

**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.  
 ▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2019**

Open to Public Inspection

**A For the 2019 calendar year, or tax year beginning and ending**

<b>B</b> Check if applicable:  <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	<b>C Name of organization</b> <b>FRIEDREICH'S ATAXIA RESEARCH ALLIANCE</b>		<b>D Employer identification number</b> <b>52-2122720</b>
	Doing business as		<b>E Telephone number</b> <b>484-879-6160</b>
	Number and street (or P.O. box if mail is not delivered to street address) Room/suite <b>P.O. BOX 1537</b>	<b>G Gross receipts \$</b> <b>8,071,522.</b>	
	City or town, state or province, country, and ZIP or foreign postal code <b>SPRINGFIELD, VA 22151</b>		<b>H(a) Is this a group return for subordinates?</b> <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No <b>H(b) Are all subordinates included?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions)
<b>F Name and address of principal officer:</b> <b>JENNIFER FARMER</b> <b>533 W UWCHLAN AVENUE, DOWNINGTOWN, PA 19335</b>		<b>H(c) Group exemption number</b> ▶	
<b>I Tax-exempt status:</b> <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) ( ) ◀ (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527			
<b>J Website:</b> ▶ <b>WWW.CUREFA.ORG</b>			
<b>K Form of organization:</b> <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶			<b>L Year of formation:</b> <b>1998</b>
			<b>M State of legal domicile:</b> <b>VA</b>

Part I Summary		Prior Year	Current Year
<b>Activities &amp; Governance</b>	<b>1</b> Briefly describe the organization's mission or most significant activities: <b>TO TREAT AND CURE FRIEDREICH'S ATAXIA BY ADVANCING RESEARCH, AWARENESS AND PARTNERSHIPS.</b>		
	<b>2</b> Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	<b>3</b> Number of voting members of the governing body (Part VI, line 1a)	<b>3</b>	<b>17</b>
	<b>4</b> Number of independent voting members of the governing body (Part VI, line 1b)	<b>4</b>	<b>15</b>
	<b>5</b> Total number of individuals employed in calendar year 2019 (Part V, line 2a)	<b>5</b>	<b>12</b>
	<b>6</b> Total number of volunteers (estimate if necessary)	<b>6</b>	<b>500</b>
	<b>7a</b> Total unrelated business revenue from Part VIII, column (C), line 12	<b>7a</b>	<b>0.</b>
<b>b</b> Net unrelated business taxable income from Form 990-T, line 39	<b>7b</b>	<b>0.</b>	
<b>Revenue</b>	<b>8</b> Contributions and grants (Part VIII, line 1h)	<b>7,662,625.</b>	<b>7,146,157.</b>
	<b>9</b> Program service revenue (Part VIII, line 2g)	<b>0.</b>	<b>0.</b>
	<b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d)	<b>40,534.</b>	<b>47,588.</b>
	<b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	<b>-99,614.</b>	<b>-116,156.</b>
	<b>12</b> Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	<b>7,603,545.</b>	<b>7,077,589.</b>
<b>Expenses</b>	<b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1-3)	<b>6,078,662.</b>	<b>6,011,313.</b>
	<b>14</b> Benefits paid to or for members (Part IX, column (A), line 4)	<b>0.</b>	<b>0.</b>
	<b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	<b>665,841.</b>	<b>724,265.</b>
	<b>16a</b> Professional fundraising fees (Part IX, column (A), line 11e)	<b>0.</b>	<b>0.</b>
	<b>b</b> Total fundraising expenses (Part IX, column (D), line 25) ▶ <b>128,511.</b>		
	<b>17</b> Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	<b>305,349.</b>	<b>746,853.</b>
<b>18</b> Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	<b>7,049,852.</b>	<b>7,482,431.</b>	
<b>19</b> Revenue less expenses. Subtract line 18 from line 12	<b>553,693.</b>	<b>-404,842.</b>	
<b>Net Assets or Fund Balances</b>	<b>20</b> Total assets (Part X, line 16)	<b>Beginning of Current Year</b> <b>5,108,402.</b>	<b>End of Year</b> <b>4,187,243.</b>
	<b>21</b> Total liabilities (Part X, line 26)	<b>130,166.</b>	<b>394,326.</b>
	<b>22</b> Net assets or fund balances. Subtract line 21 from line 20	<b>4,978,236.</b>	<b>3,792,917.</b>

**Part II Signature Block**

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

<b>Sign Here</b>	Signature of officer	Date			
	<b>JENNIFER FARMER, CHIEF EXECUTIVE OFFICER</b> Type or print name and title				
<b>Paid Preparer Use Only</b>	Print/Type preparer's name <b>EDWARD FRONCZKOWSKI CPA</b>	Preparer's signature	Date	Check if self-employed <input type="checkbox"/>	PTIN <b>P01259092</b>
	Firm's name ▶ <b>MAILLIE LLP</b>	Firm's EIN ▶ <b>23-1518888</b>		Phone no. ( <b>610</b> ) <b>696-4353</b>	
Firm's address ▶ <b>600 WILLOWBROOK LANE, SUITE 624 WEST CHESTER, PA 19382</b>					

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

Part III Statement of Program Service Accomplishments

Check if Schedule O contains a response or note to any line in this Part III [X]

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, GOV'T 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? [ ] Yes [X] No

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? [ ] Yes [X] No

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code: ) (Expenses \$ 5,518,193. including grants of \$ 5,309,603.) (Revenue \$ ) RESEARCH AND GRANT PROGRAM

FARA AWARDED OVER \$6 MILLION IN RESEARCH FUNDING IN 2019. IN 2019, 38 LETTERS OF INTENT WERE SUBMITTED TO FARA AND 24 OF THESE WERE SELECTED FOR SUBMISSION OF A FULL GRANT APPLICATION. AFTER PEER REVIEW, 15 NEW GRANTS WERE FUNDED, WHILE 10 GRANTS APPROVED IN PREVIOUS YEARS RECEIVED CONTINUED FUNDING. FIVE OF THE NEW GRANTS WERE AWARDED TO INVESTIGATORS WHO HAD NOT PREVIOUSLY RECEIVED FARA FUNDING, INCLUDING 2 JUNIOR INVESTIGATORS. CURRENTLY, RESEARCHERS IN 7 COUNTRIES ARE RECEIVING FUNDING FROM THE FARA RESEARCH GRANT PROGRAM. FARA ALSO PROVIDES ONGOING SUPPORT FOR THE COLLABORATIVE CLINICAL RESEARCH NETWORK IN FA (CCRN), THE FA CENTER OF EXCELLENCE, BIOMARKER DEVELOPMENT CONSORTIA

4b (Code: ) (Expenses \$ 528,576. including grants of \$ 2,500.) (Revenue \$ ) RESEARCH CONFERENCES

FARA ORGANIZES AND SUPPORTS A NUMBER OF CONFERENCES TO IMPROVE SHARING OF KNOWLEDGE, INSIGHTS AND ADVANCES AND BUILD COLLABORATIONS AND SYNERGISTIC CONNECTIONS BETWEEN FA RESEARCHERS, INDUSTRY AND GOVERNMENT PARTNERS AND PATIENTS.

