS EXPENSE				197,999.
PAR	T XII, LINE 4B - OTHER ADJUSTMENTS:				
IND	IRECT EVENTS EXPENSE				197,999.

Schedule D (Form 990) 2016

SCHEDULE F (Form 990)

Department of the Treasury

Internal Revenue Service

Statement of Activities Outside the United States

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

► Attach to Form 990.

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

OMB No. 1545-0047 Open to Public Inspection

Name of the organization

THE ASSOCIATION FOR FRONTOTEMPORAL

Employer identification number

DEGENERATION 41-2073220 General Information on Activities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 14b. 1 For grantmakers. Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? _____X Yes _____No 2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States. 3 Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.) (a) Region (b) Number of (c) Number of (d) Activities conducted in the region (e) If activity listed in (d) (f) Total employees, agents, and independent expenditures is a program service, offices (by type) (such as, fundraising, profor and in the region describe specific type gram services, investments, grants to investments contractors recipients located in the region) of service(s) in the region in the region in the region EUROPE (INCLUDING ICELAND & GREENLAND) MEDICAL RESEARCH GRANTS 808,686. 3 a Sub-total 0 808,686. **b** Total from continuation 0.

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

0

Schedule F (Form 990) 2016

808,686.

sheets to Part I

c Totals (add lines 3a

and 3b)

41-2073220

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	RESEARCH PILOT GRANT	60,000.	CHECK	0.		
				,				
		EUROPE	RESEARCH PILOT GRANT	60,000.	СНЕСК	0.		
		EUROPE	BIOMARKERS INITIATIVE	450,000.	СНЕСК	0.		
		EUROPE	BIOMARKERS INITIATIVE	238,686.	CHECK	0.		
		BONOT E	PIOMIGRACIA INTITATIVE	230,000.	CHECK	<u> </u>		
			recognized as charities by the					
the IRS, or for which t	he grantee or couns	el has provided a section	n 501(c)(3) equivalency letter					4

Part III can be duplicated if a	dditional space is neede	d. (c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of noncash assistance	(g) Description of noncash assistance	(h) Method of valuation (book, FMV, appraisal, other)		

Part IV	Foreign	Forms

1	Was the organization a U.S. transferor of property to a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)	Yes	X No
2	Did the organization have an interest in a foreign trust during the tax year? If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; do not file with Form 990)	Yes	X No
3	Did the organization have an ownership interest in a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain Foreign Corporations (see Instructions for Form 5471)	Yes	X No
4	Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)	Yes	X No
5	Did the organization have an ownership interest in a foreign partnership during the tax year? If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865)	Yes	X No
6	Did the organization have any operations in or related to any boycotting countries during the tax year? If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; do not file with Form 990)	Yes	X No

Schedule F (Form 990) 2016

Part V	_	upplem															
												line 3, column Part III (acc					
												ovide any a					
D3.D#	_		_														
PART	⊥,	LINE	۷:														
RESEA	RCF	GRA	NTS:	GRA	NTEI	ES S	UBMI	т :	INTER	ΙM	AND	FINAL	REPOR	RTS	WITH	PROG	RESS
AND F	TNT	MCTA	T TN	г∩рм	`A TT () NT											
WIND I.	TIME	писти	т ти	I OKH	VI T	714 •											

SCHEDULE G

(Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service

Supplemental Information Regarding Fundraising or Gaming Activities

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

► Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

Open to Public Inspection

Name of the organization

THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION

Employer identification number 41-2073220

Part I Fundraising Activities required to complete this pa	Complete if the organization answert.	ered "Y	es" or	n Form 990, Part IV,	line 17. Form 990-EZ	I filers are not
 Indicate whether the organization rai Mail solicitations Internet and email solicitation Phone solicitations In-person solicitations Did the organization have a written key employees listed in Form 990, F If "Yes," list the 10 highest paid ind compensated at least \$5,000 by the 	e Solicita f Solicita g X Special or oral agreement with any individua Part VII) or entity in connection with prividuals or entities (fundraisers) pursu	tion of tion of fundra I (includer profess	non-g gover lising o ding o ional f	overnment grants nment grants events fficers, directors, true fundraising services?	stees, or Yes	
(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) fundr have con or con contribu	trol of	(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
EVENT ASSOCIATES, INC 162	FUND RAISING EVENT	Yes	No			
WEST 56TH STREET SUITE 405,	PLANNING		Х	1,893,277.	51,576.	1,841,701.
3 List all states in which the organizati or licensing.	on is registered or licensed to solicit	contrib	utions	1,893,277. s or has been notified	51,576. d it is exempt from re	
						

