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.

OMB No. 1545-0047 Open to Public Inspection

Department of the Treasury Internal Revenue Service

Go to www.irs.gov/Form990 for instructions and the latest information. A For the 2022 calendar year, or tax year beginning and ending

B c	heck if pplicabl	C Name of organization	<u> </u>	D Employer identif	ication number			
	Addre	FRIEDREICH'S ATAXIA RESEARCH ALLIANCE						
	Name chang			52-21227	20			
	Initial return		Room/sui					
	Final return	D O BOY 1537		484-879-	6160			
	termin ated	City or town, state or province, country, and ZIP or foreign postal code		G Gross receipts \$	12,313,824.			
	Amen return	SPRINGFIELD, VA 22151		H(a) Is this a group r	return			
	Application	F Name and address of principal officer: O ENNITE EX FARMER		for subordinate	s? Yes X No			
	pendi	1 533 W UWCHLAN AVENUE, DOWNINGTOWN, PA	<u> 19335</u>	H(b) Are all subordinates i	included? Yes No			
<u> </u>	ax-ex	empt status: X 501(c)(3) 501(c) () (insert no.) 4947(a)(1) or X	or 5	27 If "No," attach a	a list. See instructions			
	Vebsi			H(c) Group exemption				
		organization: X Corporation Trust Association Other	L Ye	ar of formation: 1998	M State of legal domicile: VA			
Pa	rt I	Summary						
Φ	1	Briefly describe the organization's mission or most significant activities: TO TI	REAT	AND CURE FRI	EDREICH S			
Activities & Governance		ATAXIA (FA) BY ADVANCING RESEARCH, AWAREN						
ern		Check this box if the organization discontinued its operations or dispos			1			
્ટ્રે				<u>3</u>				
જ		Number of independent voting members of the governing body (Part VI, line 1b) Total number of individuals employed in calendar year 2022 (Part V, line 2a)						
ties		Total number of individuals employed in calendar year 2022 (Fart v, line 2a) Total number of volunteers (estimate if necessary)			500			
ξį		Total unrelated business revenue from Part VIII, column (C), line 12			_			
Ą		Net unrelated business taxable income from Form 990-T, Part I, line 11						
		The difference business taxable meeting from the first state, and the		Prior Year	Current Year			
	8	Contributions and grants (Part VIII, line 1h)		7,683,701.	11,604,349.			
nge		Program service revenue (Part VIII, line 2g)		0.	<u> </u>			
Revenue		Investment income (Part VIII, column (A), lines 3, 4, and 7d)		306,924.	78,516.			
æ		Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)		-272,847.	-639,954.			
		Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)		7,717,778.	11,042,911.			
	13	Grants and similar amounts paid (Part IX, column (A), lines 1-3)		7,398,876.	9,234,269.			
	14	Benefits paid to or for members (Part IX, column (A), line 4)		0.				
S	15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		1,160,225.				
Expenses	16a	Professional fundraising fees (Part IX, column (A), line 11e)		0.	0.			
xpe	b	Total fundraising expenses (Part IX, column (D), line 25) 225, 12						
Ш	17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		552,566.				
	18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)		9,111,667.				
	19	Revenue less expenses. Subtract line 18 from line 12		-1,393,889.	'			
Assets or Balances			μ'	Beginning of Current Year	End of Year			
Sset	20	Total assets (Part X, line 16)	····· -	7,478,784.				
et A	21	Total liabilities (Part X, line 26) Net assets or fund balances. Subtract line 21 from line 20	····· -	283,508.				
P	rt II	Signature Block		7,195,276.	6,830,425.			
		Ities of perjury, I declare that I have examined this return, including accompanying schedules	e and etate	ments and to the hest of m	v knowledge and helief it is			
	•	it, and complete. Declaration of preparer (other than officer) is based on all information of wh		•	y knowledge and belief, it is			
ti do,	001100	ts and complete. Becautation of property (early than emotify is based on an information of wi	non propui	or rias arry knowledge.				
Sigi	1	Signature of officer		Date				
Her		JENNIFER FARMER, CHIEF EXECUTIVE OFFICER						
		Type or print name and title						
		Print/Type preparer's name Preparer's signature		Date Check	PTIN			
Paid		HELEN M. MARTIN		if self-emplo	P01330899			
Prep	arer	Firm's name EISNER ADVISORY GROUP LLC	ROUP LLC Firm's EIN 87-1353108					
Use	Only	Firm's address 130 NORTH 18TH STREET, SUITE 3000)					
		PHILADELPHIA, PA 19103-2757		Phone no. (2	215) 881-8800			
May	the II	RS discuss this return with the preparer shown above? See instructions			X Yes No			

Form **8868**

(Rev. January 2022)

Application for Automatic Extension of Time To File an **Exempt Organization Return**

Department of the Treasury

File a separate application for each return. ► Go to www.irs.gov/Form8868 for the latest information. OMB No. 1545-0047

Electronic filing (e-file). You can electronically file Form 8868 to request a 6-month automatic extension of time to file any of the forms listed below with the exception of Form 8870, Information Return for Transfers Associated With Certain Personal Benefit

Contracts, for which an extension request must be sent to the IRS in paper format (see instructions). For more details on the electronic filing of this form, visit www.irs.gov/e-file-providers/e-file-for-charities-and-non-profits. Automatic 6-Month Extension of Time. Only submit original (no copies needed). All corporations required to file an income tax return other than Form 990-T (including 1120-C filers), partnerships, REMICs, and trusts must use Form 7004 to request an extension of time to file income tax returns. Name of exempt organization or other filer, see instructions. Taxpayer identification number (TIN) Type or print FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 File by the Number, street, and room or suite no. If a P.O. box, see instructions. due date for filing your P.O. BOX 1537 return. See instructions City, town or post office, state, and ZIP code. For a foreign address, see instructions. SPRINGFIELD, VA 22151 Enter the Return Code for the return that this application is for (file a separate application for each return) 0 | 1 Application Return Application Return Is For Code Is For Code Form 990 or Form 990-EZ Form 1041-A 01 Form 4720 (individual) 03 Form 4720 (other than individual) 09 Form 990-PF 04 Form 5227 10 Form 6069 Form 990-T (sec. 401(a) or 408(a) trust) 05 11 Form 990-T (trust other than above) Form 8870 Form 990-T (corporation) JENNIFER FARMER The books are in the care of ► 533 W. UWCHLAN AVENUE - DOWNINGTOWN, PA 19335 Telephone No. ► 484-879-6160 Fax No. If the organization does not have an office or place of business in the United States, check this box If this is for a Group Return, enter the organization's four digit Group Exemption Number (GEN) ______. If this is for the whole group, check this box 🕨 🔲 . If it is for part of the group, check this box 🕨 🔲 and attach a list with the names and TINs of all members the extension is for. I request an automatic 6-month extension of time until NOVEMBER 15, 2023, to file the exempt organization return for the organization named above. The extension is for the organization's return for: ► X calendar year 2022 or tax year beginning ___ , and ending _ Initial return If the tax year entered in line 1 is for less than 12 months, check reason: Change in accounting period 3a If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less 0. any nonrefundable credits. See instructions. За b If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit. 3b c Balance due. Subtract line 3b from line 3a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions. Зс Caution: If you are going to make an electronic funds withdrawal (direct debit) with this Form 8868, see Form 8453-TE and Form 8879-TE for payment

For Privacy Act and Paperwork Reduction Act Notice, see instructions.

Form 8868 (Rev. 1-2022)

Pai	t III Statement of Program Service Accomplishments
	Check if Schedule O contains a response or note to any line in this Part III
1	Briefly describe the organization's mission:
	TO MARSHAL AND FOCUS THE RESOURCES AND RELATIONSHIPS NEEDED TO CURE FA
	BY RAISING FUNDS FOR RESEARCH, PROMOTING PUBLIC AWARENESS AND ALIGNING
	SCIENTISTS, PATIENTS, CLINICIANS, GOVERNMENT AGENCIES AND
	PHARMACEUTICAL COMPANIES DEDICATED TO CURING FA AND RELATED DISORDERS.
2	Did the organization undertake any significant program services during the year which were not listed on the
	prior Form 990 or 990-EZ?
	If "Yes," describe these new services on Schedule O.
3	Did the organization cease conducting, or make significant changes in how it conducts, any program services?
•	If "Yes," describe these changes on Schedule O.
4	Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses.
•	Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and
4a	(Code:) (Expenses \$ 9,012,749. including grants of \$ 8,460,000.) (Revenue \$
Tu	SEE SCHEDULE O
	ELL BENEDOLL C
	(Code:) (Expenses \$ 1,021,876. including grants of \$ 774,269.) (Revenue \$
4b	
	CLINICAL RESEARCH INFRASTRUCTURE
	IN ADDITION TO RESEARCH GRANTS, FARA FUNDS THE ONGOING DEVELOPMENT OF
	DOMAIN RESOURCES IN THE FORM OF VITAL CLINICAL RESEARCH INFRASTRUCTURE.
	CLINICAL RESEARCH INFRASTRUCTURE REFERS TO THE RESOURCES NEEDED TO
	FACILITATE ANY TYPE OF RESEARCH, INCLUDING CLINICAL TRIALS THAT INVOLVE
	PATIENTS. THESE RESOURCES INCLUDE PROGRAMS LIKE:
	FRIEDREICH'S ATAXIA GLOBAL PATIENT REGISTRY: THE FRIEDREICH'S ATAXIA
	GLOBAL PATIENT REGISTRY (FAGPR) IS THE ONLY WORLDWIDE REGISTRY OF
	FRIEDREICH'S ATAXIA PATIENTS. THE GOALS OF THE FAGPR ARE TO COLLECT
	INFORMATION ON ALL FA PATIENTS IN ONE REGISTRY, TO DEVELOP THE REGISTRY
	INTO A POWERFUL RESOURCE FOR RESEARCH, AND TO ENGAGE THE FA COMMUNITY
_	
4C	(Code:) (Expenses \$ 372,529. including grants of \$
	EDUCATION, AWARENESS & OUTREACH PROGRAMS
	FRIEDREICH ATAXIA (FA) IS A RARE DISEASE, AFFECTING 1 IN 50,000
	INDIVIDUALS. FARA IS DEDICATED TO ADVOCACY AND RAISING AWARENESS FOR
	FA. FARA HAS UTILIZED BOTH TRADITIONAL AND SOCIAL MEDIA STRATEGIES TO
	BRING GREATER AWARENESS TO FA IN THE GENERAL PUBLIC AND TO ENGAGE AND
	EDUCATE THE FA COMMUNITY. FOR EXAMPLE, FARA CONDUCTED A SOCIAL MEDIA
	CAMPAIGN THAT ENCOURAGED COMMUNITY PARTICIPATION LEADING UP TO RARE
	DISEASE DAY AND FA AWARENESS DAY.
	FARA AND THE NATIONAL ATAXIA FOUNDATION (NAF) ALSO PARTNERED ON SEVERAL
	ADVOCACY INITIATIVES RELEVANT TO THE ATAXIA COMMUNITY. MOSTLY NOTABLY,
	THE EFFORTS OF THE TWO ORGANIZATIONS RESULTED IN FA BEING ADDED TO THE
4d	Other program services (Describe on Schedule O.)
	(Expenses \$ 222,693 • including grants of \$) (Revenue \$)
4e	Total program service expenses 10,629,847.
	Form 990 (2022

Form 990 (2022) FRIEDREICH 'S Part IV Checklist of Required Schedules

			Yes	No
1 1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)?			
1	If "Yes," complete Schedule A	1	X	
2	Is the organization required to complete Schedule B, Schedule of Contributors? See instructions	2	Х	
	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for			
	public office? If "Yes," complete Schedule C, Part I	3		_X_
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect			
	during the tax year? If "Yes," complete Schedule C, Part II	4	X	
	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or			
	similar amounts as defined in Rev. Proc. 98-19? If "Yes," complete Schedule C, Part III	5		_X_
	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		_X_
	Did the organization receive or hold a conservation easement, including easements to preserve open space,			7.7
	the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II	7		<u> X</u>
	Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete	_		77
	Schedule D, Part III	8		_X_
	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?			v
	If "Yes," complete Schedule D, Part IV	9		_X_
	Did the organization, directly or through a related organization, hold assets in donor-restricted endowments	40		Х
	or in quasi endowments? If "Yes," complete Schedule D, Part V	10		
	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VIII, VIII, IX, or X,			
	as applicable. Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D,			
		11a		х
	Part VI Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total	Ha		
	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII	11b		х
	Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more of its total	110		
	assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII	11c		Х
	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		Х
e l	Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X	11e	Х	
	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	Х	
	Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete			
	Schedule D, Parts XI and XII	12a	Х	
b \	Was the organization included in consolidated, independent audited financial statements for the tax year?			
1	If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional	12b		X
	Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	13		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?	14a	X	
b i	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business,			
	investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000			
	or more? If "Yes," complete Schedule F, Parts I and IV	14b	X	
	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	
	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to			37
	or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV	16		_ <u>X</u> _
	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX,			v
	column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I. See instructions	17		_X_
	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines	ا مد ا	~	
40	1c and 8a? If "Yes," complete Schedule G, Part II	18	<u>X</u>	
	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes,"	4.		v
	complete Schedule G, Part III	19		_ <u>X</u> _
	Did the organization operate one or more hospital facilities? If "Yes," complete Schedule H	20a		
	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or	20b		
	domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II	21	Х	
				(2022)

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			Yes	No
22	Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on			
	Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III	22		Х
23	Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current			
	and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete			
	Schedule J	23	X	
24 a	Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the			
	last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete			
	Schedule K. If "No," go to line 25a	24a		X
	Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b		
С	Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease	١		
	any tax-exempt bonds?	24c		
	Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d		
25 a	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
h	Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and	25a		22
b	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		Х
26	Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current	200		
	or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35%			
	controlled entity or family member of any of these persons? If "Yes," complete Schedule L, Part II	26		х
27	Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee,			
	creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled			
	entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III	27		Х
28	Was the organization a party to a business transaction with one of the following parties (see the Schedule L, Part IV,			
	instructions for applicable filing thresholds, conditions, and exceptions):			
а	A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If			
	"Yes," complete Schedule L, Part IV	28a		X
	A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV	28b		X
С	A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? If			,,
	"Yes," complete Schedule L, Part IV	28c	37	X
29	Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M	29	X	
30	Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation			x
24	contributions? If "Yes," complete Schedule M Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I	30		X
31 32	Did the organization requirements, or dissolve and cease operations? If "Yes," complete Schedule N, Part I Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete	31		
32		32		х
33	Schedule N, Part II Did the organization own 100% of an entity disregarded as separate from the organization under Regulations	32		
00	sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I	33		Х
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
35 a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a		Х
b	If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity			
	within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2	35b		
36	Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization?			
	If "Yes," complete Schedule R, Part V, line 2	36		Х
37	Did the organization conduct more than 5% of its activities through an entity that is not a related organization			l
	and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI	37		X
38	Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19?		v	
Pa	Note: All Form 990 filers are required to complete Schedule O rt V Statements Regarding Other IRS Filings and Tax Compliance	38	X	
· a	Check if Schedule O contains a response or note to any line in this Part V			
	Oneon it obtredule o contains a response of note to any line in this Part v		V	NIA
4.	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable 1a 3		Yes	No
	Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable 1a 5 Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable 1b 0			
	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming			
J	(gambling) winnings to prize winners?	1c	х	
22200			990	(2022

					Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements,					
	filed for the calendar year ending with or within the year covered by this return	2a	16			
b	If at least one is reported on line 2a, did the organization file all required federal employment tax return	าร?		2b	Х	
За	Did the organization have unrelated business gross income of \$1,000 or more during the year?			За		Х
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule	Ο.		3b		
	At any time during the calendar year, did the organization have an interest in, or a signature or other a					ĺ
	financial account in a foreign country (such as a bank account, securities account, or other financial a	ccou	nt)?	4a		X
b	If "Yes," enter the name of the foreign country		_			
	See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Advanced Financial Advanced Financial Advanced Financial Advanced Financial Advanced Financial Advanced Financial Financial Advanced Financial Fina	ccour	ts (FBAR).			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?			5a		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction			5b		X
С	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?			5c		-
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the					37
	any contributions that were not tax deductible as charitable contributions?			6a		Х
b	If "Yes," did the organization include with every solicitation an express statement that such contribution					ĺ
_	were not tax deductible?			6b		
7	Organizations that may receive deductible contributions under section 170(c).		arouided to the never	7-	X	
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and ser			7a 7b	X	
b			uirod	70		
С	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it wa to file Form 8282?			7c		х
d	If "Yes," indicate the number of Forms 8282 filed during the year	7d	1	70		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit or		•	7e		х
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contra			7f		Х
g	If the organization received a contribution of qualified intellectual property, did the organization file Fo			7g		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization			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.					
а	Did the sponsoring organization make any taxable distributions under section 4966?			9a		<u> </u>
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?			9b		
10	Section 501(c)(7) organizations. Enter:					
а	Initiation fees and capital contributions included on Part VIII, line 12	10a				
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b				
11	Section 501(c)(12) organizations. Enter:	١	1			
а	Gross income from members or shareholders	11a				
b	Gross income from other sources. (Do not net amounts due or paid to other sources against	441				
120	amounts due or received from them.) Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form	11b	2	12a		
	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b	1	ıza		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.	120				
а	Is the organization licensed to issue qualified health plans in more than one state?			13a		
	Note: See the instructions for additional information the organization must report on Schedule O.					
b	Enter the amount of reserves the organization is required to maintain by the states in which the					
	organization is licensed to issue qualified health plans	13b				
С	Enter the amount of reserves on hand	13c				
14a				14a		Х
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedul			14b		
15	Is the organization subject to the section 4960 tax on payment(s) of more than $$1,000,000$ in remuner					_
	excess parachute payment(s) during the year?			15		X
	If "Yes," see the instructions and file Form 4720, Schedule N.					
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment	inco	ne?	16		X
	If "Yes," complete Form 4720, Schedule O.					
17	Section 501(c)(21) organizations. Did the trust, or any disqualified or other person engage in any act					1
	that would result in the imposition of an excise tax under section 4951, 4952 or 4953?			17		
	If "Yes," complete Form 6069.				990	(0000)

232005 12-13-22

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 Part VI Governance, Management, and Disclosure. For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions. X Check if Schedule O contains a response or note to any line in this Part VI Section A. Governing Body and Management Yes No 18 1a Enter the number of voting members of the governing body at the end of the tax year 1a If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O. 16 **b** Enter the number of voting members included on line 1a, above, who are independent Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other X officer, director, trustee, or key employee? 2 3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person? 3 X Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? 4 5 Did the organization become aware during the year of a significant diversion of the organization's assets? 5 Did the organization have members or stockholders? 6 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? X 7a b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? Х 7b Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: Х a The governing body? 8a Х b Each committee with authority to act on behalf of the governing body? 8b Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes." provide the names and addresses on Schedule O X 9 Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.) No Yes 10a Did the organization have local chapters, branches, or affiliates? 10a Х b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? 10b Х 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11a **b** Describe on Schedule O the process, if any, used by the organization to review this Form 990. Х 12a Did the organization have a written conflict of interest policy? If "No," go to line 13 12a Х b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe Х on Schedule O how this was done 12c Х 13 Did the organization have a written whistleblower policy? 13 14 Did the organization have a written document retention and destruction policy? Х 14 15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? Х a The organization's CEO, Executive Director, or top management official Other officers or key employees of the organization Х 15b If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions. 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a Х taxable entity during the year? 16a b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements? Section C. Disclosure List the states with which a copy of this Form 990 is required to be filed AL, AK, AZ, AR, CA, CO, CT, FL, GA, IL, KS, KY Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. X Own website Another's website X Upon request Other (explain on Schedule O) Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year. State the name, address, and telephone number of the person who possesses the organization's books and records

STATES

533 W.

UWCHLAN AVENUE, DOWNINGTOWN, SEE SCHEDULE O FOR FULL LIST OF

JENNIFER FARMER - 484-879-6160

Page 7

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

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

- 1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year. • List all of the organization's current officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation.
- Enter -0- in columns (D), (E), and (F) if no compensation was paid.
 - List all of the organization's current key employees, if any. See the instructions for definition of "key employee."
- List the organization's five current highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (box 5 of Form W-2, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's former officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's former directors or trustees that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations. See the instructions for the order in which to list the persons above.

(A)	(B)			(0	C)			(D)	(E)	(F)
Name and title	Average	(do	not c	Posi	ition	າ than d	nne	Reportable	Reportable	Estimated
	hours per	box	, unles	ss per	son i	s both	n an	compensation	compensation	amount of
	week (list any	—		a a a		174405		from the	from related organizations	other compensation
	hours for	direct				-		organization	(W-2/1099-MISC/	from the
	related	ee or	stee			nsate		(W-2/1099-MISC/	1099-NEC)	organization
	organizations	ll trus	nal trı		loyee	ompe		1099-NEC)		and related
	below	individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			organizations
41)	line)	트	lus	JJ0	Ke	훈등	윤			
(1) BARBARA A TATE	40.00	1				х		250 000	0.	7 100
CHIEF SCIENTIFIC OFFICER	40 00					X		250,000.	0.	7,108.
(2) JENNIFER M FARMER	40.00	1		v				150 000	_	F 220
CHIEF EXECUTIVE OFFICER	40.00			Х				150,000.	0.	5,228.
(3) ELISABETTA SORAGNI DIRECTOR OF RESEARCH	40.00	1				х		106,090.	0.	14,246.
(4) RONALD BARTEK	40.00					^		100,090.	0.	14,240.
PRESIDENT/DIRECTOR	40.00	x		х				110,000.	0.	3,811.
(5) RUTH ACTON	25.00	┢		Δ				110,000.	0.	3,011.
TREASURER/DIR OF FINANCE ADMIN, HR	23.00	x		х				45,203.	0.	13,197.
(6) PAUL AVERY	10.00	122		22				43,203.	0.	13,137.
CHAIRMAN/ DIRECTOR	10.00	x		х				0.	0.	0.
(7) MARILYN E. DOWNING	10.00	<u> </u>								
SECRETARY/ DIRECTOR		Х		х				0.	0.	0.
(8) DR. SANJAY BIDICHANDANI	10.00							-	-	-
DIRECTOR		х						0.	0.	0.
(9) BRIGID BRENNAN	20.00									
DIRECTOR/ GENERAL COUNSEL		X						0.	0.	0.
(10) THOMAS BRENNINKMEIJER	10.00									
DIRECTOR		X						0.	0.	0.
(11) ALEX FIELDING	10.00									
DIRECTOR		Х						0.	0.	0.
(12) JENNIFER GOOD	10.00									
DIRECTOR		Х						0.	0.	0.
(13) THOMAS HAMILTON	10.00									
DIRECTOR		Х						0.	0.	0.
(14) DR. HOLLY HEDRICK	10.00								_	_
DIRECTOR		Х						0.	0.	0.
(15) DEREK G. HENNECKE	10.00	ļ								_
DIRECTOR	1000	Х						0.	0.	0.
(16) DR. STEVE KLASKO	10.00	 								_
DIRECTOR	10.00	Х						0.	0.	0.
(17) DR. KATHY MATHEWS	10.00	٠,,							_	_
DIRECTOR		Х						0.	0.	0.

232007 12-13-22

Form **990** (2022)

Part VII Section A. Officers, Directors, Trus	tees, Key Em	oloy	ees,	and	iH t	ghes	t C	compensated Employee	s (continued)				
(A)	(B)				C)			(D)	(E)			(F)	
Name and title	Average	(do		Pos		າ than d	200	Reportable	Reportable	,	Es	timate	ed
	hours per	box	, unle	ss per	rson i	is both	n an	compensation	compensation	n nc	an	nount (of
	week	\vdash	cer ar	nd a d	irecto	or/trus	tee)	from	from related	ť	l	other	
	(list any	ecto						the	organization			pensa	
	hours for related	or di	8			ated		organization	(W-2/1099-MIS			om the	
	organizations	ustee	trust		92	suedi		(W-2/1099-MISC/	1099-NEC)			anizati d relate	
	below	ual tr	tional		ploye	t com	L	1099-NEC)				a relation	
	line)	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former				l	ai iizati	7113
(18) DR. JAMES MCARTHUR	10.00	 =	=	0	~	1 0	_			-			
DIRECTOR		x						0.		0.	1		0.
(19) TONY PLOHOROS	10.00	 					\vdash			<u> </u>			<u> </u>
DIRECTOR	10.00	x						0.		0.	1		0.
(20) PATRICK RITSCHEL	10.00	125					\vdash	•		••			<u> </u>
DIRECTOR	10.00	x						0.		0.			0.
(21) DR. JAMES R. RUSCHE	10.00							0.		••			<u> </u>
DIRECTOR	10.00	X						0.		0.			0.
DIRECTOR		^						0.		0.			<u> </u>
		┨											
							┢			\longrightarrow			
		┨											
		-				-	⊢						
		┨											
		_				_	_						
													
								111 111			<u> </u>		
1b Subtotal								661,293.		0.	4	3,59	
c Total from continuation sheets to Part VI	I, Section A							0.		0.			0.
d Total (add lines 1b and 1c)								661,293.		0.	4	3,59	<u> 30.</u>
2 Total number of individuals (including but n	ot limited to th	ose	liste	d ab	oove	e) wh	o re	eceived more than \$100,	000 of reportable	Э			
compensation from the organization													4
												Yes	No
3 Did the organization list any former officer,	director, trust	ee, ł	кеу е	empl	loye	e, or	hig	hest compensated emp	oyee on				
line 1a? If "Yes," complete Schedule J for s	uch individual										3		X
4 For any individual listed on line 1a, is the su	ım of reportabl	le co	mpe	ensa	tion	and	oth	ner compensation from t	ne organization				
and related organizations greater than \$150	0,000? If "Yes.	" co	male	ete S	Sche	edule	J f	for such individual	-		4	Х	
5 Did any person listed on line 1a receive or a													
rendered to the organization? If "Yes." com	plete Schedule	e J f	or su	ıch ı	ners	on .					5		Х
Section B. Independent Contractors													
Complete this table for your five highest co	mpensated inc	depe	nder	nt co	ontra	acto	rs th	hat received more than \$	100,000 of com	oensa ^t	tion fro	om	
the organization. Report compensation for	=	-											
(A)	,			<u> </u>				(B)			(0	2)	
Name and business	address							Description of s	ervices	С	ompe	nsatior	า
CAMENE BVBA-MYRIAM ABOUAZ	AR-RAI.							INTERNATIONA	ւ				
BRUSSELBAAN 473, SINT-PIE			w.					RESEARCH AND		ı	10	3,32	21.
			,				_		112 1 0 0110			- ,	
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										ı			
							\dashv						
										ı			
	1 0		<u>.</u>										
2 Total number of independent contractors (in	-	ot lir	nited	to t			ted	above) who received mo	ore tnan				
\$100,000 of compensation from the organization	zation					L						000	
											Form	990 ₍₂	2022)

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 Page 9 Form 990 (2022) Part VIII Statement of Revenue Check if Schedule O contains a response or note to any line in this Part VIII (B) (C) (D) Related or exempt Unrelated Revenue excluded Total revenue from tax under function revenue business revenue sections 512 - 514 1 a Federated campaigns 11,998. 1a **b** Membership dues 1b 4,008,043. c Fundraising events d Related organizations **e** Government grants (contributions) f All other contributions, gifts, grants, and 7,584,308 similar amounts not included above 232,995. Q Noncash contributions included in lines 1a-1f 11,604,349. h Total. Add lines 1a-1f **Business Code** 2 a Program Service Revenue f All other program service revenue g Total. Add lines 2a-2f . Investment income (including dividends, interest, and other similar amounts) 65,540. 65,540. Income from investment of tax-exempt bond proceeds Royalties (ii) Personal 6 a Gross rents **b** Less: rental expenses ... 6b c Rental income or (loss) d Net rental income or (loss) (i) Securities (ii) Other 7 a Gross amount from sales of 222,576. assets other than inventory **b** Less: cost or other basis 209,600. and sales expenses 7b c Gain or (loss) 12,976. 12,976. d Net gain or (loss) 8 a Gross income from fundraising events (not 4,008,043. of including \$ ___ contributions reported on line 1c). See Part IV, line 18 421,359. b Less: direct expenses 1,061,313. -639,954. -639,954. c Net income or (loss) from fundraising events 9 a Gross income from gaming activities. See Part IV, line 19 **b** Less: direct expenses c Net income or (loss) from gaming activities

12 To 232009 12-13-22

-561,438. Form **990** (2022)

11,042,911.