INTERNATIONAL ATAXIA RESEARCH CONFERENCE FARA IN PARTNERSHIP WITH ATAXIA UK, FARA AUSTRALIA AND GOFAR HOSTED THE 2019 INTERNATIONAL ATAXIA RESEARCH CONFERENCE, NOVEMBER 14-16, 2019; A TWO AND A HALF DAY CONFERENCE WITH 50 ORAL PRESENTATIONS, 200 POSTER PRESENTERS WITH SELECTED FLASH TALKS AND A MENTORING SESSION FOR YOUNG

4c (Code: ) (Expenses \$ 277,770. including grants of \$ ) (Revenue \$ ) EDUCATION, AWARENESS & OUTREACH PROGRAMS

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 ALSO HOSTED A VIDEO INTERVIEW SERIES, WITH RESEARCHERS AT THE INTERNATIONAL ATAXIA RESEARCH CONFERENCE, TO EDUCATE AND INFORM THE COMMUNITY ABOUT THE LATEST DEVELOPMENTS IN FA RESEARCH AND SOME OF THE RESULTS OF FUNDED GRANTS.

4d Other program services (Describe on Schedule O.) (Expenses \$ 844,106. including grants of \$ 699,210.) (Revenue \$ )

4e Total program service expenses 7,168,645.

**Part IV Checklist of Required Schedules**

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

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

	Yes	No
<b>22</b> 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? <i>If "Yes," complete Schedule I, Parts I and III</i> .....		X
<b>23</b> 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? <i>If "Yes," complete Schedule J</i> .....		X
<b>24a</b> Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i> .....		X
<b>24b</b> Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? .....		
<b>24c</b> Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? .....		
<b>24d</b> Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? .....		
<b>25a</b> <b>Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations.</b> Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i> .....		X
<b>25b</b> Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i> .....		X
<b>26</b> Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part II</i> .....		X
<b>27</b> 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? <i>If "Yes," complete Schedule L, Part III</i> .....		X
<b>28</b> Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions, for applicable filing thresholds, conditions, and exceptions):		
<b>28a</b> A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>28b</b> A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>28c</b> A 35% controlled entity of one or more individuals and/or organizations described in lines 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i> .....	X	
<b>29</b> Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> .....	X	
<b>30</b> Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i> .....		X
<b>31</b> Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> .....		X
<b>32</b> Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i> .....		X
<b>33</b> Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i> .....		X
<b>34</b> Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i> .....		X
<b>35a</b> Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
<b>35b</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)? <i>If "Yes," complete Schedule R, Part V, line 2</i> .....		
<b>36</b> <b>Section 501(c)(3) organizations.</b> Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i> .....		X
<b>37</b> Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i> .....		X
<b>38</b> Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? .....	X	

**Note:** All Form 990 filers are required to complete Schedule O

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

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

	Yes	No
<b>1a</b> Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable .....		
<b>1b</b> Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable .....		
<b>1c</b> Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? .....	X	

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

Table with columns for question number, question text, and Yes/No columns. Includes questions 2a through 16 regarding employee reporting, tax returns, unrelated business income, foreign accounts, prohibited transactions, and charitable contributions.

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.

Check if Schedule O contains a response or note to any line in this Part VI [X]

Section A. Governing Body and Management

Table with 4 columns: Question, 1a, 1b, Yes, No. Rows include: 1a Enter the number of voting members... 17; 1b Enter the number of voting members... 15; 2 Did any officer, director, trustee... X; 3 Did the organization delegate control... X; 4 Did the organization make any significant changes... X; 5 Did the organization become aware... X; 6 Did the organization have members... X; 7a Did the organization have members... X; 7b Are any governance decisions... X; 8a The governing body... X; 8b Each committee... X; 9 Is there any officer, director, trustee... X.

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)

Table with 4 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters... X; 10b If "Yes," did the organization have written policies...; 11a Has the organization provided a complete copy... X; 11b Describe in Schedule O the process...; 12a Did the organization have a written conflict of interest policy... X; 12b Were officers, directors, or trustees... X; 12c Did the organization regularly and consistently monitor... X; 13 Did the organization have a written whistleblower policy... X; 14 Did the organization have a written document retention... X; 15 Did the process for determining compensation...; 15a The organization's CEO... X; 15b Other officers or key employees... X; 16a Did the organization invest in, contribute assets to... X; 16b If "Yes," did the organization follow a written policy... X.

Section C. Disclosure

- 17 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
18 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 [X] Another's website [X] Upon request [ ] Other (explain on Schedule O)
19 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.
20 State the name, address, and telephone number of the person who possesses the organization's books and records JENNIFER FARMER - 484-879-6160
533 W. UWCHLAN AVENUE, DOWNINGTOWN, PA 19335

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

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

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

**1a** Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

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

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) EDWARD RAMSEY DIRECTOR	0.00	X						0.	0.	0.
(2) MARILYN E. DOWNING SECRETARY/ DIRECTOR	0.00	X		X				0.	0.	0.
(3) RUTH ACTON TREASURER/ DIRECTOR	25.00	X		X				40,000.	0.	10,292.
(4) JENNIFER GOOD DIRECTOR	0.00	X						0.	0.	0.
(5) PAUL AVERY CHAIRMAN/ DIRECTOR	0.00	X		X				0.	0.	0.
(6) DR. HOLLY HEDRICK DIRECTOR	0.00	X						0.	0.	0.
(7) GEOFFREY LEVITT DIRECTOR	0.00	X						0.	0.	0.
(8) DR. STEVE KLASKO DIRECTOR	0.00	X						0.	0.	0.
(9) THOMAS HAMILTON DIRECTOR	0.00	X						0.	0.	0.
(10) DR. SANJAY BIDICHANDANI SCIENTIFIC DIRECTOR	0.00	X						0.	0.	0.
(11) DEREK G. HENNECKE DIRECTOR	0.00	X						0.	0.	0.
(12) DR. JAMES MCARTHUR SCIENTIFIC DIRECTOR	0.00	X						0.	0.	0.
(13) TONY PLOHOROS DIRECTOR	0.00	X						0.	0.	0.
(14) PATRICK RITSCHER DIRECTOR	0.00	X						0.	0.	0.
(15) RONALD BARTEK PRESIDENT/DIRECTOR	40.00	X		X				100,000.	0.	3,049.
(16) BRIGID BRENNAN DIRECTOR	0.00	X						0.	0.	0.
(17) DR. JAMES R. RUSCHE SCIENTIFIC DIRECTOR	0.00	X						0.	0.	0.