632081 09-12-16

Schedule G (Form 990 or 990-EZ) 2016

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

SEE PART IV FOR CONTINUATIONS

Schedule G (Form 990 or 990-EZ) 2016 DEGENERATION

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

		of fundraising event contributions and gr				ots greater than \$5,000.
			(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
					NONE	(add col. (a) through
			HOPE RISING	, , , ,		col. (c))
e			(event type)	(event type)	(total number)	
Revenue	_	Our and an artists	1,893,277.			1,893,277.
Re	1	Gross receipts	1,000,277.			1,055,277
	2	Less: Contributions	1,812,677.			1,812,677.
	_	2000. CONTRIBUTIONS				
	3	Gross income (line 1 minus line 2)	80,600.			80,600.
		,				
	4	Cash prizes				
"	5	Noncash prizes				
JSes						
Direct Expenses	6	Rent/facility costs				
ώ H	7	Food and beverages	92,875.			92,875.
)irec	′	rood and beverages	32,073.			32,073•
	8	Entertainment				
	9	Other direct expenses	2,061.			2,061.
	10		n 9 in column (d)		>	94,936.
		Net income summary. Subtract line 10 from li	ine 3, column (d)		>	-14,336.
Pa	rt I		answered "Yes" on Form	n 990, Part IV, line 19, or	reported more than	
		\$15,000 on Form 990-EZ, line 6a.	1	a Dullack of contact		l.,
ne			(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
Revenue				Singo/progressive singe		coi. (a) through coi. (c)
æ	4	Gross revenue				
	•	aross revenue				
S	2	Cash prizes				
nse						
Direct Expenses	3	Noncash prizes				
出出						
Öİre	4	Rent/facility costs				
_	_	011				
	5	Other direct expenses	Yes %	Yes %	Yes %	
	6	Volunteer labor	No Yes%	No Yes%	No Yes	
	U	volunteer labor	I NO		140	
	7	Direct expense summary. Add lines 2 through	n 5 in column (d)		•	
			. ,			
	8	Net gaming income summary. Subtract line 7	from line 1, column (d)		>	
		ter the state(s) in which the organization condu	-			
		the organization licensed to conduct gaming a				Yes No
b	IT "	No," explain:				
10a	We	ere any of the organization's gaming licenses re	evoked, suspended, or te	erminated during the tax	vear?	Yes No
		Yes," explain:		_	•	
	_					