Business Code

10 a Gross sales of inventory, less returns

d All other revenue ______ e Total. Add lines 11a-11d ______

Total revenue. See instructions

and allowances

b Less: cost of goods sold

c Net income or (loss) from sales of inventory

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)** Fundraising (A) Total expenses (B) Program service Do not include amounts reported on lines 6b, Management and 7b, 8b, 9b, and 10b of Part VIII. general expenses expenses Grants and other assistance to domestic organizations 7,466,286. 7,466,286 and domestic governments. See Part IV, line 21 2 Grants and other assistance to domestic individuals. See Part IV, line 22 Grants and other assistance to foreign organizations, foreign governments, and foreign 1,767,983. 1,767,983. individuals. See Part IV, lines 15 and 16 Benefits paid to or for members 5 Compensation of current officers, directors, 327,439. 218,116. 67,934. 41,389. trustees, and key employees 6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) 700,894. 607,615. 59,486. 33,793. Other salaries and wages Pension plan accruals and contributions (include <u>20,9</u>45. 12,728. section 401(k) and 403(b) employer contributions) 1,384. 6,833. 62,268. 7,326. 28,105. 26,837. Other employee benefits 9 82,840. 54,865. 7,773. 20,202. Payroll taxes Fees for services (nonemployees): 11 a Management **b** Legal 27,405. 27,405. 13,000. 13,000. Lobbying Professional fundraising services. See Part IV, line 17 Investment management fees Other. (If line 11g amount exceeds 10% of line 25, 244,166. 202,527. 22,144. 19,495. column (A), amount, list line 11g expenses on Sch O.) 12 Advertising and promotion 46,027. 14,330. 6,136. 25,561. Office expenses 13 Information technology 14 15 Royalties 44,563. 28,710. 8,373. 7,480. 16 Occupancy 17 18 Payments of travel or entertainment expenses for any federal, state, or local public officials ... 149,561. 124,349. 24,394. 818. 19 Conferences, conventions, and meetings 20 Payments to affiliates 21 22 Depreciation, depletion, and amortization 16,922. 9,278. 7,644. 23 Other expenses. Itemize expenses not covered 24 above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule 0.) 97,343. 81,515. 5,614. 10,214. SUBSCRIPTIONS & LICENSI 22,500. 22,500. b BAD DEBT 18,798. 19,070. 108. c CREDIT CARD & BANK FEES 164. 8,997. 2,778. 5,933. d FACILITIES & EQUIPMENT 286. 1,942. 6,832. 14,538. 5,764. e All other expenses 277,786. Total functional expenses. Add lines 1 through 24e 11,132,747. 10,629,847. 225,114. 25 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here if following SOP 98-2 (ASC 958-720)

Form **990** (2022)

Par	t X	Balance Sheet						
		Check if Schedule O contains a response or r	note to	any line in this Part X				
						(A) Beginning of year		(B) End of year
	1	Cash - non-interest-bearing				3,334,786.	1	3,002,584
	2	Savings and temporary cash investments		1,807,813.	2	1,961,536		
	3	Pledges and grants receivable, net		259,819.	3	369,612		
	4	Accounts receivable, net					4	
	5	Loans and other receivables from any current						
		trustee, key employee, creator or founder, su						
		controlled entity or family member of any of the	hese pe	rsons			5	
	6	Loans and other receivables from other disqu						
		under section 4958(f)(1)), and persons describ	oed in s	ection 4958(c)(3)(B)			6	
n	7	Notes and loans receivable, net					7	
Assets	8	Inventories for sale or use					8	
Ĩ	9	B				94,042.	9	52,39
	10a	Land, buildings, and equipment: cost or othe	r					
		basis. Complete Part VI of Schedule D	10	a	0.			
	b	Less: accumulated depreciation				0.	10c	
	11	Investments - publicly traded securities				1,976,866.	11	1,728,750
	12	Investments - other securities. See Part IV, lin					12	
	13	Investments - program-related. See Part IV, lir				5,458.	13	5,45
	14	Intangible assets					14	
	15	Other assets. See Part IV, line 11				0.	15	140,43
	16	Total assets. Add lines 1 through 15 (must e				7,478,784.	16	7,260,77
	17	Accounts payable and accrued expenses				261,148.	17	276,96
	18	Grants payable					18	
	19	Deferred revenue				22,360.	19	11,49
	20	Tax-exempt bond liabilities					20	
	21	Escrow or custodial account liability. Comple			·····		21	
,	22	Loans and other payables to any current or fo	ormer of					
		trustee, key employee, creator or founder, su						
LIADIIII		controlled entity or family member of any of the					22	
Ĭ	23	Secured mortgages and notes payable to unr	-		Г		23	
	24	Unsecured notes and loans payable to unrela					24	
	25	Other liabilities (including federal income tax,			·····			
		parties, and other liabilities not included on lin	 nes 17-2	24). Complete Part X				
		of Schedule D				0.	25	141,89
	26	Total liabilities. Add lines 17 through 25				283,508.	26	430,34
		Organizations that follow FASB ASC 958, o	heck h	ere X				
Ď		and complete lines 27, 28, 32, and 33.						
	27	Net assets without donor restrictions				4,608,013.	27	5,146,27
3	28	Net assets with donor restrictions				2,587,263.	28	1,684,15
2		Organizations that do not follow FASB ASC						
2		and complete lines 29 through 33.						
5	29	Capital stock or trust principal, or current fun	Г		29			
	30	Paid-in or capital surplus, or land, building, or					30	
É	31	Retained earnings, endowment, accumulated					31	
Net Assets of Fund balances	32	Total net assets or fund balances				7,195,276.	32	6,830,42
_	33	Total liabilities and net assets/fund balances				7,478,784.	33	7,260,774

Form **990** (2022)

Pa	TT XI Reconciliation of Net Assets					
	Check if Schedule O contains a response or note to any line in this Part XI			<u></u>		X
1	Total revenue (must equal Part VIII, column (A), line 12)	1	11,	04	2,9	<u>11.</u>
2	Total expenses (must equal Part IX, column (A), line 25)	2	11,	<u> 13</u> 2	2,7	<u>47.</u>
3	Revenue less expenses. Subtract line 2 from line 1	3				<u> 36.</u>
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	7,	19!	5,2	76.
5	Net unrealized gains (losses) on investments	5		· 34	9,4	<u>45.</u>
6	Donated services and use of facilities	6				
7	Investment expenses	7				
8	Prior period adjustments	8				
9	Other changes in net assets or fund balances (explain on Schedule O)	9		74	4,4	30.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32,					
	column (B))	10	6,	830	0,4	25.
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 on Schedule O.					
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?			2a		X
	If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed	on a				
	separate basis, consolidated basis, or both:					
	Separate basis Consolidated basis Both consolidated and separate basis					
b	Were the organization's financial statements audited by an independent accountant?			2b	Х	<u> </u>
	If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate	basis,				
	consolidated basis, or both:					
	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 the	audit,				
	review, or compilation of its financial statements and selection of an independent accountant?			2c	Х	
	If the organization changed either its oversight process or selection process during the tax year, explain on Scho	edule O				
За	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the					
	Uniform Guidance, 2 C.F.R. Part 200, Subpart F?			За		X
b	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required	ed aud	it			1
	or audits, explain why on Schedule O and describe any steps taken to undergo such audits	<u></u>		3b		
			I	Form	990	(2022)

SCHEDULE A

(Form 990)

Total

Department of the Treasury nternal Revenue Service

Name of the organization

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust. Attach to Form 990 or Form 990-EZ.

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

OMB No. 1545-0047

Open to Public Inspection

Employer identification number

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 Reason for Public Charity Status. (All organizations must complete this part.) See instructions. The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.) 1 A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i). A school described in section 170(b)(1)(A)(ii). (Attach Schedule E (Form 990).) 2 3 A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii). A medical research organization operated in conjunction with a hospital described in section 170(b)(1)(A)(iii). Enter the hospital's name, An organization operated for the benefit of a college or university owned or operated by a governmental unit described in 5 section 170(b)(1)(A)(iv). (Complete Part II.) A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v). 7 X An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in section 170(b)(1)(A)(vi). (Complete Part II.) 8 A community trust described in section 170(b)(1)(A)(vi). (Complete Part II.) An agricultural research organization described in section 170(b)(1)(A)(ix) operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See section 509(a)(2). (Complete Part III.) An organization organized and operated exclusively to test for public safety. See section 509(a)(4). An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See section 509(a)(3). Check the box on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g. Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. You must complete Part IV, Sections A and B. Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). You must complete Part IV, Sections A and C. Type III functionally integrated. A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). You must complete Part IV, Sections A, D, and E. Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). You must complete Part IV, Sections A and D, and Part V. Check this box if the organization received a written determination from the IRS that it is a Type II, Type III, Type III, functionally integrated, or Type III non-functionally integrated supporting organization. **f** Enter the number of supported organizations g Provide the following information about the supported organization(s). iv) Is the organization listed (i) Name of supported (iii) Type of organization (v) Amount of monetary (vi) Amount of other (described on lines 1-10 organization support (see instructions) support (see instructions) Yes above (see instructions))

Schedule A (Form 990) 2022 FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122 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) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
1	Gifts, grants, contributions, and						
	membership fees received. (Do not						
	include any "unusual grants.")	7662625.	7146206.	12628384.	7808772.	11604349.	46850336.
2	Tax revenues levied for the organ-						
	ization's benefit and either paid to						
	or expended on its behalf						
3	The value of services or facilities						
	furnished by a governmental unit to						
	the organization without charge						
4	Total. Add lines 1 through 3	7662625.	7146206.	12628384.	7808772.	11604349.	46850336.
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)						9138897.
6	Public support. Subtract line 5 from line 4.						37711439.
Sec	ction B. Total Support						
Cale	ndar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
7	Amounts from line 4	7662625.	7146206.	12628384.	7808772.	11604349.	46850336.
8	Gross income from interest,						
	dividends, payments received on						
	securities loans, rents, royalties,						
	and income from similar sources	42,296.	45,345.	38,997.	47,170.	65,540.	239,348.
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						47089684.
12	Gross receipts from related activities,	etc. (see instruction	ons)			12	
	First 5 years. If the Form 990 is for the			fourth, or fifth tax y	year as a section 5	i01(c)(3)	
	organization, check this box and stop	p here					
Sec	ction C. Computation of Publi	ic Support Per	centage				
	Public support percentage for 2022 (I					14	80.08 %
15	Public support percentage from 2021	Schedule A, Part	II, line 14			15	83.16 %
16a	33 1/3% support test - 2022. If the	organization did no	t check the box o	n line 13, and line	14 is 33 1/3% or m	ore, check this bo	
	stop here. The organization qualifies		•				
b	33 1/3% support test - 2021. If the	organization did no	t check a box on l	ine 13 or 16a, and	line 15 is 33 1/3%	or more, check th	is box
	and stop here. The organization qual	lifies as a publicly s	supported organiza	ation			
17a	10% -facts-and-circumstances test	: - 2022. If the org	anization did not o	check a box on line	e 13, 16a, or 16b, a	and line 14 is 10%	or more,
	and if the organization meets the fact	s-and-circumstance	es test, check this	box and stop he	re. Explain in Part	VI how the organiz	zation
	meets the facts-and-circumstances te	est. The organizatio	n qualifies as a pu	iblicly supported o	rganization		
b	10% -facts-and-circumstances test	- 2021. If the org	anization did not d	check a box on line	e 13, 16a, 16b, or	17a, and line 15 is	10% or
	more, and if the organization meets the	ne facts-and-circum	stances test, che	ck this box and st	top here. Explain i	n Part VI how the	
	organization meets the facts-and-circu						
18	Private foundation. If the organization	on did not check a l	box on line 13, 16	a, 16b, 17a, or 17b	o, check this box a	nd see instruction	s
						Schedule A	(Form 990) 2022

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Schedule A (Form 990) 2022 FRIEDREICH'S ATAXIA RESEARCH A
Part III Support Schedule for Organizations Described in Section 509(a)(2)

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

Se	ction A. Public Support	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	,				
Cale	ndar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 202	22 (f) Total
1	Gifts, grants, contributions, and						
	membership fees received. (Do not						
	include any "unusual grants.")						
2	Gross receipts from admissions,						
	merchandise sold or services per-						
	formed, or facilities furnished in						
	any activity that is related to the organization's tax-exempt purpose						
3	Gross receipts from activities that						
Ū	are not an unrelated trade or bus-						
	iness under section 513						
4	Tax revenues levied for the organ-						
7	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						
7	Amounts included on lines 1, 2, and						
_	3 received from disqualified persons						
ŀ	Amounts included on lines 2 and 3 received from other than disqualified persons that						
	exceed the greater of \$5,000 or 1% of the						
	amount on line 13 for the year						
(Add lines 7a and 7b						
	Public support. (Subtract line 7c from line 6.)						
Se	ction B. Total Support						
Cale	ndar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 202	22 (f) Total
9	Amounts from line 6						
10	Gross income from interest,						
	dividends, payments received on securities loans, rents, royalties,						
	and income from similar sources						
ŀ	Unrelated business taxable income						
	(less section 511 taxes) from businesses						
	acquired after June 30, 1975						
	Add lines 10a and 10b						
	Net income from unrelated business						
	activities not included on line 10b,						
	whether or not the business is regularly carried on						
12							
	or loss from the sale of capital						
13	assets (Explain in Part VI.) Total support. (Add lines 9, 10c, 11, and 12.)						
	First 5 years. If the Form 990 is for the	ne organization's fi	rst second third t	fourth or fifth tax	vear as a section 5	01(c)(3) ora:	anization
•	check this box and stop here	•			•		
Se	ction C. Computation of Publi	c Support Per	centage				
	Public support percentage for 2022 (I			rolumn (fl)		15	%
	Public support percentage from 2021		•			16	<u> </u>
	ction D. Computation of Inves					10	
	Investment income percentage for 20			ne 13 column (fl)		17	%
	Investment income percentage from					18	
	a 33 1/3% support tests - 2022. If the	•		on line 14, and line			
136	more than 33 1/3%, check this box ar						, 17 13 HOL
	33 1/3% support tests - 2021. If the	-	-		• •		
	line 18 is not more than 33 1/3%, che	-					
20				=		-	
<u> 20</u>	Private foundation. If the organization	ni did not check a	box on line 14, 19a	a, or 190, check th	iis dox and see ins	Tructions	

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Part IV | Supporting Organizations

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

Section A. All Supporting Organizations

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

Yes	No
	Yes

Schedule A (Form 990) 2 232024 12-09-22

Sched	dule A (Form 990) 2022 FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-21	2272	0 Pa	age 5
Par				
			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 on lines 11b and			
	11c below, the governing body of a supported organization?	11a		
	A family member of a person described on line 11a above?	11b		
С	A 35% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide			
	detail in Part VI.	11c		
Sect	ion B. Type I Supporting Organizations			
	r		Yes	No
1	Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or			
	more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, 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 officers, 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		
	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,			
Sact	supervised, or controlled the supporting organization. ion C. Type II Supporting Organizations	2		
0001	ion of Type in Supporting Organizations		V	NI.
4	Ware a majority of the arganization's directors or tructoes during the tay year also a majority of the directors		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	ion D. All Type III Supporting Organizations			
	, · · · · · · · · · · · · · · · · ·		Yes	No
1	Did the organization provide to each of its supported organizations, by the last day of the fifth month of the			
	organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax			
	year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the			
	organization's governing documents in effect on the date of notification, to the extent not previously provided?	1		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported			
	organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how			
	the organization maintained a close and continuous working relationship with the supported organization(s).	2		
3	By reason of the relationship described on line 2, above, did the organization's supported organizations have a			
	significant voice in the organization's investment policies and in directing the use of the organization's			
	income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's			
	supported organizations played in this regard.	3		
Sect	ion E. Type III Functionally Integrated Supporting Organizations			
1	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).			
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 governmental entity (see ins	truction		
2	Activities Test. Answer lines 2a and 2b 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	0-		
L	that these activities constituted substantially all of its activities.	2a		
b	Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement,			
	one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in			
	Part VI the reasons for the organization's position that its supported organization(s) would have engaged in	Oh.		
3	these activities but for the organization's involvement. Parent of Supported Organizations. Answer lines 3a and 3b below.	2b		
	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or			
а	Did the digametation have the power to regularly appoint or clost a majority of the officers, directors, or			

of its supported organizations? If "Yes." describe in Part VI the role played by the organization in this regard. Schedule A (Form 990) 2022

trustees of each of the supported organizations? If "Yes" or "No" provide details in Part VI.

b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each

За

Pa	t v Type III Non-Functionally Integrated 509(a)(3) Supporti	ng Organiz	zations	
1	Check here if the organization satisfied the Integral Part Test as a qualify	ng trust on N	ov. 20, 1970 (explain in	Part VI). See instructions.
	All other Type III non-functionally integrated supporting organizations mu	st complete S	ections A through E.	
Sect	ion A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	1		
2	Recoveries of prior-year distributions	2		
3	Other gross income (see instructions)	3		
4	Add lines 1 through 3.	4		
5	Depreciation and depletion	5		
6	Portion of operating expenses paid or incurred for production or			
	collection of gross income or for management, conservation, or			
	maintenance of property held for production of income (see instructions)	6		
7	Other expenses (see instructions)	7		
8	Adjusted Net Income (subtract lines 5, 6, and 7 from line 4)	8		
	ion B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see			
	instructions for short tax year or assets held for part of year):			
a	Average monthly value of securities	1a		
b	Average monthly cash balances	1b		
С	Fair market value of other non-exempt-use assets	1c		
d	Total (add lines 1a, 1b, and 1c)	1d		
	Discount claimed for blockage or other factors			
	(explain in detail in Part VI):			
2	Acquisition indebtedness applicable to non-exempt-use assets	2		
3	Subtract line 2 from line 1d.	3		
4	Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount,			
	see instructions).	4		
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5		
6	Multiply line 5 by 0.035.	6		
7	Recoveries of prior-year distributions	7		
8	Minimum Asset Amount (add line 7 to line 6)	8		
	ion C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, column A)	1		
2	Enter 0.85 of line 1.	2		
3	Minimum asset amount for prior year (from Section B, line 8, column A)	3		
4	Enter greater of line 2 or line 3.	4		
5	Income tax imposed in prior year	5		
6	Distributable Amount. Subtract line 5 from line 4, unless subject to			
	emergency temporary reduction (see instructions).	6		
7	Check here if the current year is the organization's first as a non-function	ally integrated	Type III supporting orga	nization (see

Schedule A (Form 990) 2022

instructions).