**Part VIII Statement of Revenue**

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

			(A)	(B)	(C)	(D)	
			Total revenue	Related or exempt function revenue	Unrelated business revenue	Revenue excluded from tax under sections 512 - 514	
<b>Contributions, Gifts, Grants and Other Similar Amounts</b>	1 a	Federated campaigns	1a 14,305.				
	b	Membership dues	1b				
	c	Fundraising events	1c 3,830,337.				
	d	Related organizations	1d				
	e	Government grants (contributions)	1e				
	f	All other contributions, gifts, grants, and similar amounts not included above	1f 3,301,515.				
	g	Noncash contributions included in lines 1a-1f	1g \$ 6,944.				
	h	<b>Total.</b> Add lines 1a-1f		7,146,157.			
<b>Program Service Revenue</b>			<b>Business Code</b>				
	2 a						
	b						
	c						
	d						
	e						
	f	All other program service revenue					
g	<b>Total.</b> Add lines 2a-2f						
<b>Other Revenue</b>	3	Investment income (including dividends, interest, and other similar amounts)		45,345.		45,345.	
	4	Income from investment of tax-exempt bond proceeds					
	5	Royalties					
	6 a	Gross rents	6a	(i) Real (ii) Personal			
		Less: rental expenses	6b				
		Rental income or (loss)	6c				
	d	Net rental income or (loss)					
	7 a	Gross amount from sales of assets other than inventory	7a	(i) Securities (ii) Other			
		Less: cost or other basis and sales expenses	7b				
		Gain or (loss)	7c				
	d	Net gain or (loss)			2,243.	2,243.	
	8 a	Gross income from fundraising events (not including \$ 3,830,337. of contributions reported on line 1c). See Part IV, line 18	8a				
		Less: direct expenses	8b				
		Net income or (loss) from fundraising events			-129,629.		-129,629.
	9 a	Gross income from gaming activities. See Part IV, line 19	9a				
Less: direct expenses		9b					
Net income or (loss) from gaming activities							
10 a	Gross sales of inventory, less returns and allowances	10a					
	Less: cost of goods sold	10b					
	Net income or (loss) from sales of inventory						
<b>Miscellaneous Revenue</b>	11 a <b>MISCELLANEOUS REVENUE</b>		<b>Business Code</b>				
			900099	13,473.		13,473.	
	b						
	c						
	d	All other revenue					
e	<b>Total.</b> Add lines 11a-11d			13,473.			
12	<b>Total revenue.</b> See instructions			7,077,589.	0.	0.	
						-68,568.	

**Part IX Statement of Functional Expenses**

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	4,411,532.	4,411,532.		
2 Grants and other assistance to domestic individuals. See Part IV, line 22				
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	1,599,781.	1,599,781.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	309,265.	209,764.	62,818.	36,683.
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages	415,000.	342,866.	29,097.	43,037.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits				
10 Payroll taxes				
11 Fees for services (nonemployees):				
a Management				
b Legal				
c Accounting	14,200.		14,200.	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees	15,544.		15,544.	
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O.)	49,437.	37,980.	4,678.	6,779.
12 Advertising and promotion	5,480.	5,000.	455.	25.
13 Office expenses	28,342.	14,672.	6,964.	6,706.
14 Information technology				
15 Royalties				
16 Occupancy	33,440.	19,109.	4,777.	9,554.
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	424,249.	386,551.	35,846.	1,852.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	386.		386.	
23 Insurance	8,393.		2,816.	5,577.
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a <b>FACILITIES &amp; EQUIPMENT</b>	98,424.	95,440.	2,984.	0.
b <b>BOOKS, SUBSCRIPTIONS &amp;</b>	38,468.	30,952.	2,613.	4,903.
c <b>CREDIT CARD &amp; BANK FEES</b>	19,187.	9,698.	748.	8,741.
d <b>BUSINESS REGISTRATION F</b>	5,383.		834.	4,549.
e All other expenses	5,920.	5,300.	515.	105.
25 <b>Total functional expenses.</b> Add lines 1 through 24e	7,482,431.	7,168,645.	185,275.	128,511.
26 <b>Joint costs.</b> 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)

**Part X Balance Sheet**

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

		(A) Beginning of year		(B) End of year
<b>Assets</b>	<b>1</b> Cash - non-interest-bearing .....	2,162,521.	<b>1</b>	1,821,067.
	<b>2</b> Savings and temporary cash investments .....		<b>2</b>	
	<b>3</b> Pledges and grants receivable, net .....	195,821.	<b>3</b>	191,637.
	<b>4</b> Accounts receivable, net .....		<b>4</b>	
	<b>5</b> Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons .....		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B) .....		<b>6</b>	
	<b>7</b> Notes and loans receivable, net .....		<b>7</b>	
	<b>8</b> Inventories for sale or use .....		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges .....	37,323.	<b>9</b>	35,477.
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....	<b>10a</b> 7,135.		
	<b>b</b> Less: accumulated depreciation .....	<b>10b</b> 7,015.	506.	<b>10c</b> 120.
	<b>11</b> Investments - publicly traded securities .....	1,620,731.	<b>11</b>	2,128,027.
	<b>12</b> Investments - other securities. See Part IV, line 11 .....		<b>12</b>	
	<b>13</b> Investments - program-related. See Part IV, line 11 .....	1,091,500.	<b>13</b>	10,915.
	<b>14</b> Intangible assets .....		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11 .....		<b>15</b>	
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 33) .....	5,108,402.	<b>16</b>	4,187,243.	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses .....	130,166.	<b>17</b>	385,252.
	<b>18</b> Grants payable .....		<b>18</b>	
	<b>19</b> Deferred revenue .....		<b>19</b>	9,074.
	<b>20</b> Tax-exempt bond liabilities .....		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D .....		<b>21</b>	
	<b>22</b> Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons .....		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties .....		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties .....		<b>24</b>	
	<b>25</b> Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D .....		<b>25</b>	
	<b>26 Total liabilities.</b> Add lines 17 through 25 .....	130,166.	<b>26</b>	394,326.
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow FASB ASC 958, check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27, 28, 32, and 33.</b>			
	<b>27</b> Net assets without donor restrictions .....	4,914,855.	<b>27</b>	3,668,941.
	<b>28</b> Net assets with donor restrictions .....	63,381.	<b>28</b>	123,976.
	<b>Organizations that do not follow FASB ASC 958, check here</b> <input type="checkbox"/> <b>and complete lines 29 through 33.</b>			
	<b>29</b> Capital stock or trust principal, or current funds .....		<b>29</b>	
	<b>30</b> Paid-in or capital surplus, or land, building, or equipment fund .....		<b>30</b>	
	<b>31</b> Retained earnings, endowment, accumulated income, or other funds .....		<b>31</b>	
	<b>32 Total net assets or fund balances</b> .....	4,978,236.	<b>32</b>	3,792,917.
<b>33 Total liabilities and net assets/fund balances</b> .....	5,108,402.	<b>33</b>	4,187,243.	

Form 990 (2019)

**Part XI Reconciliation of Net Assets**

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	7,077,589.
2	Total expenses (must equal Part IX, column (A), line 25)	2	7,482,431.
3	Revenue less expenses. Subtract line 2 from line 1	3	-404,842.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	4,978,236.
5	Net unrealized gains (losses) on investments	5	307,052.
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	-1,087,529.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	3,792,917.

**Part XII Financial Statements and Reporting**

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

	Yes	No
1 Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.		
2a Were the organization's financial statements compiled or reviewed by an independent accountant? _____ 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: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
b Were the organization's financial statements audited by an independent accountant? _____ 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: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	X	
c 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? _____ If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	X	
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? _____		X
b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits _____		

Form 990 (2019)

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

Department of the Treasury  
Internal Revenue Service

**Public Charity Status and Public Support**

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

▶ Attach to Form 990 or Form 990-EZ.