632082 09-12-16

Schedule G (Form 990 or 990-EZ) 2016

THE ASSOCIATION FOR FRONTOTEMPORAL

Sch	edule G (Form 990 or 990-EZ) 2016 DEGENERATION 41-2	0732	220	Page 3
11	Does the organization conduct gaming activities with nonmembers?	$\overline{}$	es	No
	Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity formed			
	to administer charitable gaming?	Y	es	☐ No
13	Indicate the percentage of gaming activity conducted in:			
а	The organization's facility	13a		%
	An outside facility	13b		%
14	Enter the name and address of the person who prepares the organization's gaming/special events books and records:			
	Name			
	Address			
15a	Does the organization have a contract with a third party from whom the organization receives gaming revenue?	. — Y	es	☐ No
b	If "Yes," enter the amount of gaming revenue received by the organization > \$ and the amount			
	of gaming revenue retained by the third party \$\bigs\\$			
С	If "Yes," enter name and address of the third party:			
	Name			
	Address ►			
16	Gaming manager information:			
	Name			
	Gaming manager compensation \$			
	Description of services provided			
	Director/officer Employee Independent contractor			
	Mandatory distributions:			
а	Is the organization required under state law to make charitable distributions from the gaming proceeds to		·	
	retain the state gaming license?	. — Y	es	☐ No
b	Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the			
Da	organization's own exempt activities during the tax year \$\text{tV} \text{Supplemental Information.} Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, line 2b.	200 0 0	h 10	15h
ı a	Supplemental Information. Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, line 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions	1165 9, 9	b, 101	J, 13D,
	100, 10, and 170, as applicable. Also provide any additional morniation. God motifications			
SC	HEDULE G, PART I, LINE 2B, LIST OF TEN HIGHEST PAID FUNDRAISER	S:		
(I) NAME OF FUNDRAISER: EVENT ASSOCIATES, INC.			
<u>`</u>	, 11111 01 101/2111122111 21211 112200111122, 11101			
<u>(I</u>) ADDRESS OF FUNDRAISER:			
16	2 WEST 56TH STREET SUITE 405, NEW YORK, NY 10019			
PA	RT I, LINE 2B, COLUMN (V):			
	ORDINATION AND PLANNING OF FUND RAISING EVENT "HOPE RISING" IN			
SE	PTEMBER 2016.			

THE ASSOCIATION FOR FRONTOTEMPORAL

Schedule (G (Form 990 or 990-EZ)	DEGENERATION	41-2073220 Page 4
Part IV	G (Form 990 or 990-EZ) Supplemental Info	rmation (continued)	
	_		
			Schedule G (Form 990 or 990-EZ)

632084 04-01-16

SCHEDULE I (Form 990)

Department of the Treasury Internal Revenue Service

Name of the organization

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

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

Attach to Form 990.

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

THE ASSOCIATION FOR FRONTOTEMPORAL

OMB No. 1545-0047 **2016**

Open to Public Inspection

Employer identification number

DEGENERAT	ION						41-2073220
Part I General Information on Grants a	nd Assistance						
1 Does the organization maintain records	to substantiate th	e amount of the grant	s or assistance, the	grantees' eligibilit	y for the grants or ass	sistance, and the selec	tion
criteria used to award the grants or assis	stance?						No
2 Describe in Part IV the organization's pro	ocedures for mon	itoring the use of gran	t funds in the United	d States.			
Part II Grants and Other Assistance to	_				anization answered "\	Yes" on Form 990, Part	IV, line 21, for any
recipient that received more than S		<u> </u>	1		(f) Mathad of	_	
(a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
ALZHEIMER DRUG DISCOVERY							
FOUNDATION - 57 W. 57TH STREET,							
STE 10019 - NEW YORK, NY 10019	20-1082179	501(C)(3)	600,000.	0.			DRUG DISCOVERY
BOSTON CHILDREN'S HOSPITAL 300 LONGWOOD AVENUE BOSTON , MA 02115	04-2774441	501(C)(3)	515,000.	0.			BIOMARKERS INITIATIVE
UNIVERSITY OF PITTSBURGH, DEPARTMENT OF NEUROLOGY - P O BOX 371220 - PITTSBURGH, PA 15251-7220	25-0965591	501(C)(3)	110,000.	0.			MEDICAL RESEARCH
ICAHN SCHOOL OF MEDICINE 1 GUSTAVE L. LEVY PLACE NEW YORK, NY 10029	13-6171197	501(C)(3)	110,000.	0.			MEDICAL RESEARCH
WASHINGTON UNIVERSITY 700 ROSEDALE AVENUE ST. LOUIS, MO 63112	43-0653611	501(C)(3)	495,453.	0.			BIOMARKERS INITIATIVE
MAYO CLINIC JACKSONVILLE 4500 SAN PABLO ROAD JACKSONVILLE, FL 32224	59-0714831	501(C)(3)	300,000.	0.			BIOMARKERS INITIATIVE
2 Enter total number of section 501(c)(3) a3 Enter total number of other organizations							7. 7.