Schedule A (Form 990) 2022

b Excess from 2019 c Excess from 2020 d Excess from 2021 e Excess from 2022

Schedule B

Department of the Treasury Internal Revenue Service

(Form 990)

Schedule of Contributors

Attach to Form 990 or Form 990-PF.
Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2022

Name of the organization

Employer identification number

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 Organization type (check one): Filers of: Section: X 501(c)(3) (enter number) organization Form 990 or 990-EZ 4947(a)(1) nonexempt charitable trust **not** treated as a private foundation 527 political organization 501(c)(3) exempt private foundation Form 990-PF 4947(a)(1) nonexempt charitable trust treated as a private foundation 501(c)(3) taxable private foundation Check if your organization is covered by the General Rule or a Special Rule. Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions. **General Rule** For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions. **Special Rules** X For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000; or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II. For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 exclusively for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III. I For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions exclusively for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc., purpose. Don't complete any of the parts unless the General Rule applies to this organization because it received nonexclusively religious, charitable, etc., contributions totaling \$5,000 or more during the year \$ Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990), but it must answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify

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

that it doesn't meet the filing requirements of Schedule B (Form 990).

Schedule B (Form 990) (2022)

SCHEDULE C

(Form 990)

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

OMB No. 1545-0047

2022

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

 Section 501(c)(4), (5), or (6) organizations: Complete Part III. Name of organization Employer identification number FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 Complete if the organization is exempt under section 501(c) or is a section 527 organization. 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV. Political campaign activity expenditures 3 Volunteer hours for political campaign activities Complete if the organization is exempt under section 501(c)(3). Part I-B 1 Enter the amount of any excise tax incurred by the organization under section 4955 \$_ 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? 4a Was a correction made? b If "Yes," describe in Part IV. Complete if the organization is exempt under section 501(c), except section 501(c)(3). 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities \$ 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities \$ _ 3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL, line 17b 4 Did the filing organization file Form 1120-POL for this year? 5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC). If additional space is needed, provide information in Part IV. (a) Name (b) Address (c) EIN (d) Amount paid from (e) Amount of political contributions received and filing organization's funds. If none, enter -0-. 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) 2022

LHA

232041 11-08-22

Schedule C (Form 990) 2022

625,854.

938,781.

20,419.

185,550.

3,567.

141,027.

5,966.

157,467.

<u>3,5</u>70.

141,810.

7,316.

d Grassroots nontaxable amounte Grassroots ceiling amount

(150% of line 2d, column (e))

f Grassroots lobbying expenditures

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)).

1 During the year, did the filing organization attempt to influence foreign, national, state, or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of: a Volunteers? b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)? c Media advertisements? d Mailings to members, legislators, or the public? e Publications, or published or broadcast statements? f Grants to other organizations for lobbying purposes? g Direct contact with legislators, their staffs, government officials, or a legislative body? h Railies, demonstrations, seminars, conventions, speeches, lectures, or any similar means? i Other activities? j Total. Add lines to through 1i 2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)? bif "Yes," enter the amount of any tax incurred under section 4912 cl If "Yes," enter the amount of any tax incurred under section 4912 cl If "Yes," enter the amount of any tax incurred under section 4912 cl If the filing organization incurred a section 4912 at a lift the Form 4720 for this year? Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6). 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 of the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes." 1 Dues, assessments and similar amounts from members 2 Section 162(e) nondeductible lobbying and political expensions of the excess does the organization agree to carry over to the reasonable estimate of nondeductible lobbying and political expenses for which the section 527(f) tax was paid). 4 If notices were sent and the amount of in line 2 exceedes the amou		ch "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description	(a	1)	(b	o)
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d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year? Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6). Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? The part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes." Dues, assessments and similar amounts from members Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid). Carryover from last year Carryover from last year Carryover from last year Carryover from last year Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? Taxable amount of lobbying and political expenditures. See instructions						
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501(c)(6). Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes." 1 Dues, assessments and similar amounts from members 2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid). a Current year b Carryover from last year c Total 3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? 4 Taxable amount of lobbying and political expenditures. See instructions 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes." 1 Dues, assessments and similar amounts from members 1 2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenditures						
Yes N	Part		n 501(c)(5	o), or sec	tion	
Were substantially all (90% or more) dues received nondeductible by members? Did the organization make only in-house lobbying expenditures of \$2,000 or less? Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? Did the organization agree to carry over lobbying and political expenditures (do not include amounts of political expenditures from the prior year? Did the organization agree to carry over lobbying and political expenditures from the prior year? Did the organization agree to carry over lobbying and political expenditures from the prior year? Did the organization agree to carry over lobbying and political expenditures from the prior year? Did the organization agree to carry over lobbying and political expenditures from the prior year? Did the organization agree to carry over lobbying and political expenditures. See instructions		501(c)(6).				
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 prior year? 3 Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? 3 Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? 3 Did the organization agree to carry over lobbying and political expenditures from the prior year? 4 Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? 4 Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? 4 Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? 5 Did the organization agree to carry over lobbying and political expenditures from the prior year? 5 Did the organization agree to carry over lobbying expenditures of lobbying and political expenditures. See instructions					Yes	No
3 Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes." 1 Dues, assessments and similar amounts from members 2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid). a Current year b Carryover from last year c Total Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? 5 Taxable amount of lobbying and political expenditures. See instructions 5		• • • • • • • • • • • • • • • • • • • •				
Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes." 1 Dues, assessments and similar amounts from members 2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid). a Current year b Carryover from last year c Total 2 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? 5 Taxable amount of lobbying and political expenditures. See instructions 5 Taxable amount of lobbying and political expenditures. See instructions	2	Did the organization make only in-house lobbying expenditures of \$2,000 or less?		2		
501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes." 1 Dues, assessments and similar amounts from members 2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid). a Current year b Carryover from last year c Total 2 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? 5 Taxable amount of lobbying and political expenditures. See instructions 5						
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1 Dues, assessments and similar amounts from members 2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid). a Current year b Carryover from last year c Total 3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? 5 Taxable amount of lobbying and political expenditures. See instructions 5			'No" OR ((b) Part I	II-A, line	3, IS
2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid). a Current year b Carryover from last year c Total 2 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues 3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? 4 Taxable amount of lobbying and political expenditures. See instructions 5						
expenses for which the section 527(f) tax was paid). a Current year b Carryover from last year c Total 3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? 5 Taxable amount of lobbying and political expenditures. See instructions 5				1		
a Current year b Carryover from last year c Total 2 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues 3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? 4 Taxable amount of lobbying and political expenditures. See instructions 5	2	Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of politic	cal			
b Carryover from last year c Total Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? Taxable amount of lobbying and political expenditures. See instructions 2b 2c 3 4 5		expenses for which the section 527(f) tax was paid).				
c Total Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? Taxable amount of lobbying and political expenditures. See instructions 5						
3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? 4 Taxable amount of lobbying and political expenditures. See instructions 5						
4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? 5 Taxable amount of lobbying and political expenditures. See instructions 5	C	Total		2c		
does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? Taxable amount of lobbying and political expenditures. See instructions 5	3	Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues		3		
expenditures next year? Taxable amount of lobbying and political expenditures. See instructions 5	4	If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the exc	ess			
5 Taxable amount of lobbying and political expenditures. See instructions 5		, , ,				
5 Taxable amount of lobbying and political expenditures. See instructions 5		expenditures next year?		4		
	5	Taxable amount of lobbying and political expenditures. See instructions		5		
Part IV Supplemental Information	Part	IV Supplemental Information				
Provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, lines 1 and 2 (See	Part Provid	IV Supplemental Information	list); Part II-	A, lines 1 a	nd 2 (See	

SCHEDULE D

(Form 990)

Department of the Treasury Internal Revenue Service

Supplemental Financial Statements

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

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

OMB No. 1545-0047 Open to Public

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number 52-2122720

Pai	Organizations Maintaining Donor Advised organization answered "Yes" on Form 990, Part IV, line	d Funds or Other Similar Funds	or Accounts. Complete if the
		(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year	(a) a construction and a	(a) and and and and
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 v	vriting that the assets held in donor advis	ed funds
Ū	are the organization's property, subject to the organization's		
6	Did the organization inform all grantees, donors, and donor as		
·	for charitable purposes and not for the benefit of the donor or		•
	• •		
Pai			
1	Purpose(s) of conservation easements held by the organization	·	, ,
-	Preservation of land for public use (for example, recreat		f a historically important land area
	Protection of natural habitat	· —	f a certified historic structure
	Preservation of open space		
2	Complete lines 2a through 2d if the organization held a qualifi	ed conservation contribution in the form	of a conservation easement on the last
_	day of the tax year.		Held at the End of the Tax Year
а	Total number of conservation easements		2a
b			1 - 1
c	Number of conservation easements on a certified historic stru		
	Number of conservation easements included in (c) acquired a		
	historic structure listed in the National Register		2d
3	Number of conservation easements modified, transferred, rele		
	year	, , ,	
4	Number of states where property subject to conservation eas	ement is located	
5	Does the organization have a written policy regarding the peri	iodic monitoring, inspection, handling of	
	violations, and enforcement of the conservation easements it	holds?	Yes No
6	Staff and volunteer hours devoted to monitoring, inspecting,		
7	Amount of expenses incurred in monitoring, inspecting, hand	ling of violations, and enforcing conservat	tion easements during the year
8	Does each conservation easement reported on line 2(d) above	e satisfy the requirements of section 1700	b)(4)(B)(i)
9	In Part XIII, describe how the organization reports conservation		
•	balance sheet, and include, if applicable, the text of the footn	' '	
	organization's accounting for conservation easements.		
Pai	t III Organizations Maintaining Collections of	•	her Similar Assets.
	Complete if the organization answered "Yes" on Form	990, Part IV, line 8.	
1a	If the organization elected, as permitted under FASB ASC 958	B, not to report in its revenue statement a	nd balance sheet works
	of art, historical treasures, or other similar assets held for pub	lic exhibition, education, or research in fu	ırtherance of public
	service, provide in Part XIII the text of the footnote to its finan	cial statements that describes these item	IS.
b	If the organization elected, as permitted under FASB ASC 958	B, to report in its revenue statement and b	palance sheet works of
	art, historical treasures, or other similar assets held for public	exhibition, education, or research in furth	nerance of public service,
	provide the following amounts relating to these items:		
	(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 treat	asures, or other similar assets for financial	
	the following amounts required to be reported under FASB A	S .	
а	Revenue included on Form 990, Part VIII, line 1		
b	Assets included in Form 990, Part X		\$

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

Schedule D (Form 990) 2022

Schedule D (Form 990) 2022

	S ATAXIA RESEA	ARCH ALLIANCE	52-2122720 Page 3
Part VII Investments - Other Securities.			
Complete if the organization answered "Yes"			
(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost	or end-of-year market value
(1) Financial derivatives			
(2) Closely held equity interests			
(3) Other			
(A)			
(B)			
(C)			
(D)			
(E)			
(F)			
(G)			
(H)			
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 12.)			
Part VIII Investments - Program Related.			
Complete if the organization answered "Yes"			
(a) Description of investment	(b) Book value	(c) Method of valuation: Cost	or end-of-year market value
(1)			
(2)			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 13.)			
Part IX Other Assets.			
Complete if the organization answered "Yes"	on Form 990, Part IV, line 1	1d. See Form 990, Part X, line 15.	
(a)	Description		(b) Book value
(1)			
(2)			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
Total. (Column (b) must equal Form 990, Part X, col. (B) lin	e 15.)		
Part X Other Liabilities.			
Complete if the organization answered "Yes"	on Form 990, Part IV, line 1	1e or 11f. See Form 990, Part X, li	
1. (a) Description of liability			(b) Book value
(1) Federal income taxes			
(2) LEASE LIABILITIES, CURREN	T PORTION		57,082.
(3) LONG-TERM LEASE LIABILITI	ES		84,815.
(4)			
(5)			
(6)			
(7)			
(8)			

organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII Schedule D (Form 990) 2022

141,897.

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the

Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.) ...