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2019**

Open to Public  
Inspection

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

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

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1  A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i).**
- 2  A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E (Form 990 or 990-EZ).)
- 3  A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**
- 4  A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state: \_\_\_\_\_
- 5  An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II.)
- 6  A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**
- 7  An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
- 8  A community trust described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
- 9  An 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 university: \_\_\_\_\_
- 10  An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions - subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2).** (Complete Part III.)
- 11  An organization organized and operated exclusively to test for public safety. See **section 509(a)(4).**
- 12  An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2).** See **section 509(a)(3).** Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
  - a  **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.**
  - 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.**
  - 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.**
  - d  **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.**
  - e  Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.

f Enter the number of supported organizations .....

g Provide the following information about the supported organization(s).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
<b>Total</b>						

**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.)

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....	5,701,123.	5,388,847.	7,518,776.	7,662,625.	7,146,206.	33,417,577.
<b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....						
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge .....						
<b>4 Total.</b> Add lines 1 through 3 .....	5,701,123.	5,388,847.	7,518,776.	7,662,625.	7,146,206.	33,417,577.
<b>5</b> 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) .....						5,444,432.
<b>6 Public support.</b> Subtract line 5 from line 4.						27,973,145.

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
<b>7</b> Amounts from line 4 .....	5,701,123.	5,388,847.	7,518,776.	7,662,625.	7,146,206.	33,417,577.
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....	19,755.	29,213.	37,283.	42,296.	45,345.	173,892.
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on .....						
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....						
<b>11 Total support.</b> Add lines 7 through 10						33,591,469.
<b>12</b> Gross receipts from related activities, etc. (see instructions) .....					12	
<b>13 First five years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and <b>stop here</b> .....						<input type="checkbox"/>

**Section C. Computation of Public Support Percentage**

<b>14</b> Public support percentage for 2019 (line 6, column (f) divided by line 11, column (f)) .....	<b>14</b>	83.27 %
<b>15</b> Public support percentage from 2018 Schedule A, Part II, line 14 .....	<b>15</b>	89.13 %
<b>16a 33 1/3% support test - 2019.</b> If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization .....		<input checked="" type="checkbox"/>
<b>b 33 1/3% support test - 2018.</b> If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization .....		<input type="checkbox"/>
<b>17a 10% -facts-and-circumstances test - 2019.</b> If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and <b>stop here.</b> Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization .....		<input type="checkbox"/>
<b>b 10% -facts-and-circumstances test - 2018.</b> If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and <b>stop here.</b> Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization .....		<input type="checkbox"/>
<b>18 Private foundation.</b> If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions .....		<input type="checkbox"/>

**Part III Support Schedule for Organizations Described in Section 509(a)(2)**

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

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....						
<b>2</b> Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose .....						
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 .....						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge .....						
<b>6 Total.</b> Add lines 1 through 5 .....						
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons .....						
<b>b</b> Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year .....						
<b>c</b> Add lines 7a and 7b .....						
<b>8 Public support.</b> (Subtract line 7c from line 6.)						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ►	(a) 2015	(b) 2016	(c) 2017	(d) 2018	(e) 2019	(f) Total
<b>9</b> Amounts from line 6 .....						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources .....						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 .....						
<b>c</b> Add lines 10a and 10b .....						
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on .....						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....						
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.)						

**14 First five years.** If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here**

**Section C. Computation of Public Support Percentage**

<b>15</b> Public support percentage for 2019 (line 8, column (f), divided by line 13, column (f)) .....	<b>15</b>	%
<b>16</b> Public support percentage from 2018 Schedule A, Part III, line 15 .....	<b>16</b>	%

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for 2019 (line 10c, column (f), divided by line 13, column (f)) .....	<b>17</b>	%
<b>18</b> Investment income percentage from 2018 Schedule A, Part III, line 17 .....	<b>18</b>	%

**19a 33 1/3% support tests - 2019.** If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

**b 33 1/3% support tests - 2018.** If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

**20 Private foundation.** If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

**Part IV Supporting Organizations**

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

**Section A. All Supporting Organizations**

	Yes	No
<b>1</b> Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>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.</i>		
<b>2</b> Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
<b>3a</b> Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer (b) and (c) below.</i>		
<b>b</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)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>		
<b>c</b> Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>		
<b>4a</b> Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>		
<b>b</b> Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>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.</i>		
<b>c</b> 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)? <i>If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i>		
<b>5a</b> Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>		
<b>b</b> <b>Type I or Type II only.</b> Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
<b>c</b> <b>Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
<b>6</b> 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? <i>If "Yes," provide detail in Part VI.</i>		
<b>7</b> 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? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
<b>8</b> Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
<b>9a</b> 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))? <i>If "Yes," provide detail in Part VI.</i>		
<b>b</b> Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i>		
<b>c</b> Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i>		
<b>10a</b> 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)? <i>If "Yes," answer 10b below.</i>		
<b>b</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.)		



**Part IV Supporting Organizations** *(continued)*

	Yes	No
<b>11</b> Has the organization accepted a gift or contribution from any of the following persons?		
<b>a</b> A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?		
<b>11a</b>		
<b>b</b> A family member of a person described in (a) above?		
<b>11b</b>		
<b>c</b> A 35% controlled entity of a person described in (a) or (b) above? <i>If "Yes" to a, b, or c, provide detail in Part VI.</i>		
<b>11c</b>		

**Section B. Type I Supporting Organizations**

	Yes	No
<b>1</b> Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
<b>1</b>		
<b>2</b> 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? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.</i>		
<b>2</b>		

**Section C. Type II Supporting Organizations**

	Yes	No
<b>1</b> 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)? <i>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).</i>		
<b>1</b>		

**Section D. All Type III Supporting Organizations**

	Yes	No
<b>1</b> 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?		
<b>1</b>		
<b>2</b> 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? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
<b>2</b>		
<b>3</b> By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		
<b>3</b>		

**Section E. Type III Functionally Integrated Supporting Organizations**

<b>1</b> Check the box next to the method that the organization used to satisfy the Integral Part Test during the year <i>(see instructions)</i> .		
<b>a</b> <input type="checkbox"/> The organization satisfied the Activities Test. <i>Complete line 2 below.</i>		
<b>b</b> <input type="checkbox"/> The organization is the parent of each of its supported organizations. <i>Complete line 3 below.</i>		
<b>c</b> <input type="checkbox"/> The organization supported a governmental entity. <i>Describe in Part VI how you supported a government entity (see instructions).</i>		
<b>2</b> Activities Test. <b>Answer (a) and (b) below.</b>	Yes	No
<b>a</b> 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? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
<b>2a</b>		
<b>b</b> Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
<b>2b</b>		
<b>3</b> Parent of Supported Organizations. <b>Answer (a) and (b) below.</b>		
<b>a</b> Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>Provide details in Part VI.</i>		
<b>3a</b>		
<b>b</b> Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>		
<b>3b</b>		

**Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations**

1  Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (explain in Part VI). **See instructions.** All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

<b>Section A - Adjusted Net Income</b>		(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	<b>Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4)	8	
<b>Section B - Minimum Asset Amount</b>		(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	
c	Fair market value of other non-exempt-use assets	1c	
d	<b>Total</b> (add lines 1a, 1b, and 1c)	1d	
e	<b>Discount</b> claimed for blockage or other factors (explain in detail in <b>Part VI</b> ):		
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 1-1/2% 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 .035.	6	
7	Recoveries of prior-year distributions	7	
8	<b>Minimum Asset Amount</b> (add line 7 to line 6)	8	
<b>Section C - Distributable Amount</b>			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1	
2	Enter 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	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6	
7	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).		