Page 1

DEGENERATION

Part II Continuation of Grants and Other Assistance to Governments and Organizations in the United States (Schedule I (Form 990), Part II.) (c) IRC section (h) Purpose of grant (a) Name and address of (b) EIN (d) Amount of (e) Amount of (f) Method of (g) Description of organization or government if applicable cash grant valuation non-cash assistance or assistance non-cash assistance (book, FMV, appraisal, other) THE FTD DISORDERS REGISTRY LLC 637 CAROLINA STREET 0 SAN FRANCISCO, CA 94107 47-3601782 501(C)(3) 100,000. PATIENT REGISTRY

THE ASSOCIATION FOR FRONTOTEMPORAL

Schedule I (Form 990) (2016)

DEGENERATION

41-2073220

Page 2

(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
RESPITE CARE AND TRAVEL GRANTS	180	87,649.	0.		
Part IV Supplemental Information. Provide the information red	quired in Part I, lin	ie 2; Part III, column	(b); and any other a	dditional information.	
PART I, LINE 2:					
RESPITE AND TRAVEL GRANTS: GRANTER	ES SUBMIT	RECEIPTS	AND PAYMEN	T IS MADE VIA	
REIMBURSEMENT.					
RESEARCH GRANTS: GRANTEES SUBMIT	INTERIM A	ND FINAL R	EPORTS WIT	H PROGRESS	
AND FINANCIAL INFORMATION.					

SCHEDULE J (Form 990)

Compensation Information

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

Compensated Employees

Complete if the organization answered "Yes" on Form 990, Part IV, line 23. ► Attach to Form 990.

OMB No. 1545-0047

Open to Public Inspection

Internal Revenue Service Name of the organization

Part I Questions Regarding Compensation

Department of the Treasury

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

Employer identification number 41-2073220

Schedule J (Form 990) 2016

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

632111 09-09-16

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

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-MI	SC compensation	(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	Denents	(B)(I)-(U)	reported as deferred on prior Form 990
(1) SUSAN DICKINSON	(i)	142,500.	0.	0.	0.	13,250.	155,750.	0.
CHIEF EXECUTIVE OFFICER	(ii)	0.	0.	0.	0.	0.	0.	0.
(2) NADINE TATTON	(i)	138,500.	0.	0.	0.	15,571.		0.
SCIENTIFIC DIRECTOR	(ii)	0.	0.	0.	0.	0.	0.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
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	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii) (i)							
	(ii)							
	[(II)						1	<u> </u>

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.

SCHEDULE M (Form 990)

Noncash Contributions

OMB No. 1545-0047

2016

Open To Public Inspection

Department of the Treasury Internal Revenue Service

Name of the organization

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

Attach to Form 990.

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

THE ASSOCIATION FOR FRONTOTEMPORAL **DEGENERATION**

Employer identification number 41-2073220

Pai	rt I Types of Property							
		(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of do noncash contrib	etermin	_	s
1	Art - Works of art		itomo contributou	Tominood, rant vini, iirio 1g				
2	Art - Historical treasures							
3	Art - Fractional interests							
4	Books and publications							
5	Clothing and household goods							
6	Cars and other vehicles							
7	Boats and planes							
8	Intellectual property							
9	Securities - Publicly traded	X	7	51,258.	DAILY AVG.	MAR:	KET	VA
10	Securities - Closely held stock							
11	Securities - Partnership, LLC, or							
	trust interests							
12	Securities - Miscellaneous							
13	Qualified conservation contribution -							
	Historic structures							
14	Qualified conservation contribution - Other							
15	Real estate - Residential							
16	Real estate - Commercial							
17	Real estate - Other							
18	Collectibles							
19 20	Food inventory							
21	Drugs and medical supplies							
22	Historical artifacts							
23	Scientific specimens							
24	Archeological artifacts							
25	Other ()							
26	Other ()							
27	Other ()							
28	Other ()							
29	Number of Forms 8283 received by the organi	zation durin	g the tax year for o	contributions	•			
	for which the organization completed Form 82	83, Part IV,	Donee Acknowled	gement 29				
							Yes	No
30a	During the year, did the organization receive b	y contribution	on any property re	ported in Part I, lines 1 throu	gh 28, that it			
	must hold for at least three years from the dat	e of the initia	al contribution, and	d which isn't required to be ι	ised for			
	exempt purposes for the entire holding period	?				30a		X
b	If "Yes," describe the arrangement in Part II.							
31	Does the organization have a gift acceptance	policy that re	equires the review	of any nonstandard contribu	utions?	31	Х	
32a	Does the organization hire or use third parties contributions?		-	· · · ·		32a	х	
b	contributions? If "Yes," describe in Part II.					JZ4		
33	If the organization didn't report an amount in o	column (c) fo	r a type of propert	v for which column (a) is che	ecked.			
	describes to Deat II				, o., o.,			
	Gescribe in Part II.			-	Cahadula M			