	Complete if the organization answered "Yes" on Form 990, Part IV, line 12a	a.			
1				1	11,734,298.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:				
а	Net unrealized gains (losses) on investments	. 2a	-349,445.		
b	Donated services and use of facilities		153,000.		
С	Recoveries of prior year grants				
d	Other (Describe in Part XIII.)		887,832.		
е	Add lines 2a through 2d			2e	691,387.
3	Subtract line 2e from line 1			3	11,042,911.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:				
а	Investment expenses not included on Form 990, Part VIII, line 7b	4a			
b	Other (Describe in Part XIII.)	4b			
С	Add lines 4a and 4b			4c	0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990. Part I. line 12.)			5	11,042,911.
Pa	T XII Reconciliation of Expenses per Audited Financial Statem		Expenses per H	letur	n.
	Complete if the organization answered "Yes" on Form 990, Part IV, line 12a				10 000 140
1	Total expenses and losses per audited financial statements			1	12,099,149.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:	1.1	152 000		
а	Donated services and use of facilities		153,000.		
b	Prior year adjustments				
С	Other losses		012 400		
d	Other (Describe in Part XIII.)		813,402.		0.66 400
е	Add lines 2a through 2d			2e	966,402.
3	Subtract line 2e from line 1			3	11,132,747.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:	1.1			
а	Investment expenses not included on Form 990, Part VIII, line 7b				
b	Other (Describe in Part XIII.)	4b			
	Add lines 4a and 4b			4c	0.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990. Part I. line 18.)			5	11,132,747.
	t XIII Supplemental Information.	+ N / 15 1-	and Obs Dart V. Pass 4	. D t	V. Kara Or Davit VI
	de the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Par	•		; Part	X, line 2; Part XI,
iines	2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any add	ditional inforr	nation.		
PAF	RT X, LINE 2:				
	11 11 11 11				
THE	E INTERNAL REVENUE SERVICE HAS CLASSIFIED	FARA A	S EXEMPT FR	OM	FEDERAL
			-		
INC	COME TAXES UNDER SECTION 501(C)(3) OF THE	INTERN	AL REVENUE	COD	E.
ACC	COUNTING FOR UNCERTAINTY IN INCOME TAXES C	LARIFI	ES THE ACCO	UNT	ING FOR
UNC	CERTAINTY IN INCOME TAXES RECOGNIZED IN AN	ENTER	PRISE'S FIN	ANC	IAL
ST	ATEMENTS. MANAGEMENT HAS ANALYZED THE TAX	POSIT	ONS TAKEN	BY	FARA, AND
HAS	S CONCLUDED THAT AS OF DECEMBER 31, 2022 A	ND 202	L, THERE AR	E N	0
UNC	CERTAIN TAX POSITIONS TAKEN OR EXPECTED TO	BE TAI	KEN THAT WO	ULD	REQUIRE
REC	COGNITION OF A LIABILITY OR DISCLOSURE IN	THE FII	NANCIAL STA	TEM	ENTS.
		5 0			
FAI	RA RECOGNIZES ACCRUED INTEREST AND PENALTI	ES ASS	CIATED WIT	H U	NCERTAIN
m	, boatmiona to any mucho tiphe no trace.	m 3 37 . D.		D E ~	m on
	Y POSITIONS, IF ANY. THERE WERE NO INCOME	TAX R			
23205	1 09-01-22			Sche	dule D (Form 990) 2022

Schedule D (Form 990) 2022 FRIEDREICH S ATAXIA RESEARCH ALLIANCE 5. Part XIII Supplemental Information (continued)	Z-Z1ZZ/ZU Page 5
PENALTIES RECORDED FOR THE YEARS ENDED DECEMBER 31, 2022 AND 20)21.
PART XI, LINE 2D - OTHER ADJUSTMENTS:	
SPECIAL EVENTS EXPENSE	813,402.
PRIOR YEAR GRANT REFUNDS INCLUDED IN SUPPORT ON FINANCIAL	
STATEMENTS	74,430.
TOTAL TO SCHEDULE D, PART XI, LINE 2D	887,832.
PART XII, LINE 2D - OTHER ADJUSTMENTS:	
SPECIAL EVENTS EXPENSE	813,402.

SCHEDULE F (Form 990)

Department of the Treasury Internal Revenue Service

Statement of Activities Outside the United States

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

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

2022
Open to Public Inspection

Name of the organization

Employer identification number

FRIEDREICH'S AT.	AXIA RESI	EARCH AL	LIANCE		52-212272	20
Part I General Infor	mation on A	ctivities Out	side the United States. Comple	ete if the organi	ization answered "	Yes" on
Form 990, Part IV	/, line 14b.					
			ds to substantiate the amount of its gra			. —
the grantees' eligibility fo	or the grants or a	issistance, and t	the selection criteria used to award the	grants or assis	tance? <u>X</u>	Yes No
United States.			procedures for monitoring the use of its		ner assistance outs	side the
		Γ΄	n be duplicated if additional space is n (d) Activities conducted in the region		ite : linto al in (al)	(6) Takal
(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	is a prog describe	vity listed in (d) gram service, specific type (s) in the region	(f) Total expenditures for and investments in the region
			GRANTS TO RECIPIENTS	RESEARCH AN	D GRANT	
EUROPE	0	1	LOCATED IN REGION	PROGRAM		963,807.
EAST ASIA AND THE			GRANTS TO RECIPIENTS	RESEARCH AN	D CDANIII	
PACIFIC	0	0	LOCATED IN REGION	PROGRAM	D GRANI	642,045.
	-	<u> </u>				
			GRANTS TO RECIPIENTS	RESEARCH AN	D GRANT	
SOUTH AMERICA	0	0	LOCATED IN REGION	PROGRAM		142,631.
			GRANTS TO RECIPIENTS	RESEARCH AN	D GRANT	
CANADA	0	0	LOCATED IN REGION	PROGRAM		19,500.
	_	-				1 767 000
3 a Subtotal	0	1				1,767,983.
b Total from continuation sheets to Part I	0	0				0.
c Totals (add lines 3a	0	1				1 767 983.

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

Schedule F (Form 990) 2022

Schedule F (Form 990) 2022 Part II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

2 Enter total number o exempt 501(c)(3) org									1 (a) Name of organization
of recipient organization ganization by the IRS, o									(b) IRS code section and EIN (if applicable)
ns listed above that are or for which the grantee	SOUTH AMERICA - ARGENTINA, BOLIVIA, BRAZIL, CHILE, COLUMBIA,	EUROPE	EAST ASIA AND THE	EAST ASIA AND THE	EUROPE	EAST ASIA AND THE	EUROPE	EAST ASIA AND THE	(c) Region
Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter	MEDICAL RESEARCH	MEDICAL RESEARCH	MEDICAL RESEARCH	MEDICAL RESEARCH	MEDICAL RESEARCH	MEDICAL RESEARCH	MEDICAL RESEARCH	MEDICAL RESEARCH	(d) Purpose of grant
foreign country, I tion 501(c)(3) equ	46,935.WIRE	30,454.	6,800.	107,470.	185,250.	254,716.	91,292.	221,139.	(e) Amount of cash grant
ecognized as a tax ivalency letter	WIRE	WIRE	WIRE	WIRE	WIRE	WIRE	WIRE	WIRE	(f) Manner of cash disbursement
V	0.	0.	0.	0.	0.	0.	0.	٠0.	(g) Amount of noncash assistance
									(h) Description of noncash assistance
16									(i) Method of valuation (book, FMV appraisal, other)

3 Enter total number of other organizations or entities

									1 (a) Nam
									(a) Name of organization
									(b) IRS code section and EIN (if applicable)
EUROPE	EUROPE	EUROPE	EUROPE	EAST ASIA AND THE PACIFIC	EUROPE	EUROPE	EUROPE	CANADA, MEXICO (NOT UNITED STATES)	(c) Region
MEDICAL RESEARCH	MEDICAL RESEARCH	MEDICAL RESEARCH	MEDICAL RESEARCH	MEDICAL RESEARCH	the property of the property o				
72,536.	20,000. WIRE	5,110.	167,607. WIRE	45,800.WIRE	36,617.	125,000. WIRE	229,940. WIRE	19,500.	(e) Amount of cash grant
WIRE	WIRE	WIRE	WIRE	WIRE	WIRE	WIRE	WIRE	WIRE	(f) Manner of cash disbursement
0.	0.	0.	0.	0.	0.	0.	0.	0.	(g) Amount of non-cash assistance
									(h) Description of non-cash assistance
									(i) Method of valuation (book, FMV, appraisal, other)

Page 2

ď				ı	1			
Part II Continuation of	f Grants and Other A	\ssistance to Organizat	Continuation of Grants and Other Assistance to Organizations or Entities Outside the United States.		(Schedule F (Form 9	(Form 990), Part II, line 1)		
(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		SOUTH AMERICA -						
		ARGENTINA,						
		•) 1		>		
		CHILLE, COLUMNIA,	MEDICAL NEGLATICA	, , , , , , , , , , , , , , , , , , ,	N LIVE	•		
		EAST ASIA AND THE						
		PACIFIC	MEDICAL RESEARCH	6,120.WIRE	WIRE	0.		

Schedule F (Form 990) 2022 FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720

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

Part III can be duplicated if additional space is needed.

				(a) Type of grant or assistance (b) Region
				(b) Region
				(c) Number of recipients
				(c) Number of (d) Amount of recipients 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)

Schedule F (Form 990) 2022 FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 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		37
	U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990)	Yes	X No
3	Did the organization have an ownership interest in a foreign corporation during the tax year? If "Yes,"		
	the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to		
	Certain Foreign Corporations (see Instructions for Form 5471)	Yes	X No
4	Was the organization a direct or indirect shareholder of a passive foreign investment company or a		
	qualified electing fund during the tax year? If "Yes," the organization may be required to file Form 8621,		
	Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing		
	Fund (see Instructions for Form 8621)	Yes	X No
5	Did the organization have an ownership interest in a foreign partnership during the tax year? If "Yes."		
	the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain		
	Foreign Partnerships (see Instructions for Form 8865)	Yes	X No
	, , , , , , , , , , , , , , , , , , , ,		
6	Did the organization have any operations in or related to any boycotting countries during the tax year? If		
	"Yes," the organization may be required to separately file Form 5713, International Boycott Report (see		
	Instructions for Form 5713; don't file with Form 990)	Yes	X No

Schedule F (Form 990) 2022

232075 10-17-22 Schedule F (Form 990) 2022

SCHEDULE G (Form 990)

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

Attach to Form 990 or Form 990-EZ.

Department of the Treasury Internal Revenue Service Name of the organization organization entered more than \$15,000 on Form 990-EZ, line 6a.

OMB No. 1545-0047

Inspection

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

Employer identification number

	ICH S ATAXIA RESEA				52-2122	
Fundraising Activities. required to complete this part	Complete if the organization answett.	red "Y	es" or	n Form 990, Part IV, I	ine 17. Form 990-EZ	filers are not
 1 Indicate whether the organization rais a Mail solicitations b Internet and email solicitations c Phone solicitations d In-person solicitations 2 a Did the organization have a written of key employees listed in Form 990, P b If "Yes," list the 10 highest paid individed compensated at least \$5,000 by the 	e Solicitar f Solicitar g Special or oral agreement with any individual art VII) or entity in connection with priduals or entities (fundraisers) pursu	tion of tion of fundra (includ	non-g gover lising of ling of onal fu	overnment grants nment grants events ficers, directors, trus undraising services?	Yes	
(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) 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
		Yes	No			
Total 3 List all states in which the organizatio or licensing.	n is registered or licensed to solicit o	contrib	 utions	or has been notified	it is exempt from re	gistration

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

Schedule G (Form 990) 2022

Schedule G (Form 990) 2022 FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 Page 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 gro	oss income on Form 990	-EZ, lines 1 and 6b. List e	vents with gross receipt	s greater than \$5,000.
			(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
			FARA ENERGY	RIDEATAXIA		(add col. (a) through
			BALL	PHILA	17	
			(event type)	(event type)	(total number)	col. (c))
Revenue						
š	1	Gross receipts	1,980,460.	408,942.	2,040,000.	4,429,402.
Ä	·	G. 000 (000,ptc				
	2	Less: Contributions	1,782,630.	395,117.	1,830,296.	4,008,043.
	_	2555. 5571415445715		000,000		
	3	Gross income (line 1 minus line 2)	197,830.	13,825.	209,704.	421,359.
_		chiese mostrio (mile i mile e mile 2)				
	4	Cash prizes				
	•					
	5	Noncash prizes				
Ś	3	1401104311 p1/203				
nse	6	Rent/facility costs	174,038.			174,038.
Direct Expenses	0	Tient/facility costs	171,030.			174,030.
Ť Ü	_	Food and houses				
rec	′	Food and beverages				
ቯ	_	Entertainment	10 540			10 540
	8	Entertainment	10,540. 316,423.	75,434.	484,878.	10,540. 876,735.
	9	Other direct expenses		•		1,061,313.
		Direct expense summary. Add lines 4 through				
Da		Net income summary. Subtract line 10 from li		000 D-+ N/ E 40		-639,954.
Г	ונו	Gaming. Complete if the organization a \$15,000 on Form 990-EZ, line 6a.	answered "Yes" on Form	1990, Part IV, line 19, or r	eported more than	
		\$15,000 on Form 990-EZ, line 6a.	1	(L) Dull take (in atom)		(N Tatal manais a facilit
ē			(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c)
Revenue				billigo/progressive billigo		coi. (a) through coi. (c)
Rev		-				
	1	Gross revenue				
es	2	Cash prizes				
Expenses						
ž	3	Noncash prizes				
ct E						
Direct	4	Rent/facility costs				
_						
	5	Other direct expenses				
			Yes %		Yes %	
	6	Volunteer labor	No	No	No	
	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	_			
а	ls t	the organization licensed to conduct gaming ac	ctivities in each of these	states?		Yes No
b	If "	No," explain:				
		ere any of the organization's gaming licenses re	• •	,	ear?	Yes No
b	If "	Yes," explain:				

232082 10-27-22

Schedule G (Form 990) 2022

Schedule G (Fo	orm 990) 2022	FRIEDREICH'S	ATAXIA	RESEARCH .	ALLIANCE	52-2122720 Page 3
11 Does the	organization conduct g	aming activities with nonmer	mbers?			Yes No
		neficiary or trustee of a trust,				
to admini	ster charitable gaming?)				Yes No
		ng activity conducted in:				
						13a
		he person who prepares the				
			J	0 0 1		
Name	FELICIA DER	OSA				
Address	533 W. UWC	CHLAN AVENUE -	DOWNING	TOWN, PA	19335	
				-		
15a Does the	organization have a co	ntract with a third party from	whom the or	ganization receives	gaming revenue?	Yes No
		. ,				
b If "Yes," e	enter the amount of gar	ming revenue received by the	organization	\$	and the a	mount
		ne third party \$				
	enter name and address					
,		, ,				
Name						
	_					
Address						
71441000	-					
16 Gaming n	nanager information:					
io daning n	lanager information.					
Name						
Name						
Gaming n	nanager compensation	\$				
Gariling in	lanager compensation	\$				
Description	on of services provided					
Description	on or services provided					
-						
	rector/officer	Employee	Indone	endent contractor		
	ector/officer	Linployee	пиере	endent contractor		
17 Mandator	y distributions:					
	,	er state law to make charitab	la distribution	o from the gaming	nraaaada ta	
•	•	er state law to make chantab				Yes No
		s required under state law to		i to other exempt o	rganizations or speni	. In the
		ities during the tax year		irod by Port L line 2	the columns (iii) and (v); and Part III, lines 9, 9b, 10b,
						n, and Part III, lines 9, 90, 100,
	50, 150, 16, and 170, a	s applicable. Also provide ar	iy additional ii	normation. See ins	tructions.	

Schedule G	(Form 990)	FRIEDREICH S	ATAXIA	RESEARCH	ALLIANCE	52-2122/20	Page 4
Part IV	Supplement	al Information (continued)					
		,					
-							

SCHEDULE I (Form 990)

Department of the Treasury Internal Revenue Service

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

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

Attach to Form 990.