**Part V** Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations *(continued)*

Section D - Distributions	Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	
4 Amounts paid to acquire exempt-use assets	
5 Qualified set-aside amounts (prior IRS approval required)	
6 Other distributions (describe in Part VI). See instructions.	
7 <b>Total annual distributions.</b> Add lines 1 through 6.	
8 Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.	
9 Distributable amount for 2019 from Section C, line 6	
10 Line 8 amount divided by line 9 amount	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2019	(iii) Distributable Amount for 2019
1 Distributable amount for 2019 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2019 (reasonable cause required- explain in Part VI). See instructions.			
3 Excess distributions carryover, if any, to 2019			
a From 2014			
b From 2015			
c From 2016			
d From 2017			
e From 2018			
f <b>Total</b> of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2019 distributable amount			
i Carryover from 2014 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4 Distributions for 2019 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2019 distributable amount			
c Remainder. Subtract lines 4a and 4b from 4.			
5 Remaining underdistributions for years prior to 2019, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions.			
6 Remaining underdistributions for 2019. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.			
7 <b>Excess distributions carryover to 2020.</b> Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2015			
b Excess from 2016			
c Excess from 2017			
d Excess from 2018			
e Excess from 2019			

Schedule A (Form 990 or 990-EZ) 2019



**Schedule B**

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

Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

▶ Attach to Form 990, Form 990-EZ, or Form 990-PF.  
▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2019**

Name of the organization

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE**

Employer identification number

**52-2122720**

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

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

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

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

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

501(c)(3) taxable private foundation

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

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

**General Rule**

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

**Special Rules**

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

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

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

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

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

**Political Campaign and Lobbying Activities**

OMB No. 1545-0047

**2019**

**Open to Public Inspection**

Department of the Treasury  
Internal Revenue Service

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](http://www.irs.gov/Form990) for instructions and the latest information.**

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 <b>FRIEDREICH'S ATAXIA RESEARCH ALLIANCE</b>	Employer identification number <b>52-2122720</b>
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**Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.**

- 1 Provide a description of the organization's direct and indirect political campaign activities in Part IV.
- 2 Political campaign activity expenditures ..... ▶ \$ \_\_\_\_\_
- 3 Volunteer hours for political campaign activities ..... \_\_\_\_\_

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

- 1 Enter the amount of any excise tax incurred by the organization under section 4955 ..... ▶ \$ \_\_\_\_\_
  - 2 Enter the amount of any excise tax incurred by organization managers under section 4955 ..... ▶ \$ \_\_\_\_\_
  - 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? .....  Yes  No
  - 4a Was a correction made? .....  Yes  No
- b If "Yes," describe in Part IV.

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

- 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities ..... ▶ \$ \_\_\_\_\_
- 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt 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? .....  Yes  No
- 5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC). If additional space is needed, provide information in Part IV.

(a) Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds. If none, enter -0-.	(e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-.

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Schedule C (Form 990 or 990-EZ) 2019

LHA

932041 11-26-19

**Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).**

**A** Check  if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).

**B** Check  if the filing organization checked box A and "limited control" provisions apply.

<b>Limits on Lobbying Expenditures</b> (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals												
<b>1a</b> Total lobbying expenditures to influence public opinion (grassroots lobbying) .....		7,316.													
<b>b</b> Total lobbying expenditures to influence a legislative body (direct lobbying) .....		4,943.													
<b>c</b> Total lobbying expenditures (add lines 1a and 1b) .....		12,259.													
<b>d</b> Other exempt purpose expenditures .....		8,332,510.													
<b>e</b> Total exempt purpose expenditures (add lines 1c and 1d) .....		8,344,769.													
<b>f</b> Lobbying nontaxable amount. Enter the amount from the following table in both columns.		567,238.													
<table border="1" style="width: 100%;"> <thead> <tr> <th style="text-align: left;">If the amount on line 1e, column (a) or (b) is:</th> <th style="text-align: left;">The lobbying nontaxable amount is:</th> </tr> </thead> <tbody> <tr> <td>Not over \$500,000</td> <td>20% of the amount on line 1e.</td> </tr> <tr> <td>Over \$500,000 but not over \$1,000,000</td> <td>\$100,000 plus 15% of the excess over \$500,000.</td> </tr> <tr> <td>Over \$1,000,000 but not over \$1,500,000</td> <td>\$175,000 plus 10% of the excess over \$1,000,000.</td> </tr> <tr> <td>Over \$1,500,000 but not over \$17,000,000</td> <td>\$225,000 plus 5% of the excess over \$1,500,000.</td> </tr> <tr> <td>Over \$17,000,000</td> <td>\$1,000,000.</td> </tr> </tbody> </table>		If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:	Not over \$500,000	20% of the amount on line 1e.	Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.	Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.	Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.	Over \$17,000,000	\$1,000,000.		
If the amount on line 1e, column (a) or (b) is:	The lobbying nontaxable amount is:														
Not over \$500,000	20% of the amount on line 1e.														
Over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.														
Over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.														
Over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.														
Over \$17,000,000	\$1,000,000.														
<b>g</b> Grassroots nontaxable amount (enter 25% of line 1f) .....		141,810.													
<b>h</b> Subtract line 1g from line 1a. If zero or less, enter -0- .....		0.													
<b>i</b> Subtract line 1f from line 1c. If zero or less, enter -0- .....		0.													
<b>j</b> If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year? .....			<input type="checkbox"/> Yes <input type="checkbox"/> No												

**4-Year Averaging Period Under Section 501(h)**  
(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the separate instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2016	(b) 2017	(c) 2018	(d) 2019	(e) Total
<b>2a</b> Lobbying nontaxable amount	465,526.	531,374.	481,734.	567,238.	2,045,872.
<b>b</b> Lobbying ceiling amount (150% of line 2a, column (e))					3,068,808.
<b>c</b> Total lobbying expenditures	6,200.	6,500.	8,925.	12,259.	33,884.
<b>d</b> Grassroots nontaxable amount	116,382.	132,844.	120,434.	141,810.	511,470.
<b>e</b> Grassroots ceiling amount (150% of line 2d, column (e))					767,205.
<b>f</b> Grassroots lobbying expenditures	3,700.	3,879.	5,326.	7,316.	20,221.

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

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

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

	Yes	No
<b>1</b> Were substantially all (90% or more) dues received nondeductible by members?	<b>1</b>	
<b>2</b> Did the organization make only in-house lobbying expenditures of \$2,000 or less?	<b>2</b>	
<b>3</b> Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year?	<b>3</b>	

**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."**

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

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

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**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](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2019**

Open to Public Inspection

Name of the organization

FRIEDREICH 'S ATAXIA RESEARCH ALLIANCE

Employer identification number

52-2122720

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

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year .....		
2 Aggregate value of contributions to (during year) .....		
3 Aggregate value of grants from (during year) .....		
4 Aggregate value at end of year .....		
5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? .....	<input type="checkbox"/> Yes	<input type="checkbox"/> No
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? .....	<input type="checkbox"/> Yes	<input type="checkbox"/> No

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

1 Purpose(s) of conservation easements held by the organization (check all that apply).

Preservation of land for public use (for example, recreation or education)     Preservation of a historically important land area

Protection of natural habitat     Preservation of a certified historic structure

Preservation of open space

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

	Held at the End of the Tax Year
a Total number of conservation easements .....	2a
b Total acreage restricted by conservation easements .....	2b
c Number of conservation easements on a certified historic structure included in (a) .....	2c
d Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register .....	2d

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ▶ \_\_\_\_\_

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

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? .....

Yes     No

6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ▶ \_\_\_\_\_

7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year ▶ \$ \_\_\_\_\_

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? .....