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

Schedule M (Form 990) (2016)

Part II	is re	porting	in Part I	, column	ation. Professional (b), the notion	umber	the informatio of contributio	n required by Part I, li ns, the number of iter	nes 30b, 32b, and ns received, or a co	33, and wheth ombination of b	er the organization ooth. Also complete
SCHEE	ULE	М,	LINE	32B	}						
AFTD	RETA	INS	THE	SER	/ICES	OF	CETERA	INVESTMENT	SERVICES	LLC TO	SELL
SHARE	S OF	' SE	CURI	ries	RECE	IVEI	AS CO	NTRIBUTIONS	•		
632142 08-2	23-16									Sched	ule M (Form 990) (2016)

SCHEDULE O (Form 990 or 990-EZ)

Department of the Treasury

Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

➤ Attach to Form 990 or 990-EZ.

Open to Public Inspection

OMB No. 1545-0047

Name of the organization

Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990. THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION

Employer identification number 41-2073220

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION: FRONTOTEMPORAL DEGENERATION (FTD); PROVIDE INFORMATION, EDUCATION, SUPPORT AND ADVOCACY TO PERSONS DIAGNOSED WITH FTD, THEIR FAMILIES AND CAREGIVERS; EDUCATE PHYSICIANS AND ALLIED HEALTH PROFESSIONALS ABOUT FTD AND HOW TO IMPROVE PATIENT CARE; BRING ABOUT GREATER PUBLIC AWARENESS OF THE NATURE AND PREVALENCE OF FRONTOTEMPORAL DEGENERATION AND THE NEEDS OF THOSE WHO ARE COPING WITH IT; ADVOCATE WITH PUBLIC OFFICIALS TO PROMOTE PUBLIC AND PRIVATE PROGRAMS THAT PROVIDE APPROPRIATE, AFFORDABLE AND HIGH-QUALITY, LONG-TERM HEALTH CARE AND SOCIAL SERVICES.

FORM 990, PART III, LINE 1, DESCRIPTION OF ORGANIZATION MISSION: HEALTH PROFESSIONALS ABOUT FTD AND HOW TO IMPROVE PATIENT CARE; BRING ABOUT GREATER PUBLIC AWARENESS OF THE NATURE AND PREVALENCE OF FRONTOTEMPORAL DEGENERATION AND THE NEEDS OF THOSE WHO ARE COPING WITH IT; ADVOCATE WITH PUBLIC OFFICIALS AND PROMOTE PUBLIC AND PRIVATE PROGRAMS THAT PROVIDE APPROPRIATE, AFFORDABLE AND HIGH-QUALITY LONG-TERM HEALTH CARE AND SOCIAL SERVICES.