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

2022

Open to Public Inspection

ROCHESTER, NY 14627 BRAIN INSTITUTE, NEWELL DRIVE -DEPT OF NEUROLOGY, L3-100 MCKNIGHT WILSHIRE BLVD, 5TH FLOOR - LOS CALIFORNIA, LOS ANGELES - 10920 COLUMBUS, OH 43210 333 W. 10TH AVE & CIVIC CENTER BLVD -CENTER BLVD - PHILADELPHIA, PA PHILADELPHIA - 34TH ST & CIVIC 515 HYLAN BUILDING, RC BOX 270140 UNIVERSITY OF ROCHESTER UNIVERSITY OF FLORIDA ANGELES, CA 90024 OHIO STATE UNIVERSITY PHILADELPHIA, PA 19104 PHILADELPHIA FOUNDATION -CHILDREN'S HOSPITAL OF THE REGENTS OF THE UNIVERSITY OF CHILDREN'S HOSPITAL OF Name of the organization 1 (a) Name and address of organization Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection Enter total number of section 501(c)(3) and government organizations listed in the line 1 table Enter total number of other organizations listed in the line 1 table Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States. criteria used to award the grants or assistance? General Information on Grants and Assistance Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed. or government FRIEDREICH'S ATAXIA 34THTS 16-0743209 501(C)(3) 95-6006143 31-6025986 23-2237932 59-6002052 23-1352166 (b) EIN 501(C)(3) 501(C)(3) 501(C)(3) 501(C)(3) 501(C)(3) (c) IRC section (if applicable) RESEARCH ALLIANCE (d) Amount of cash grant ,146,693 417,389. 425,000 228,887. 40,950. ഗ ,300. (e) Amount of noncash 0 0 0 0 0 0 (f) Method of valuation (book, FMV, appraisal, (g) Description of noncash assistance Employer identification number 52-2122720MEDICAL RESEARCH MEDICAL RESEARCH MEDICAL RESEARCH MEDICAL RESEARCH EDICAL RESEARCH EDICAL RESEARCH **(h)** Purpose of grant or assistance X Yes No No

HA

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

Schedule I (Form 990) 2022

Schedule I (Form 990) FRIEDREICH 'S ATAXIA RESEARCH ALLIANCE Part III Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments	H'S ATAXIA	RESEARCH ALLIANCE nestic Organizations and Domestic	ALLIANCE and Domestic Go		(Schedule I (Form 990), Part II.)		52-2122720 Page 1
	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	ㅇ ㅜ ㅋ ㅣ		(g) Description of non-cash assistance	(h) Purpose of grant or assistance
ALBANY RESEARCH INSTITUTE 113 HOLLAND AVE							
ALBANY, NY 12208	14-1716021	501(C)(3)	108,445.	0.			MEDICAL RESEARCH
REES OF THE UNI LVANIA - 3451							
310 - PHILADELPHIA, PA 19104	23-1352685	501(C)(3)	342,044.	0.			MEDICAL RESEARCH
WEILL MEDICAL COLLEGE OF CORNELL UNIVERSITY - 1300 YORK AVENUE,							
C-118 - NEW YORK, NY 10065	13-1623978	501(C)(3)	100,000.	0.			MEDICAL RESEARCH
STANFORD UNIVERSITY 2770 SAND HILL ROAD							
	94-1156365	501(C)(3)	125,000.	0.			MEDICAL RESEARCH
THE BROAD INSTITUTE 415 MAIN STREET CAMBRIDGE, MA 02142	26-3428781	501(C)(3)	2,291,000.	o .			MEDICAL RESEARCH
BURKE NEUROLOGICAL INSTITUTE							
WHITE PLAINS, NY 10605	13-3434924	501(C)(3)	75,000.	0.			MEDICAL RESEARCH
N BIOMO:							
MASSACHUSETTS GENERAL HOSPITAL							
55 FRUIT STREET BOSTON, MA 02114	04-1564655	501(C)(3)	71,875.	0.			MEDICAL RESEARCH
ST. JUDE CHILDREN'S RESEARCH HOSPITAL - 262 DANNY THOMAS PLACE							
- MEMPHIS, IN SOLOS	07-0040072	DOT(C)(3)	64,902.	٠			MEDICAL RESEARCH

Schodula I (Form 000)							
MEDICAL RESEARCH			0.	248,611.		84-2449757	VESIGEN, INC 790 MEMORIAL DRIVE, SUITE 103 CAMBRIDGE, MA 01239
MEDICAL RESEARCH			0.	365,500.	501(C)(3)	75-6002868	UT SOUTHWESTERN MEDICAL CENTER 5323 HARRY HINES BLVD DALLAS, TX 75390
MEDICAL RESEARCH			0.	169,390.		26-1512085	STEALTH BIOTHERAPEUTICS, INC 123 HIGHLAND AVENUE, FLOOR 2 NEEDHAM HEIGHTS, MA 02494
MEDICAL RESEARCH			0.	67,361.	501(C)(3)	95-1643307	CALIFORNIA INSTITUTE OF TECHNOLOGY 1200 EAST CALIFORNIA BLVD PASADENA, CA 91125
MEDICAL RESEARCH			0.	200,000.	501(C)(3)	13-5598093	THE TRUSTEES OF COLUMBIA UNIVERSITY IN THE CITY OF NEW YORK - 154 HAVEN AVENUE, SECOND FLOOR - NEW YORK, NY 10032
MEDICAL RESEARCH			0.	50,000.	501(C)(3)	59-0879015	UNIVERSITY OF SOUTH FLORIDA FOUNDATION - 4202 EAST FOWLER AVE - TAMPA, FL 33620
MEDICAL RESEARCH			0.	150,000.	501(C)(3)	23-2829095	THOMAS JEFFERSON UNIVERSITY 1020 WALNUT STREET PHILADELPHIA, PA 19107
MEDICAL RESEARCH			0.	278,913.	501(C)(3)	41-6007513	THE REGENTS OF THE UNIVERSITY OF MINNESOTA - 200 SE OAK ST, #600 - MINNEAPOLIS, MN 55455
MEDICAL RESEARCH			0.	125,000.	501(C)(3)	95-6006144	THE REGENTS OF THE UNIVERSITY OF CALIFORNIA, SAN DIEGO - 9500 GILMAN DRIVE - LA JOLLA, CA 92093
(h) Purpose of grant or assistance	(g) Description of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(e) Amount of noncash assistance	(d) Amount of cash grant	(c) IRC section if applicable	(b) EIN	(a) Name and address of organization or government
		(Schedule I (Form 990), Part II.)		and Domestic Go	mestic Organizations	Assistance to Do	n of G
2-2122720 Page 1	ن ا			ALLIANCE	RESEARCH	H'S ATAXIA	Schedule I (Form 990) FRIEDREICH'S

				TRUSTEES OF THE INDIANA UNIVERSITY 509 EAST 3RD ST BLOOMINGTON, IN 47401 35-6001673 501(C)(3) 137,187. 0.	YALE UNIVERSITY 25 SCIENCE PARK, 150 MUNSON STREET NEW HAVEN, CT 06520 06-0646973 501(C)(3) 100,000. 0.	WHITEHEAD INSTITUTE FOR BIOMEDICAL RESEARCH - 455 MAIN STREET - 06-1043412 501(C)(3) 100,000. 0.	(a) Name and address of organization or government (b) EIN (c) IRC section organization or government (b) EIN (c) IRC section of assistance organization or government (b) EIN (c) IRC section organization or government (d) Amount of non-cash assistance assistance assistance appraisal, other) (g) Description of non-cash assistance appraisal, other)	Part II Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments (Schedule I (Form 990), Part II.)
Schedule I (Form 990)				MEDICAL RESEARCH	MEDICAL RESEARCH	MEDICAL RESEARCH	(h) Purpose of grant ce or assistance	L L L L L L L L L L L L L L L L L L L

Page 2

	Part III	
Part III can be duplicated if additional space is needed.	Part III Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22.	Controlled (1 Only 200) FORE

Part III can be duplicated if additional space is needed.					
1 1	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non- cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
Part IV Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information. PART I, LINE 2:	ired in Part I, line ا	2; Part III, column	(b); and any other ad	ditional information.	
GRANTS ARE REVIEWED BY INDEPENDENT	SCIENTIFIC	SCIENTIFIC ADVISORS A	S AND APPROVED	OVED BY	
NANCIAL REPORTS FROM THE INST	INSTITUTIONS.	·			

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

Department of the Treasury
Internal Revenue Service

Name of the organization

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

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number 52-2122720

Pa	art I Questions Regarding Compensation			
			Yes	No
1a	Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990,			
	Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.			
	First-class or charter travel Housing allowance or residence for personal use			
	Travel for companions Payments for business use of personal residence			
	Tax indemnification and gross-up payments Health or social club dues or initiation fees			
	Discretionary spending account Personal services (such as maid, chauffeur, chef)			
b	If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or			
	reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain	1b		
2	Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors,			
	trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a?	2		
_				
3	Indicate which, if any, of the following the organization used to establish the compensation of the organization's			
	CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to			
	establish compensation of the CEO/Executive Director, but explain in Part III.			
	X Compensation committee Written employment contract ☐ Independent compensation consultant Compensation survey or study			
	Form 990 of other organizations X Approval by the board or compensation committee			
	Tomin 330 of other organizations			
4	During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing			
•	organization or a related organization:			
а	Receive a severance payment or change-of-control payment?	4a		Х
b		4b		Х
С	Participate in or receive payment from an equity-based compensation arrangement?	4c		Х
	If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.			
	Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.			
5	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation			
	contingent on the revenues of:			
	The organization?	5a		X
b	Any related organization?	5b		Х
	If "Yes" on line 5a or 5b, describe in Part III.			
6	For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation			
	contingent on the net earnings of:			7.7
	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	-		v
_	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			Х
•	initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III	8		Λ
9	If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in			
	Regulations section 53.4958-6(c)?	9		

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

Schedule J (Form 990) 2022

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

Do not list any individuals that aren't listed on Form 990, Part VII. 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).

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.

	긐	B) Breakdown of W	(B) Breakdown of W-2 and/or 1099-MISC and/or 1099-NEC	and/or 1099-NEC	(C) Retirement and	ıble	(E) Total of columns	(F) Compensation
(A) Name and Title		(i) Base compensation	(ii) Bonus & incentive	(iii) Other reportable	compensation		123	reported as deferred on prior Form 990
			compensation	compensation				
(1) BARBARA A TATE	Ξ	250,000.	0.	0.	6,350.	758.	257,108.	0.
CHIEF SCIENTIFIC OFFICER	≘	0.	0.	0.		0.	0.	0.
(2) JENNIFER M FARMER	(i)	150,000.	0.	0.	4,500.	728.	155,228.	0.
CHIEF EXECUTIVE OFFICER	≘_	0.	0.	0.	0.	0.	0.	0.
	≘							
	≘							
	Ξ							
	(ii)							
	Ξ							
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	Ξ							
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Schedule J (Form 990) 2022 FRIEDREICH'S ATAXIA RESEARCH ALLIANCE	52-2122720	Page 3
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.	is part for any additional information.	
	Schedule J (Form 990) 2022	990) 2022

SCHEDULE M (Form 990)

Noncash Contributions

202

QUZZ
Open to Public Inspection

OMB No. 1545-0047

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.

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

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number 52-2122720

Pai	rt I Types of Property									
		(a) Check if applicable	(b) Number of contributions or litems contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of de noncash contribu	•	ts			
1	Art - Works of art									
2	Art - Works of art 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	Х	5	176 540	HI-LOW DATE	OF GT	ETT.			
9	Securities - Publicly traded			170,540.	III DOW DAIE	OF GI	<u> </u>			
10	Securities - Closely held stock									
11	Securities - Partnership, LLC, or									
40	trust interests									
12	Securities - Miscellaneous Qualified conservation contribution -									
13										
44	Historic structures Qualified conservation contribution - Other									
14	Real estate - Residential									
15										
16	Real estate - Commercial									
17	Real estate - Other									
18	Collectibles									
19	Food inventory									
20	Drugs and medical supplies				 					
21	Taxidermy				 					
22	Historical artifacts				+					
23	Scientific specimens				+					
24	Archeological artifacts	Х	196	56,455.	 					
25	Other (AUCTION ITEMS)		190	30,433.	 					
26	Other ()				 					
27	Other ()									
28	Other ()									
29	Number of Forms 8283 received by the organization completed Form 828									
	for which the organization completed Form 828	oo, Part V, L	onee Acknowledg	ement 29		Vac	TNo			
20-	During the year did the experientian receive by	, contributio	n any nranasty ram	arted in Dort Llings 1 throug	sh 00 that it	Yes	No			
Sua	Da During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least 3 years from the date of the initial contribution, and which isn't required to be used for									
	•			•		30a	Х			
b	exempt purposes for the entire holding period? If "Yes," describe the arrangement in Part II.					30a	 ^			
	Does the organization have a gift acceptance p	olicy that re	acuires the review	of any nonetandard contribut	tions?	31 X				
31		•	· ·	•	110115 !	31 X	+-			
o∠d	2a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash									
L	contributions?									
	 b If "Yes," describe in Part II. 3 If the organization didn't report an amount in column (c) for a type of property for which column (a) is checked, 									
33	•	olullili (C) 10	a type of property	non willion column (a) is ched	oneu,					
LHA	describe in Part II. For Paperwork Reduction Act Notice, see	the Instruct	tions for Earm 000	<u> </u>	Schedule M	L/Earm 000	1/ 2022			
_	i oi i apei work neudolion Act Notice, see			/ ·	Scriedule IV	. (1 01111 990	, 2022			

SCHEDULE O (Form 990)

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 Form 990-EZ.

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

2022
Open to Public Inspection

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number 52-2122720

FORM 990, PART III, LINE 4A, DESCRIPTION OF PROGRAM SERVICE: RESEARCH AND GRANT PROGRAM FARA DEPLOYS FINANCIAL RESOURCES TO ACCELERATE RESEARCH FOR FRIEDREICH'S ATAXIA (FA). IN 2022, FARA AWARDED NEARLY \$8.5 MILLION IN RESEARCH FUNDING. THIS INCLUDED 50 ACTIVE RESEARCH PROJECTS THROUGH FARA'S INVESTIGATOR-INITIATED GRANT PROGRAM, INSTITUTIONAL BASED RESEARCH AND FARA DIRECTED PROJECTS. FARA GRANT PROGRAM FARA'S INVESTIGATOR-INITIATED GRANT PROGRAM AWARDED TWENTY-TWO NEW GRANTS AND APPROVED CONTINUED FUNDING FOR SIXTEEN GRANTS. NINE OF THESE NEW GRANTS WERE AWARDED TO INVESTIGATORS NEW TO FA RESEARCH, INCLUDING FOUR JUNIOR INVESTIGATORS. RESEARCHERS IN SEVEN COUNTRIES ARE RECEIVING RESEARCH FUNDING FROM FARA. FARA'S GRANT PROGRAM IS FUNDING RESEARCH THAT FURTHERS THE UNDERSTANDING OF FA AT A VERY BASIC OR MECHANISTIC LEVEL, PROMOTES DRUG DISCOVERY, ADVANCES GENE AND CELL THERAPY APPROACHES, SEEKS TO IDENTIFY NEW BIOMARKERS AND CLINICAL OUTCOME ASSESSMENTS THAT CAN INFORM AND SUPPORT FUTURE CLINICAL TRIALS AND INVESTIGATES APPROACHES TO IMPROVE CLINICAL OUTCOMES FOR THOSE LIVING WITH FA. SEVERAL OF THESE GRANTS WERE CO-FUNDED WITH FARA'S FA ADVOCACY GROUP PARTNERS; THIS COLLABORATIVE APPROACH BOTH INCREASES THE NUMBER OF AVAILABLE RESEARCH DOLLARS AND HELPS TO MINIMIZE DUPLICATION OF EFFORT. FARA HAS IDENTIFIED OPPORTUNITIES TO FUND RESEARCH AT INSTITUTIONS WHERE THERE ARE MULTIPLE INVESTIGATORS WITH AN EXPERTISE AND COMMITMENT TO FA RESEARCH AND/OR OPPORTUNITY TO LEVERAGE TECHNOLOGIES, INNOVATION OR NEW GROWTH TO THE FA COMMUNITY. BY ESTABLISHING THESE INSTITUTIONAL LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Schedule O (Form 990) 2022