Yes     No

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

**Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items.

b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) 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 treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items:

a 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) 2019

932051 10-02-19

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

- 3 Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply):
- a  Public exhibition
  - b  Scholarly research
  - c  Preservation for future generations
  - d  Loan or exchange program
  - e  Other \_\_\_\_\_
- 4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection?  Yes  No

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

- 1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X?  Yes  No
- b If "Yes," explain the arrangement in Part XIII and complete the following table:
- |                                 | Amount |
|---------------------------------|--------|
| c Beginning balance             | 1c     |
| d Additions during the year     | 1d     |
| e Distributions during the year | 1e     |
| f Ending balance                | 1f     |
- 2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?  Yes  No
- b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided on Part XIII

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
- a Board designated or quasi-endowment  \_\_\_\_\_ %
  - b Permanent endowment  \_\_\_\_\_ %
  - c Term endowment  \_\_\_\_\_ %
- The percentages on lines 2a, 2b, and 2c should equal 100%.
- 3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:
- |  | Yes    | No |
|--|--------|----|
| (i) Unrelated organizations  | 3a(i)  |    |
| (ii) Related organizations   | 3a(ii) |    |
| b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R? | 3b     |    |
- 4 Describe in Part XIII the intended uses of the organization's endowment funds.

**Part VI Land, Buildings, and Equipment.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other		7,135.	7,015.	120.
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)				120.

**Part VII Investments - Other Securities.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(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) .....		
<b>Total.</b> (Col. (b) must equal Form 990, Part X, col. (B) line 12.) ▶		

**Part VIII Investments - Program Related.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
<b>Total.</b> (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 11d. See Form 990, Part X, line 15.

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 15.) ▶	

**Part X Other Liabilities.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII...

**Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements		1	8,224,491.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	307,052.	
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d	862,338.	
e	Add lines 2a through 2d	2e		1,169,390.
3	Subtract line 2e from line 1	3		7,055,101.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b	22,488.	
c	Add lines 4a and 4b	4c		22,488.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)	5		7,077,589.

**Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements		1	9,409,810.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a		
b	Prior year adjustments	2b		
c	Other losses	2c	1,080,585.	
d	Other (Describe in Part XIII.)	2d	862,338.	
e	Add lines 2a through 2d	2e		1,942,923.
3	Subtract line 2e from line 1	3		7,466,887.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:			
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a		
b	Other (Describe in Part XIII.)	4b	15,544.	
c	Add lines 4a and 4b	4c		15,544.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)	5		7,482,431.

**Part XIII Supplemental Information.**

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

PART XI, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENTS EXPENSE

PART XI, LINE 4B - OTHER ADJUSTMENTS:

INVESTMENT MANAGEMENT FEES

NONCASH CONTRIBUTIONS

PART XII, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENTS EXPENSE

PART XII, LINE 4B - OTHER ADJUSTMENTS:



**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](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2019**

Open to Public  
Inspection

Name of the organization <b>FRIEDREICH'S ATAXIA RESEARCH ALLIANCE</b>	Employer identification number <b>52-2122720</b>
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**Part I** General Information on Activities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

**1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? .....  **Yes**  **No**

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

**3 Activities per Region.** (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
EUROPE	0	0	GRANTS TO RECIPIENTS LOCATED IN REGION	RESEARCH AND GRANT PROGRAM	991,457.
EAST ASIA AND THE PACIFIC	0	0	GRANTS TO RECIPIENTS LOCATED IN REGION	RESEARCH AND GRANT PROGRAM	533,324.
SOUTH AMERICA	0	0	GRANTS TO RECIPIENTS LOCATED IN REGION	RESEARCH AND GRANT PROGRAM	72,500.
CANADA	0	0	GRANTS TO RECIPIENTS LOCATED IN REGION	RESEARCH AND GRANT PROGRAM	2,500.
<b>3 a</b> Subtotal .....	0	0			1,599,781.
<b>b</b> Total from continuation sheets to Part I .....	0	0			0.
<b>c Totals</b> (add lines 3a and 3b) .....	0	0			1,599,781.

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

Schedule F (Form 990) 2019

**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.

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
			EAST ASIA AND THE PACIFIC	MEDICAL RESEARCH	70,300.	WIRE	0.		
			EUROPE	MEDICAL RESEARCH	79,620.	WIRE	0.		
			EUROPE	MEDICAL RESEARCH	141,761.	WIRE	0.		
			EUROPE	MEDICAL RESEARCH	125,000.	WIRE	0.		
			SOUTH AMERICA - ARGENTINA, BOLIVIA, BRAZIL, CHILE, COLUMBIA,	MEDICAL RESEARCH	72,500.	WIRE	0.		
			EAST ASIA AND THE PACIFIC	MEDICAL RESEARCH	187,184.	WIRE	0.		
			EUROPE	MEDICAL RESEARCH	75,000.	WIRE	0.		
			EAST ASIA AND THE PACIFIC	MEDICAL RESEARCH	138,734.	WIRE	0.		

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter 9

3 Enter total number of other organizations or entities 2

Part II Continuation of Grants and Other Assistance to Organizations or Entities Outside the United States. (Schedule F (Form 990), Part II, line 1)										
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)	
			EUROPE	MEDICAL RESEARCH	223,642.	WIRE	0.			
			EUROPE	MEDICAL RESEARCH	346,434.	WIRE	0.			
			EAST ASIA AND THE PACIFIC	MEDICAL RESEARCH	132,107.	WIRE	0.			





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





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

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events
		FARA ENERGY BALL (event type)	RIDE ATAXIA PHILADELPHIA (event type)	52 (total number)	(add col. (a) through col. (c))
Revenue	<b>1</b> Gross receipts .....	1,514,577.	654,430.	2,394,039.	4,563,046.
	<b>2</b> Less: Contributions .....	1,019,257.	606,057.	2,205,023.	3,830,337.
	<b>3</b> Gross income (line 1 minus line 2) .....	495,320.	48,373.	189,016.	732,709.
Direct Expenses	<b>4</b> Cash prizes .....				
	<b>5</b> Noncash prizes .....				
	<b>6</b> Rent/facility costs .....				
	<b>7</b> Food and beverages .....				
	<b>8</b> Entertainment .....				
	<b>9</b> Other direct expenses .....	372,919.	55,846.	433,573.	862,338.
	<b>10</b> Direct expense summary. Add lines 4 through 9 in column (d) .....				862,338.
	<b>11</b> Net income summary. Subtract line 10 from line 3, column (d) .....				-129,629.

**Part III Gaming.** Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

		(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
Revenue	<b>1</b> Gross revenue .....				
Direct Expenses	<b>2</b> Cash prizes .....				
	<b>3</b> Noncash prizes .....				
	<b>4</b> Rent/facility costs .....				
	<b>5</b> Other direct expenses .....				
	<b>6</b> Volunteer labor .....	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	
	<b>7</b> Direct expense summary. Add lines 2 through 5 in column (d) .....				
	<b>8</b> Net gaming income summary. Subtract line 7 from line 1, column (d) .....				