FORM 990, PART III, LINE 4C, PROGRAM SERVICE ACCOMPLISHMENTS: WITHOUT FTD CANNOT BECOME REALITY UNTIL OUR NEIGHBORS, PHYSICIANS, PROFESSIONAL CAREGIVERS, POLITICAL REPRESENTATIVES AND NEWS REPORTERS ALL UNDERSTAND THIS ESPECIALLY CRUEL FORM OF NEURODEGENERATION AND WHAT IT STEALS FROM OUR LOVED ONES. AFTD HELPED TO SPREAD FTD AWARENESS AROUND THE GLOBE WITH THE SECOND ANNUAL WORLD FTD AWARENESS WEEK, WHICH INCLUDED A TODAY SHOW SEGMENT ON FTD. WITH DONOR SUPPORT, FTD AWARENESS LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Schedule O (Form 990 or 990-EZ) (2016)

632211 08-25-16

Name of the organization THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION

Employer identification number 41-2073220

ADS RAN IN TWO SUNDAY ISSUES OF THE NEW YORK TIMES. WITH HELP FROM

DISCOVERY COMMUNICATIONS, AN AFTD PSA REACHED MORE THAN 100 MILLION

VIEWERS BY AIRING ON DISCOVERY'S NETWORKS.

ADVOCACY

OUR COMMUNITY IS LEADING THE WAY TO SEND THE MESSAGE THAT DEMENTIA IS A
MULTI-FACETED DISEASE THAT CAN OCCUR AT A YOUNG AGE AND BEGIN WITH

SYMPTOMS UNRELATED TO MEMORY. AFTD IS WORKING HARD TO ENSURE THAT THIS

MESSAGE IS HEARD IN WASHINGTON DC AND OTHER SEATS OF POWER, WHERE

DECISIONS ABOUT RESEARCH FUNDING AND SERVICES ARE MADE. AFTD

REPRESENTED OUR COMMUNITY AT EVERY QUARTERLY MEETING OF THE NATIONAL

ALZHEIMER'S PROJECT ACT (NAPA) COUNCIL IN WASHINGTON. WE VISITED

SEVERAL CONGRESSIONAL OFFICES IN MAY TO PROVIDE BACKGROUND ON THE NEED

FOR A GREATER FEDERAL FOCUS ON FTD.

FORM 990, PART VI, SECTION A, LINE 2:

MICHAEL STOWELL AND BONNIE SHEPHERD HAVE A FAMILY RELATIONSHIP - SON AND MOTHER.

STEPHEN AND DEBBIE FENOGLIO HAVE A FAMILY RELATIONSHIP - SIBLINGS-IN-LAW

FORM 990, PART VI, SECTION B, LINE 11B:

THE COMPLETE 990 WAS FORWARDED TO AFTD'S AUDIT COMMITTEE, WHICH REVIEWED IT IN DETAIL AND FORWARDED IT ALONG TO THE BOARD OF DIRECTORS. BOARD MEMBERS RECEIVE A COPY OF THE COMPLETED 990 IN ADVANCE OF FILING, AND WERE ADVISED THAT THEY WOULD NEED TO READ IT IN FULL. THE AUDIT COMMITTEE CHAIR, TREASURER, CEO AND CFO WERE AVAILABLE TO CLARIFY ANY ISSUES. DURING A BOARD MEETING IN SEPTEMBER 2017 TIME WAS RESERVED FOR REVIEW AND DISCUSSION OF THE 990. THE 990 WAS APPROVED BY THE BOARD BEFORE FILING.

632212 08-25-16

Employer identification number 41-2073220

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

ALL BOARD MEMBERS AND CEO SIGN THE CONFLICT OF INTEREST FORM EVERY YEAR. IF AN ISSUE WERE TO ARISE IT WOULD BE ADDRESSED BY THE EXECUTIVE COMMITTEE AND THE BOARD MEMBER/CEO IN QUESTION.