Name of the organization **Employer identification number** FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 FUNDING PROGRAMS, FARA IS ABLE TO PROMOTE COLLABORATION AND SYNERGY ACROSS BASIC, TRANSLATIONAL AND CLINICAL RESEARCH, PROVIDE A LONGER-TERM COMMITMENT FOR RESEARCH, ATTRACT NEW INVESTIGATORS, AND LEVERAGE THE INSTITUTIONS RESOURCES AND ENGAGEMENT. FARA PROVIDES INSTITUTIONAL BASED RESEARCH SUPPORT FOR THE FA CENTER OF EXCELLENCE AT PENN MEDICINE/ CHILDREN'S HOSPITAL OF PHILADELPHIA AND THE FA ACCELERATOR PROGRAM THE BROAD INSTITUTE. FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE, PHILADELPHIA, PA THE FA CENTER OF EXCELLENCE (COE) IS A TRANSLATIONAL RESEARCH AND CLINICAL CARE CENTER DEVOTED TO FRIEDREICH ATAXIA: EXPEDITING BASIC SCIENCE AND DRUG DISCOVERY FINDINGS TO NEW TREATMENTS AND DEDICATING RESOURCES TO CLINICAL RESEARCH AND CARE TO FURTHER UNDERSTAND THE DISEASE, INFORM DRUG DEVELOPMENT AND IMPROVE OUTCOMES FOR INDIVIDUALS LIVING WITH FA. THE CENTER WAS ESTABLISHED IN MARCH 2014, WITH A COMMITMENT TO PENN MEDICINE/ CHILDREN'S HOSPITAL OF PHILADELPHIA, PRESENTED BY FARA IN PARTNERSHIP WITH THE HAMILTON AND FINNERAN FAMILIES/ CUREFA FOUNDATION. PROJECTS AND INVESTIGATORS WITH CONTINUED FUNDING INCLUDED DR. ROB WILSON- DRUG DISCOVERY, DR. DAVID LYNCH- TRANSLATIONAL AND CLINICAL NEUROSCIENCE RESEARCH, DR. IAN BLAIR- BIOMARKER DISCOVERY, DR. KIM LIN-CARDIAC RESEARCH, DR. SHANA MCCORMACK- METABOLISM AND ENDOCRINOLOGY, AND DR. JENNIFER PHILLIPS CREMINS- GENETIC MODELING. THE CENTER NOT ONLY SUPPORTS WORK WITHIN THESE DISCIPLINES, BUT ALSO FOSTERS EFFICIENT

PATIENTS COULD BE DUE TO DYSFUNCTIONS OF SPECIFIC ENZYMES WHEN FRATAXIN

COLLABORATION AND SYNERGY ACROSS THEM. FOR EXAMPLE, DR. LYNCH, WHO

INVESTIGATING WHETHER THE METABOLIC ALTERATIONS HE HAS OBSERVED IN

ACTIVELY PARTICIPATES IN BOTH BASIC AND CLINICAL RESEARCH, IS

Schedule O (Form 990) 2022

Name of the organization **Employer identification number** FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 LEVELS ARE LOW. HIS FINDINGS HAVE THE POTENTIAL TO IDENTIFY NEW THERAPEUTIC TARGETS. ANOTHER EXAMPLE IS THE EXRX-FA TRIAL, AN NIH SUPPORTED CLINICAL TRIAL THAT INSPIRED THE PRECLINICAL STUDIES ON MUSCLE AND HEART OF THE COE COLLABORATORS, ERIN SEIFERT, PHD AND JOSEPH BAUR, PHD. IN ADDITION, WITH SUPPORT FROM FARA, THE EXRX-FA CLINICAL TRIAL HAS BEEN EXPANDED TO INCLUDE COLLECTION OF BIOMARKER DATA, MEASURES THAT COULD BE USEFUL IN FUTURE THERAPEUTIC TRIALS. A MAJOR ACCOMPLISHMENT IN 2022, LED BY DAVID LYNCH, MD, PHD, WAS THE COMPLETION AND PUBLICATION OF STUDIES OF OMAVELOXOLONE, A NEW TREATMENT THAT HAS COMPLETED CLINICAL TRIALS IN FA. THESE STUDIES PROVIDED THE EVIDENCE NEEDED TO RECEIVE AN EXPEDITED REVIEW OF THIS FIRST NEW DRUG APPLICATION AT THE FDA. THE INVESTIGATORS AT THE COE AT CHOP CONTRIBUTE TO FINDING TREATMENTS FOR FA BY REGULARLY PUBLISHING THEIR WORK, TRAINING NEW INVESTIGATORS TO COMMIT TO RESEARCH ON FA, PARLAYING FARA FUNDING INTO LARGER GRANTS FROM NIH AND BY BEING THE LARGEST SITE FOR THE FA NATURAL HISTORY STUDY. FRIEDREICH'S ATAXIA ACCELERATOR AT THE BROAD INSTITUTE OF MIT AND HARVARD THE FRIEDREICH'S ATAXIA ACCELERATOR (FAA) AT THE BROAD INSTITUTE OF MIT AND HARVARD WAS ESTABLISHED IN AUGUST 2020. FUNDED BY FARA, IN COLLABORATION WITH THE CUREFA FOUNDATION AND ENDFA, THE FAA IS A COLLABORATIVE, MULTI-DISCIPLINARY EFFORT AIMED AT GALVANIZING RESEARCH INTO FA AND SEEDING A GROWING COMMUNITY ACROSS BROAD, MIT, HARVARD AND AFFILIATED INSTITUTIONS COMMITTED TO TACKLING FA. LED BY VAMSI MOOTHA, MD, THE FAA INVESTIGATORS INCLUDE GARY RUVJUM, PHD, DAVID LIU, PHD, CHRISTINE SEIDMAN, MD, JONATHAN SEIDMAN, PHD, ANOOPUM GUPTA, MD AND

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Name of the organization **Employer identification number** FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 ANTHONY PHILIPPAKIS, MD. THE FIRST THREE YEARS OF FAA SUPPORTED RESEARCH INITIATIVES TO UNDERSTAND THE DEEP BIOCHEMICAL BASIS OF FA AS WELL AS TO EVALUATE THE THERAPEUTIC POTENTIAL OF NEW EARLY-STAGE INNOVATIVE APPROACHES IN ANIMAL MODELS. PROJECTS INCLUDE EVALUATING HYPOXIA AS A THERAPY, DIRECT EDITING OF DNA TO REPAIR THE FA REPEAT LESION, IDENTIFYING GENETIC/CHEMICAL MODIFIERS THAT CAN BYPASS THE NEED FOR FRATAXIN, AND UNDERSTANDING THE CAUSE OF FA CARDIOMYOPATHY. OVER THE FIRST 2.5 YEARS OF FAA, INVESTMENT IN UNDERSTANDING FA BASIC AND TRANSLATIONAL BIOLOGY HAS ALREADY YIELDED NEW DISCOVERIES (WITH FOUR NEW RESEARCH PAPERS SUBMITTED) AND SUGGEST COMPLETELY NEW THERAPEUTIC AVENUES (WITH THREE NEW PATENTS SUBMITTED). IN 2022, TWO NEW PROJECTS WERE LAUNCHED. ONE TO ACCELERATE ADVANCEMENT OF EFFECTIVE TREATMENTS BY DEVELOPING AT HOME ASSESSMENTS OF MOVEMENT AND SPEECH. THE OTHER TO LEVERAGE EXISTING LARGE BIOBANKS OF GENETIC SEQUENCE DATA TO FURTHER UNDERSTAND THE PREVALENCE OF FA, AS WELL AS POTENTIALLY UNCOVER NOVEL GENETIC MODIFIERS OF THE CONDITION. FAA HAS HAD AN IMPACT IN COMMUNITY BUILDING. DURING THE PAST 2.5 YEARS, FAA HAS ENABLED OVER 20 RESEARCHERS ACROSS FIVE LABORATORIES TO APPLY THEIR EXISTING EXPERTISE TOWARD FA RESEARCH. TWO FAA POST-DOCTORAL FELLOWS HAVE JUST LAUNCHED THEIR OWN INDEPENDENT LABORATORIES THAT WILL CONTINUE FA-RELATED RESEARCH: TSLIL AST AT THE WEIZMANN INSTITUTE AND MANDA ARBAB AT THE BOSTON CHILDREN'S HOSPITAL TRANSLATIONAL NEUROSCIENCE CENTER AND HARVARD MEDICAL SCHOOL. TSLIL AST'S FA RESEARCH RECEIVED THE PRESTIGIOUS ERIC S. LANDER AWARD RECOGNIZING OUTSTANDING ACCOMPLISHMENT IN SCIENCE. FARA DIRECTED RESEARCH

IN 2022, FARA FUNDED DIRECTED RESEARCH PROGRAMS INCLUDING: 1.

Name of the organization **Employer identification number** FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 MAINTAINING A REPOSITORY OF FA CELL LINES FOR RESEARCH HTTPS://LABS.UTSOUTHWESTERN.EDU/NAPIERALA-LAB 2. TRACK-FA, A GLOBAL NEUROIMAGING CONSORTIUM ESTABLISHED IN 2020, DESIGNED A NATURAL HISTORY STUDY TO TRACK THE CHANGES IN THE BRAIN AND THE SPINAL CORD IN FA. PARTICIPATING CLINICAL SITES IN USA, BRAZIL, GERMANY, AND AUSTRALIA CONTINUED ENROLLMENT IN 2022. THE GOAL IS TO ENROLL 200 INDIVIDUALS WITH FA AND 100 MATCHED CONTROLS AND CONDUCT NEUROIMAGING OF THE BRAIN AND SPINAL, ALONG WITH CLINICAL OUTCOMES AND BLOOD BIOMARKERS. AT THE CLOSE OF 2022, 122 INDIVIDUALS WITH FA AND 43 CONTROLS HAD BEEN ENROLLED. THE CONSORTIUM PUBLISHED ITS FIRST SCIENTIFIC ARTICLE THAT PRESENTS THE BACKGROUND ON THE TRACK-FA STUDY AND THE SCIENTIFIC PROCEDURES. THE PUBLICATION IS OPEN ACCESS AT: HTTPS://JOURNALS.PLOS.ORG/PLOSONE/ARTICLE?ID=10.1371/JOURNAL.PONE.026964 9 3. FOSTERING A COLLABORATIVE EFFORT BETWEEN RESEARCHERS AT UNIVERSITY OF OKLAHOMA, UNIVERSITY OF TEXAS SOUTHWESTERN, AND UNIVERSITY OF PENNSYLVANIA TO STUDY THE PRECISE MECHANISM OF THIS GENE SILENCING IN DIFFERENT TISSUES AND MODELS OVER TIME. 4. ASSEMBLING GLOBAL CLINICAL EXPERTS TO LEAD A RE-EVALUATION AND UPDATE TO THE CLINICAL MANAGEMENT GUIDELINES (CMG) IN FA. AN UPDATE TO THE CMG FOR FA WAS PUBLISHED IN 2022 FOR REFERENCE USE BY PHYSICIANS, AND PATIENTS. THIS PROJECT, LED BY DR. LOUISE CORBEN, IS THE RESULT OF THE EFFORTS OF A 12-PERSON STEERING COMMITTEE, 70 EXPERT AUTHORS, AND AN 11-PERSON PATIENT AND CAREGIVER PANEL. THE CMGS CAN BE ACCESSED AT HTTPS://FRDAGUIDELINES.ORG AND INCLUDES TOPIC CHAPTERS, LAY SUMMARIES, RECOMMENDATIONS, BEST PRACTICE STATEMENTS, AND LINKS TO THE EVIDENCE TO RECOMMENDATION TABLES. ALSO, THERE ARE THREE NEW TOPICS: EMERGENCY MEDICINE, DIGITAL AND ASSISTIVE TECHNOLOGIES, AND MENTAL HEALTH.

Schedule O (Form 990) 2022

Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 DEVELOPMENT AND VALIDATION OF A POTENCY ASSAY FOR USE IN THE DEVELOPMENT OF GENE AND PROTEIN REPLACEMENT THERAPIES. 6. LEADING WORK TO CREATE A NEW DISEASE MODEL FOR PRE-CLINICAL RESEARCH, AN FA RAT MODEL. 7. IDENTIFYING AND FUNDING RESEARCH TO UNDERSTAND THE THERAPEUTIC WINDOW (MINIMAL AMOUNT OF FRATAXIN NEEDED FOR A THERAPEUTIC BENEFIT AND THRESHOLD FOR MAXIMUM AMOUNTS OR TOXIC AMOUNTS OF FRATAXIN IN THE CELL. OF NOTE, FA SHARES SIMILAR SYMPTOMS AND DISEASE MECHANISMS WITH OTHER DISEASES, BOTH RARE AND COMMON. RESEARCH INTO FA CAN PROVIDE INSIGHTS AND ADVANCES IN OTHER DISEASES SUCH AS MITOCHONDRIAL DISEASES, MUSCULAR DYSTROPHIES, DIABETES, AND CARDIOMYOPATHY. A COMPLETE LIST OF 2022 FUNDED GRANTS CAN BE FOUND AT: CUREFA.ORG/GRANT/GRANT-AWARDS A COMPLETE LIST OF 2022 PUBLICATIONS OF RESEARCH FUNDED BY FARA CAN BE FOUND AT: CUREFA.ORG/RESEARCH/FARA-FUNDED-RESEARCH FORM 990, PART III, LINE 4B, PROGRAM SERVICE ACCOMPLISHMENTS: IN STUDIES AIMED AT ADVANCING OUR KNOWLEDGE OF FA AND THE TREATMENTS BEING DEVELOPED. FARA PARTNERS WITH INTERNATIONAL PATIENT ADVOCACY ORGANIZATIONS THROUGH A GOVERNANCE BOARD TO ENSURE MULTI-STAKEHOLDER

TRIALS AND MANY CLINICAL RESEARCH STUDIES. TO LEARN MORE, VISIT

FA ARE ENROLLED AND FAGPR WAS USED TO RECRUIT FOR SEVERAL CLINICAL

COLLABORATIVE CLINICAL RESEARCH NETWORK IN FA (CCRN IN FA): THE CCRN IS

ENGAGEMENT AND OVERSIGHT OF THE FAGPR. MORE THAN 1000 INDIVIDUALS WITH

AN INTERNATIONAL NETWORK OF 14 CLINICAL RESEARCH CENTERS (UNITED

Employer identification number

CUREFA.NET/REGISTRY.