**9** Enter the state(s) in which the organization conducts gaming activities: \_\_\_\_\_

**a** Is the organization licensed to conduct gaming activities in each of these states?  Yes  No

**b** If "No," explain: \_\_\_\_\_

**10a** Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year?  Yes  No

**b** If "Yes," explain: \_\_\_\_\_





**SCHEDULE I  
(Form 990)**

**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](http://www.irs.gov/Form990) for the latest information.

Department of the Treasury  
Internal Revenue Service

OMB No. 1545-0047  
**2019**  
Open to Public  
Inspection

Name of the organization

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE**

Employer identification number  
**52-2122720**

**Part I** General Information on Grants and Assistance

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

2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.  Yes  No

**Part II** 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.

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
CHILDREN'S HOSPITAL OF PHILADELPHIA - 34TH ST & CIVIC CENTER BLVD - PHILADELPHIA, PA 19104	23-1352166	501(C)(3)	1,256,600.	0.			MEDICAL RESEARCH
EMORY UNIVERSITY 201 DOWMAN DR ATLANTA, GA 30322	58-0566256	501(C)(3)	14,700.	0.			MEDICAL RESEARCH
OHIO STATE UNIVERSITY 333 W. 10TH AVE COLUMBUS, OH 43210	31-6025986	501(C)(3)	7,000.	0.			MEDICAL RESEARCH
REGENTS OF THE UNIVERSITY OF MINNESOTA - 200 SE OAK ST #600 - MINNEAPOLIS, MN 55455	41-6007513	501(C)(3)	65,000.	0.			MEDICAL RESEARCH
THE REGENTS OF THE UNIVERSITY OF CALIFORNIA, LOS ANGELES - 10920 WILSHIRE BLVD, 5TH FLOOR - LOS ANGELES, CA 90024	95-6006143	501(C)(3)	48,000.	0.			MEDICAL RESEARCH
UNIVERSITY OF FLORIDA DEPT OF NEUROLOGY, I3-100 MCKNIGHT BRAIN INSTITUTE, NEWELL DRIVE - GAINESVILLE	59-6002052	501(C)(3)	469,740.	0.			MEDICAL RESEARCH

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table **20.**

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

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule I (Form 990) (2019)



**Part II** Continuation of Grants and Other Assistance to Governments and Organizations in the United States (Schedule I (Form 990), Part II)

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
UNIVERSITY OF IOWA, DEPT OF PEDIATRICS - 200 HAWKINS DRIVE - IOWA CITY, IA 52242	42-6004813	501(C)(3)	8,800.	0.			MEDICAL RESEARCH
UNIVERSITY OF ROCHESTER 515 HYLAN BUILDING, RC BOX 270140 ROCHESTER, NY 14627	16-0743209	501(C)(3)	311,150.	0.			MEDICAL RESEARCH
ALBANY RESEARCH INSTITUTE 113 HOLLAND AVE ALBANY, NY 12208	14-1716021	501(C)(3)	77,850.	0.			MEDICAL RESEARCH
THE UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER - 5323 HARRY HINES BLVD - DALLAS, TX 75390	75-6002868	501(C)(3)	45,864.	0.			MEDICAL RESEARCH
UNIVERSITY OF SOUTH FLORIDA 4202 EAST FOWLER AVENUE TAMPA, FL 33620	59-3102112	501(C)(3)	150,000.	0.			MEDICAL RESEARCH
UNIVERSITY OF MASSACHUSETTS 1 CAMPUS CENTER WAY AMHERST, MA 01003	54-2084125	501(C)(3)	173,670.	0.			MEDICAL RESEARCH
ARIZONA STATE UNIVERSITY 1151 S FOREST AVE TEMPE, AZ 85287	86-0196696	501(C)(3)	150,000.	0.			MEDICAL RESEARCH
COLUMBIA UNIVERSITY 116TH STREET & BROADWAY NEW YORK, NY 10027	13-5598093	501(C)(3)	150,000.	0.			MEDICAL RESEARCH
PRESIDENT AND FELLOWS OF HARVARD 1563 MASSACHUSETTS AVE CAMBRIDGE, MA 02138	04-2103580	501(C)(3)	34,318.	0.			MEDICAL RESEARCH

**Part II** Continuation of Grants and Other Assistance to Governments and Organizations in the United States (Schedule I (Form 990), Part II)

(a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
TRUSTEES OF THE UNIVERSITY OF PENNSYLVANIA - 3451 WALNUT ST RM 310 - PHILADELPHIA, PA 19104	23-1352685	501(C)(3)	150,000.	0.			MEDICAL RESEARCH
UNIVERSITY OF ALABAMA - BIRMINGHAM 1720 2ND AVE S BIRMINGHAM, AL 35294	63-6005396	501(C)(3)	318,500.	0.			MEDICAL RESEARCH
CRITICAL PATH INSTITUTE 1730 E. RIVER RD. #200 TUSCON, AZ 85718	20-1991334		137,925.	0.			MEDICAL RESEARCH
DESIGN THERAPEUTICS 6005 HIDDEN VALLEY ROAD, SUITE 220 CARLSBAD, CA 92011	82-3929248		400,000.	0.			MEDICAL RESEARCH
NYU SCHOOL OF MEDICINE 550 1ST AVENUE NEW YORK, NY 10016	13-5562309		75,000.	0.			MEDICAL RESEARCH
WEILL MEDICAL COLLEGE OF CORNELL UNIVERSITY - 1300 YORK AVENUE, C-118 - NEW YORK, NY 10065	13-1623978		399,697.	0.			MEDICAL RESEARCH

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

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance

**Part IV** Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

PART I, LINE 2:

GRANTS ARE REVIEWED BY INDEPENDENT SCIENTIFIC ADVISORS AND APPROVED BY BOARD. ONCE GRANTS ARE AWARDED THE ORGANIZATION REQUIRES REGULAR RESEARCH AND FINANCIAL REPORTS FROM THE INSTITUTIONS.



**SCHEDULE M  
(Form 990)**

**Noncash Contributions**

OMB No. 1545-0047

**2019**

Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

- ▶ Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.
- ▶ Attach to Form 990.
- ▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

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

Part I	Types of Property	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1	Art - Works of art				
2	Art - Historical treasures				
3	Art - Fractional interests				
4	Books and publications				
5	Clothing and household goods				
6	Cars and other vehicles				
7	Boats and planes				
8	Intellectual property				
9	Securities - Publicly traded	X	8	351,436	MARKET PRICE
10	Securities - Closely held stock				
11	Securities - Partnership, LLC, or trust interests				
12	Securities - Miscellaneous				
13	Qualified conservation contribution - Historic structures				
14	Qualified conservation contribution - Other				
15	Real estate - Residential				
16	Real estate - Commercial				
17	Real estate - Other				
18	Collectibles				
19	Food inventory	X	1	6,944	COST OF MEAT
20	Drugs and medical supplies				
21	Taxidermy				
22	Historical artifacts				
23	Scientific specimens				
24	Archeological artifacts				
25	Other ( )				
26	Other ( )				
27	Other ( )				
28	Other ( )				

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, Donee Acknowledgement **29** **1**

	Yes	No
30a 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 three years from the date of the initial contribution, and which isn't required to be used for exempt purposes for the entire holding period?		X
b If "Yes," describe the arrangement in Part II.		
31 Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions?	X	
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?		X
b If "Yes," describe in Part II.		
33 If the organization didn't report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II.		

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

Schedule M (Form 990) 2019



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

Department of the Treasury  
Internal Revenue Service

**Supplemental Information to Form 990 or 990-EZ**

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

▶ Attach to Form 990 or 990-EZ.