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

THE PERFORMANCE REVIEW OF AFTD'S CEO WAS BASED ON THE PAST FY RESULTS. INCLUDES INPUT THAT THE BOARD CHAIR, VICE CHAIR AND SECRETARY OBTAINED FROM AFTD BOARD MEMBERS, MAC MEMBERS AND MAJOR DONORS. THE PERFORMANCE REVIEW WAS DRAFTED BY THE VICE CHAIR AND SECRETARY AND FINALIZED BY THE CHAIR. Α RECOMMENDED SALARY RANGE WAS PUT FORTH BY A COMPENSATION SUBCOMMITTEE CONSISTING OF THE BOARD CHAIR AND FOUNDER/PAST CHAIR. THIS SALARY RANGE WAS DETERMINED AFTER REVIEWING EXTENSIVE SALARY COMPARABILITY DATA FOR THE GREATER PHILADELPHIA AREA. THE FINAL SALARY RANGE WAS APPROVED BY THE FULL BOARD OF DIRECTORS, WHO ALSO EMPOWERED THE EXECUTIVE COMMITTEE TO DETERMINE THE FINAL COMPENSATION PACKAGE FOR THE CEO BASED ON THE APPROVED RANGE.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990: KS,KY,ME,MD,MA,MI,MN,MS,NH,NJ,NM,NY,NC,AL,OH,OK,OR,PA,RI,SC,TN,UT,VA,WA,WV WI, AK, AZ, AR, CA, CO, CT, DC, FL, GA, HI, IL, ND

FORM 990, PART VI, SECTION C, LINE 19:

ALL GOVERNING DOCUMENTS ARE AVAILABLE UPON REQUEST FROM THE OFFICE.

FORM 990 PART XII LINE 2C

THE PROCESS IN WHICH THE ORGANIZATION ASSUMES RESPONSIBILITY FOR THE OVERSIGHT OF THE AUDIT HAS NOT CHANGED FROM THE PRIOR YEAR.

Schedule O (Form 990 or 990-EZ) (2016)

Schedule O (Form 990 or 9	90-EZ) (2016)	Page 2
Name of the organization	90.EZ) (2016) THE ASSOCIATION FOR FRONTOT: DEGENERATION	EMPORAL Employer identification number $41-2073220$
	BEGENERATION	41 2073220
632212 08-25-16	53	Schedule O (Form 990 or 990-EZ) (2016

SCHEDULE R (Form 990)

Part I

Department of the Treasury Internal Revenue Service **Related Organizations and Unrelated Partnerships**

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

➤ Attach to Form 990.

► Information about Schedule R (Form 990) at THE ASSOCIATION FOR FRONTOTEMPORAL

(b)

Primary activity

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

2016
Open to Public Inspection

OMB No. 1545-0047

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

(c)

Legal domicile (state or

(d)

Total income

(e)

End-of-year assets

Name of the organization THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION

(a)

Name, address, and EIN (if applicable)

Employer identification number 41-2073220

(f)

Direct controlling

, ,	foreign country)			er	ntity	
tions. Complete if the organization	answered "Yes" on Form 990	D, Part IV, line 34 b	pecause it had one	or more related tax-exe	mpt	
(b) Primary activity	(c) Legal domicile (state or foreign country)	(d) Exempt Code section	(e) Public charity status (if section 501(c)(3))	(f) Direct controlling entity	contr ent	512(b)(13) trolled titty?
PROVIDES PATIENT REGISTRY		504 (5) (0)				
FOR THOSE AFFECTED BY FTD	DELAWARE	DU1(C)(3)	LINE /			X
	(b) Primary activity	tions. Complete if the organization answered "Yes" on Form 990 (b) (c) Legal domicile (state or foreign country) PROVIDES PATIENT REGISTRY	tions. Complete if the organization answered "Yes" on Form 990, Part IV, line 34 I (b) (c) Legal domicile (state or foreign country) Exempt Code section PROVIDES PATIENT REGISTRY	tions. Complete if the organization answered "Yes" on Form 990, Part IV, line 34 because it had one (b) Primary activity (c) Legal domicile (state or foreign country) Exempt Code section Public charity status (if section 501(c)(3))	tions. Complete if the organization answered "Yes" on Form 990, Part IV, line 34 because it had one or more related tax-exe (b) (c) (d) (e) Primary activity Legal domicile (state or foreign country) Exempt Code section Solicing entity PROVIDES PATIENT REGISTRY	tions. Complete if the organization answered "Yes" on Form 990, Part IV, line 34 because it had one or more related tax-exempt (b) Primary activity Legal domicile (state or foreign country) Legal domicile (state or foreign country) PROVIDES PATIENT REGISTRY (c) Legal domicile (state or foreign country) Exempt Code section Exempt Code section 501(c)(3)) Direct controlling entity Yes

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.