Name of the organization **Employer identification number** FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 STATES, CANADA, AUSTRALIA, NEW ZEALAND, AND INDIA) THAT WORK TOGETHER TO ADVANCE TREATMENTS AND CLINICAL CARE FOR INDIVIDUALS WITH FRIEDREICH'S ATAXIA. HAVING SUCH A NETWORK MEANS THAT THERE ARE TRAINED PHYSICIANS AND RESEARCH COORDINATORS READY TO DO CLINICAL RESEARCH STUDIES AND TRIALS. ALSO, THIS NETWORK IS BACKED BY A DATA COORDINATION CENTER THAT FACILITATES ALL ASPECTS OF DATA COLLECTION, DATABASE MANAGEMENT, AND STATISTICAL ANALYSIS OF STUDY DATA. TO LEARN MORE AND REVIEW A LIST OF RESEARCH PUBLICATIONS. VISIT CUREFA.ORG/NETWORK.HTML THE CCRN LEADS A NATURAL HISTORY AND CLINICAL OUTCOME MEASURE STUDY, CALLED FACOMS. FACOMS HAS MORE THAN 1400 INDIVIDUALS WITH FA ENROLLED AND THE LONGITUDINAL DATA HAS LED TO A BETTER UNDERSTANDING OF SYMPTOMS AND PROGRESSION OF DISEASE. FURTHERMORE, THE CCRN AND FACOMS HAVE VALIDATED CLINICAL OUTCOME MEASURES AND THE FARS SCALE, STUDIED SPEECH, VISION AND HEARING, LAUNCHED BIOMARKER STUDIES, ESTABLISHED DNA AND RNA REPOSITORIES, AND PROVIDED MANY BLOOD SAMPLES TO RESEARCHERS AROUND THE WORLD. THE CCRN IN FA INVESTIGATORS HAVE BEEN INVOLVED IN >12 CLINICAL TRIALS INCLUDING A FEW THAT WERE DESIGNED AND CONDUCTED SOLELY THROUGH NETWORK SITES. ONE CLINICAL TRIAL CONDUCTED THROUGH CCRN CENTERS HAS LED TO THE FIRST APPROVED MEDICATION OR TREATMENT OF FA, AND THE NATURAL HISTORY STUDY DATA WAS ALSO CRITICAL IN DESIGNING THE TRIAL AND UNDERSTANDING THE MEANINGFULNESS OF THE TRIAL OUTCOMES.

THE FACOMS STUDY AND THE EFACTS NATURAL HISTORY STUDY (EUROPEAN UNION

COUNTRIES) HAVE BEEN CONDUCTED IN PARALLEL, FOR OVER A DECADE, WITH

MANY SIMILARITIES. IN 2022, FARA BROUGHT TOGETHER INVESTIGATORS OF BOTH

FACOMS AND EFACTS TO COMBINE EFFORTS INTO A SINGLE GLOBAL CONSORTIUM

Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE Employer identification number 52-2122720

WITH A UNIFIED NATURAL HISTORY AND CLINICAL RESEARCH INFRASTRUCTURE.

THE NEW FA GLOBAL CLINICAL CONSORTIUM AND A GLOBAL NATURAL HISTORY

STUDY PROTOCOL, THE UNIFAL STUDY, ARE BEING ESTABLISHED TO CONTINUE TO

IMPROVE THE PANEL OF OUTCOME MEASURES THAT CAN BE USED IN FA CLINICAL

TRIALS, WITH THE GOALS TO BETTER ORGANIZE AND HARMONIZE THE NATURAL

HISTORY ECOSYSTEM AND ALLOW FOR A COMPLETE VIEW OF DISEASE PROGRESSION

OF FA.

ADDITIONAL INFORMATION ABOUT FARA'S PROGRAMS IN 2022 CAN BE ACCESSED

VIA THE ANNUAL REPORT AT: CUREFA.ORG/FINANCIALS

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

CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP) AT THE

DEPARTMENT OF DEFENSE IN FISCAL YEAR (FY) 22, RESULTING IN SIX FA

RESEARCHERS BEING RECOMMENDED FOR FUNDING TOTALING OVER \$14 MILLION.

FARA AND NAF WERE ALSO SUCCESSFUL IN GETTING A RESOLUTION PASSED

DECLARING SEPTEMBER 25, 2022 NATIONAL ATAXIA AWARENESS DAY (S.RES 850)

AND HOSTING THE FOURTH UNITED AGAINST ATAXIA HILL DAY. IN 2022, 78

CONGRESSIONAL MEETINGS WERE HELD WITH 88 FARA AND NAF ADVOCATES

PARTICIPATING FROM 31 STATES AND THE DISTRICT OF COLUMBIA. THE PRIMARY

ASK WAS TO BROADEN THE DEFINITION ON THE CDMRP FROM "FRIEDREICH'S

ATAXIA" TO "HEREDITARY ATAXIA", WHICH WOULD PROVIDE ADDITIONAL FUNDING

FOR ATAXIA RESEARCHERS IN FY23. PRESIDENT BIDEN SIGNED THE FISCAL YEAR

(FY) 23 CONGRESSIONAL BUDGET ON DECEMBER 29 WHICH LISTED "HEREDITARY

ATAXIA" UNDER THE CDMRP'S PEER REVIEWED MEDICAL RESEARCH PROGRAM.

THE FARA AMBASSADOR PROGRAM, WHICH WAS LAUNCHED IN 2011 WITH >20

Name of the organization **Employer identification number** FRIEDREICH'S ATAXIA RESEARCH ALLIANCE 52-2122720 PARTICIPANTS HAD A YEAR OF CONTINUED GROWTH AND ACTIVITY IN 2022. THE PROGRAM NOW INCLUDES >80 PARTICIPANTS. THE MISSION OF THE FARA AMBASSADORS IS TO BE POSITIVE, SUPPORTIVE, PEER REPRESENTATIVES FOR THE FA COMMUNITY; ACTIVELY RAISING AWARENESS AND FUNDS FOR FARA. THE FARA AMBASSADOR PROGRAM MEMBERS ORGANIZE SERVICE PROJECT TEAMS INCLUDING: A BLOG TEAM THAT FACILITATES WEEKLY MEET THE COMMUNITY INTERVIEWS WITH PEOPLE LIVING WITH FA AND A MONTHLY MEET THE RESEARCHER INTERVIEW. A CARD WRITING TEAM THAT WRITES PERSONALIZED CARDS TO SEND TO THE VARIOUS STAKEHOLDERS AND COMMUNITY MEMBERS THROUGHOUT THE YEAR TO SAY THANK YOU OR TO OFFER ENCOURAGEMENT. 3. A MONTHLY PEER ZOOM HANGOUT GROUPS FOR THE GREATER FA COMMUNITY TO ATTEND AND CONNECT WITH ONE ANOTHER ONLINE (ONE IS GEARED TO ADULTS, AND ONE IS FOR TEENS WITH FA). 4. A SOCIAL MEDIA TEAM THAT GENERATES ENGAGING CONTENT IN SUPPORT OF FARA INITIATIVES AND CAMPAIGNS. 5. A SPEAKING TEAM WHERE PARTICIPANTS PRACTICE TELLING THEIR STORY LIVING WITH FA ON BEHALF OF THE ORGANIZATION. AMBASSADORS AND OTHER COMMUNITY REPRESENTATIVES CONNECTED WITH MANY OF FARA'S ACADEMIC AND INDUSTRY PARTNERS AS WELL AS REGULATORY AGENCIES LIKE THE FOOD AND DRUG ADMINISTRATION BY SERVING ON PATIENT PANELS AT 12 EVENTS. AMBASSADORS ALSO PARTICIPATED IN EDUCATION PROGRAMS TARGETING MEDICAL PROFESSIONALS, E.G., SPEAKING TO TRAINEES IN GENETIC COUNSELING PROGRAMS AND MEDICAL STUDENTS. FOR MORE INFORMATION VISIT CUREFA.ORG/AMBASSADORS.GROUP FARA HOSTED SEVERAL EDUCATION AND ENGAGEMENT INITIATIVES IN 2022. FOR EXAMPLE. FARA CONTINUED A VIDEO SERIES TO EDUCATE FA FAMILIES AND SUPPORTERS ON THE FARA GRANT PROGRAM. EACH EPISODE EXPLAINS A TYPE OF

RESEARCH FUNDED BY FARA IN A 5-MINUTE ANIMATED VIDEO, NARRATED BY AN FA

<u>Schedule O (Form 990) 2022</u> Page **2**

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

COMMUNITY MEMBER. FARA RELEASED SIX MINUTES OF SCIENCE VIDEOS IN 2022.

FARA ALSO OFFERED THE FLASH TALKS SERIES IN MAY WHICH ALLOWED YOUNG

INVESTIGATORS TO EXPLAIN THEIR RESEARCH IN LAYMAN TERMS AND TO ANSWER

QUESTIONS IN A VIRTUAL FORMAT. IN OCTOBER, FARA PUBLISHED A GUIDE FOR

CLINICAL TRIALS PARTICIPANTS. THIS 12-PAGE GUIDE CONTAINS INFORMATION

ON THE DIFFERENT PHASES OF CLINICAL TRIALS, TERMS TO KNOW, CLINICAL

TRIAL ETIQUETTE, SAFETY MONITORING, AND A GUIDE TO INFORMED CONSENT. IT

IS INTENDED TO HELP PEOPLE UNDERSTAND THE DRUG DEVELOPMENT PROCESS SO

THAT THEY CAN MAKE AN INFORMED DECISION ON PARTICIPATING IN CLINICAL

TRIALS.

FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:

WORKSHOPS, SYMPOSIA, & CONFERENCES

FARA HOSTED A HYBRID IN-PERSON AND VIRTUAL SINGLE-DAY EDUCATIONAL

SYMPOSIUM FOR >200 PATIENTS AND CAREGIVERS IN KING OF PRUSSIA, PA

(SEPTEMBER 25, 2022). THIS SYMPOSIUM PROVIDED AN OPPORTUNITY TO

EDUCATE THE PATIENT/FAMILY COMMUNITY ON RESEARCH ADVANCES, PROGRESS ON

CLINICAL TRIALS AND WAS A UNIQUE FORUM FOR PATIENTS AND RESEARCHERS TO

ENGAGE AND LEARN FROM EACH OTHER'S EXPERIENCES AND PERSPECTIVES.

INTERNATIONAL CONGRESS FOR ATAXIA RESEARCH

IN PARTNERSHIP WITH THE NATIONAL ATAXIA FOUNDATION AND ATAXIA UK, FARA

ALSO ORGANIZED AND SPONSORED THE INTERNATIONAL CONGRESS FOR ATAXIA

RESEARCH IN NOVEMBER 2022. OVER 450 PEOPLE ATTENDED, INCLUDING THOSE

FROM ACADEMIA, INDUSTRY, AND PATIENT ADVOCACY GROUPS. MORE THAN ONE

THIRD OF THE PARTICIPANTS WERE JUNIOR INVESTIGATORS WHICH SUPPORTS THE

GOAL OF BRINGING NEW TALENT TO THE FIELD AND GROWING THE NEXT

GENERATION OF ATAXIA RESEARCHERS. IN ADDITION TO THE OPPORTUNITY TO

<u>Schedule O (Form 990) 2022</u> Page **2**

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number 52-2122720

VIEW NEARLY 300 PRESENTATIONS, MOST ATTENDEES REPORTED MAKING NEW

CONTACTS, WHICH STIMULATES COLLABORATION AND PARTNERSHIPS. KEY

TAKEAWAYS FROM THE MEETING INCLUDED NEW INSIGHTS INTO THE DISEASE

MECHANISMS IN FA, POTENTIAL NEW BIOMARKERS, AND THE USE OF DIGITAL

ASSESSMENTS OF ATAXIA.

GENE THERAPY IN FA MEETING

IN 2022, FARA ORGANIZED A MEETING WITH THE FOOD AND DRUG ADMINISTRATION

(FDA) AND OVER A DOZEN COMPANIES WORKING ON GENE THERAPY AND GENE

EDITING PROGRAMS FOR FA. THE MEETING RESULTED IN ALIGNMENT WITH THE

REGULATORY AGENCY ON SEVERAL ASPECTS OF THESE INNOVATIVE APPROACHES.

EXPENSES \$ 222,693. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

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

COPIES OF 990 ARE DISTRIBUTED TO BOARD MEMBERS FOR REVIEW AND APPROVAL PRIOR TO FILING.

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

ALL NEW AND EXISTING BOARD MEMBERS ARE REQUIRED TO ANNUALLY REVIEW AND SIGN

A CONFLICT OF INTEREST POLICY AND REPORT DISCLOSURES.

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

EVALUATION AND COMPENSATION COMMITTEE PERFORMS EMPLOYEE EVALUATIONS AND

DETERMINES SALARY INCREASES ON A YEARLY BASIS FOR ALL EMPLOYEES. COMMITTEE

EXAMINES BENCHMARK DATA IN DETERMINING SALARIES FOR PRESIDENT, CEO, CSO AND

DIRECTOR FINANCE ADMINISTRATION.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:

<u>Schedule O (Form 990) 2022</u> Page **2**

Name of the organization

Employer identification number 52-2122720

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

AL, AK, AZ, AR, CA, CO, CT, FL, GA, IL, KS, KY, ME, MD, MS, MI, MN, MS, MO, NH, NJ, NM, NY, NC, ND

OH, OK, OR, PA, RI, SC, TN, UT, VA, WA, WV, WI, MA

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

FORM 990 IS AVAILABLE ON THE ORGANIZATION'S WEBSITE AS WELL AS

GUIDESTAR.ORG AND CHARITYNAVIGATOR.ORG FINANCIAL STATEMENTS ARE AVAILABLE

ON THE ORGANIZATION'S WEBSITE. THE GOVERNING DOCUMENTS, CONFLICT OF

FORM 990, PART XI, LINE 9, CHANGES IN NET ASSETS:

PRIOR YEAR GRANT REFUNDS INCLUDED IN SUPPORT ON FINANCIAL

INTEREST POLICY AND FORM 1023 ARE AVAILABLE UPON REOUEST.

STATEMENTS 74,430.

FORM 990, PART XII, LINE 2C

FARA'S AUDIT COMMITTEE CONSISTS OF THE FINANCE COMMITTEE, CEO AND ONE

AT-LARGE BOARD MEMBER. EACH YEAR THE AUDIT COMMITTEE SEEKS THE SERVICES

OF AN OUTSIDE ACCOUNTING FIRM AND CONTRACTS FOR A FULL AUDIT,

PREPARATION OF FINANCIAL STATEMENTS AND FILING OF THE 990. THE AUDIT

COMMITTEE IS RESPONSIBLE FOR REVIEWING RECOMMENDATIONS FROM THE AUDIT

AND PROPOSING NEW POLICIES AND PROCEDURES AS NECESSARY. THE AUDIT

COMMITTEE ALSO PARTICIPATES IN DETAILED REVIEW OF FINANCIAL STATEMENTS

PRIOR TO SHARING WITH THE FULL BOARD FOR A VOTE.

ALL 990 INFORMATION IS VERIFIED FOR ACCURACY AND COMPLETENESS BY FARA'S

DIRECTOR OF FINANCE, FARA'S VP OF FUNDRAISING AND COMMUNICATIONS AND

FARA'S CEO. THE VERIFIED DRAFT IS REVIEWED BY THE FARA FINANCE

COMMITTEE AND SUBMITTED TO THE FULL FARA BOARD FOR REVIEW AND APPROVAL

PRIOR TO FILING.

Schedule O (Form 990) 20	22				 Page 2
Name of the organization	FRIEDREICH'S	ATAXIA	RESEARCH	ALLIANCE	Employer identification number $52-2122720$
					_
					_

									Asset No.	FORM 9
									Description	FORM 990 PAGE 10
									Date Acquired	
									Method	
									Life	
									< = 0 O	
								_	Line No.	1
									Unadjusted Cost Or Basis	
									Bus % Excl	990
									Section 179 Expense	
									Reduction In Basis	
									Basis For Depreciation	
									Beginning Accumulated Depreciation	
									Current Sec 179 Expense	
									Current Year Deduction	
									Ending Accumulated Depreciation	

(D) - Asset disposed

* ITC, Salvage, Bonus, Commercial Revitalization Deduction, GO Zone

228111 04-01-22