<u> </u>		<u> </u>				1					
(a)	(b)	(c)	(d)	(e)	(f)	(g)	(1	h)	(i)	(j)	(k)
Name, address, and EIN of related organization	Primary activity	Legal domicile	Direct controlling	Predominant income (related, unrelated, excluded from tax under sections 512-514)	Share of total	Share of	Disproportionate allocations?		Code V-UBI	General	Percentage ownership
of related organization		(state or foreign	entity	excluded from tax under	income	end-of-year assets			amount in box 20 of Schedule K-1 (Form 1065)	partner	ownership
		country)		sections 512-514)		400010	Yes	No	K-1 (Form 1065)	Yes No	<u> </u>
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Part IV Identification of Related Organizations Taxable as a Corporation or Trust. Complete if the organization answered "Yes" on Form 990, Part IV, line 34 because it had one or more related organizations treated as a corporation or trust during the tax year.

(a) Name, address, and EIN of related organization	(b) Primary activity	(c) Legal domicile (state or foreign	(d) Direct controlling entity	(e) Type of entity (C corp, S corp, or trust)	(f) Share of total income	(g) Share of end-of-year assets	(h) Percentage ownership	Sec 512(t contr ent	tion b)(13) rolled ity?
		country)		or tracty		400010		Yes	No
									l
									
									l
									<u> </u>

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

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

Yes No

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

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

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

c Gift, grant, or capital contribution from related organization(s)				1c		X			
d Loans or loan guarantees to or for related organization(s)				1d		X			
e Loans or loan guarantees by related organization(s)				1e		X			
f Dividends from related organization(s)				1f		_X_			
g Sale of assets to related organization(s)						X			
h Purchase of assets from related organization(s)						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		X			
I Performance of services or membership or fundraising solicitations for related orga					Х				
m Performance of services or membership or fundraising solicitations by related organization(s)									
n Sharing of facilities, equipment, mailing lists, or other assets with related organization(s)									
o Sharing of paid employees with related organization(s)									
p Reimbursement paid to related organization(s) for expenses				1p		X			
q Reimbursement paid by related organization(s) for expenses									
, , , , , , , , , , , , , , , , , , , ,									
r Other transfer of cash or property to related organization(s)				1r		X			
s Other transfer of cash or property from related organization(s)						X			
2 If the answer to any of the above is "Yes," see the instructions for information on v									
(a)	(b)	(c)	(d)						
Name of related organization	Transaction	Amount involved	Method of determining amount	involved					
	type (a-s)								
(1) THE FTD DISORDERS REGISTRY LLC	В	150,000.	CASH PAYMENT						
(2) THE FTD DISORDERS REGISTRY LLC	L	139,332.	INVOICED AMOUNTS						
(3)									
(4)									
(5)									
(6)									
332163 09-06-16	56		Schedu	ıle R (Forr	n 990)	2016			

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)	(b)	(c)	(d)	Are a partners 501(c orgs)	(f)	(g)	(1	h)	(i)	(j)	(k)
Name, address, and EIN	Primary activity	Legal domicile	Predominant income (related, unrelated, excluded from tax under sections 512-514)	partners	ali s sec.	Share of	Share of	Dispr	ropor-	Code V-UBI amount in box 20 of Schedule K-1 (Form 1065)	Genera	l or Percenta
of entity		(state or foreign	(related, unrelated, leveluded from tax under	501(c)(3)	total	end-of-year	alloca	nate itions?	amount in box 20	partn	r? ownersh
		country)	sections 512-514)	Yes	Nο	income	assets	Vac	No	(Form 1065)	Yes	<u>.</u>
			,	163	140			163	110	,	103	
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THE ASSOCIATION FOR FRONTOTEMPORAL

Schedule R	(Form 990) 2016	DEGENERATION	41-2073220 Page 5
Part VII	(Form 990) 2016 Supplemental Info		
	Provide additional inform	nation for responses to questions on Schedule R. See instructions.	
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