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2019**

Open to Public  
Inspection

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number

52-2122720

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

AND CLINICAL RESEARCH INFRASTRUCTURE TO FACILITATE CLINICAL TRIALS. ALL  
OF THESE RESEARCH PROJECTS ADVANCE FA RESEARCH DEEPENING OUR  
UNDERSTANDING OF DISEASE MECHANISM, PATHOLOGY, AND PROGRESSION AND  
DISCOVERY OF INNOVATIVE APPROACHES TO THERAPY. SEVERAL OF THESE GRANTS  
WERE CO-FUNDED WITH OUR FA ADVOCACY GROUP PARTNERS; THIS COLLABORATIVE  
APPROACH BOTH INCREASES THE NUMBER OF AVAILABLE RESEARCH DOLLARS AND  
HELPS TO MINIMIZE DUPLICATION OF EFFORT.

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 OF \$3.25 MILLION (OVER 3 YEARS) TO PENN MEDICINE/ CHILDREN'S  
HOSPITAL OF PHILADELPHIA, PRESENTED BY FARA IN PARTNERSHIP WITH THE  
HAMILTON AND FINNERAN FAMILIES.

IN 2017, THAT COMMITMENT WAS RENEWED FOR AN ADDITIONAL THREE YEARS  
(\$1,403,500 IN 2017, \$1,225,500 IN 2018 AND \$1,122,000 IN 2019).

PROJECTS AND INVESTIGATORS BEING FUNDED INCLUDE DR. ROB WILSON- DRUG  
DISCOVERY, DR. DAVID LYNCH- TRANSLATIONAL AND CLINICAL NEUROSCIENCE  
RESEARCH, DR. IAN BLAIR- BIOMARKER DISCOVERY, DR. KIM LIN- CARDIAC  
RESEARCH AND DR. SHANA MCCORMACK- METABOLISM AND ENDOCRINOLOGY.

Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE	Employer identification number 52-2122720
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THE COE ESTABLISHED RESEARCH INFRASTRUCTURE CONSISTING OF FOUR CORE AREAS- NEUROLOGY, CARDIAC, BIOMARKER AND DRUG DISCOVERY. THE CENTER NOT ONLY SUPPORTS WORK WITHIN THESE DISCIPLINES, BUT ALSO FOSTERS EFFICIENT COLLABORATION AND SYNERGY ACROSS THEM. IN ITS FIRST SIX YEARS, THE COE REACHED SEVERAL SIGNIFICANT RESEARCH MILESTONES WITH THE DISCOVERY OF POSSIBLE TREATMENT CANDIDATES, THE STUDY OF NEW BIOMARKERS TO MEASURE THE DISEASE, AND LAUNCH OF PROMISING NEUROLOGIC AND CARDIAC CLINICAL TRIALS AND STUDIES.

OF NOTE, FA SHARES SIMILAR SYMPTOMS AND DISEASE MECHANISMS WITH OTHER DISEASES, BOTH RARE AND COMMON. RESEARCH INTO FA IS PROVIDING INSIGHTS AND ADVANCES IN OTHER DISEASES SUCH AS MITOCHONDRIAL DISEASES, MUSCULAR DYSTROPHIES, DIABETES, AND CARDIOMYOPATHY.

A COMPLETE LIST OF 2019 FUNDED GRANTS CAN BE FOUND AT:

CUREFA.ORG/GRANT-AWARDS

A COMPLETE LIST OF 2019 PUBLICATIONS OF RESEARCH FUNDED BY FARA CAN BE FOUND AT: CUREFA.ORG/SCIENTIFIC-NEWS/FUNDED-RESEARCH

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

INVESTIGATORS. CONFERENCE TOPICS COVERED MECHANISM OF DISEASE, THERAPEUTIC APPROACHES AND DRUG DISCOVERY, GENETICS OF DISEASE, NEUROPHYSIOLOGY AND THE CEREBELLUM, CELLULAR AND ANIMAL MODELS OF DISEASE, NATURAL HISTORY, BIOMARKERS AND ENDPOINTS, CLINICAL TRIALS AND CLINICAL DESIGN. ATTENDEES LEFT ENERGIZED FROM THE DYNAMIC EXCHANGE OF IDEAS, NEW SCIENTIFIC INSIGHTS, NETWORKING AND PLANS FOR NEW COLLABORATIONS. THE >400 ATTENDEES INCLUDED:



Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE	Employer identification number 52-2122720
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REPRESENTATIVES FROM 21 COUNTRIES,

150 ATTENDEES FROM ACADEMIA AND REGULATORY

140 ATTENDEES FROM INDUSTRY

100 JUNIOR INVESTIGATORS

17 PATIENT ADVOCACY ORGANIZATIONS

SYMPOSIUMS

FARA HOSTED AN EDUCATIONAL SYMPOSIUM FOR PATIENTS AND CAREGIVERS IN DENTON, TX (APRIL 5) AND CO-ORGANIZED A PATIENT SYMPOSIUM WITH THE CLINICAL RESEARCH NETWORK SITE- THE CHILDREN'S HOSPITAL OF PHILADELPHIA (OCTOBER 14). THESE SYMPOSIUMS PROVIDE AN OPPORTUNITY TO EDUCATE THE PATIENT/FAMILY COMMUNITY ON RESEARCH ADVANCES, PROGRESS ON CLINICAL TRIALS AND ARE A UNIQUE FORUM FOR PATIENTS AND RESEARCHERS TO ENGAGE AND LEARN FROM EACH OTHER'S EXPERIENCES AND PERSPECTIVES. COMBINED, THESE SYMPOSIUMS ACCOMMODATED MORE THAN 350 ATTENDEES.

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

THE FARA AMBASSADOR PROGRAM WHICH WAS LAUNCHED IN 2011 WITH >20 PARTICIPANTS HAD A YEAR OF CONTINUED GROWTH AND ACTIVITY IN 2019. THE PROGRAM NOW INCLUDES 75 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.

IN 2019, FARA FACILITATED FORMAL TRAINING FOR THE AMBASSADOR LEADERSHIP TEAM AND AMBASSADORS. THE FOCUS FOR THE TRAINING WAS UNDERSTANDING GENE THERAPIES (WHAT IT IS, HOW IT IS DIFFERENT FROM OTHER THERAPIES, EXPLORING RISKS AND BENEFITS AND CURRENT STATUS OF DEVELOPMENT FOR FA).

THE AMBASSADOR BLOG FEATURED POSTS SUCH AS MEET THE COMMUNITY

Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE	Employer identification number 52-2122720
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INTERVIEWS WITH PEOPLE LIVING WITH FA. IN 2019, THEY ACHIEVED >45  
 POSTS WITH OVER 18,000 VIEWS. THE AMBASSADORS ALSO CONTINUED A CARD  
 PROGRAM IN WHICH THEY DESIGNED CARDS TO SEND TO THE VARIOUS  
 STAKEHOLDERS AND COMMUNITY MEMBERS THROUGHOUT THE YEAR TO SAY THANK YOU  
 OR TO OFFER ENCOURAGEMENT. THEY ARE AVERAGING ABOUT 22 CARDS PER MONTH.  
 ANOTHER PROJECT FACILITATED BY THE AMBASSADOR GROUP ARE MONTHLY PEER  
 WEBEX 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). AMBASSADORS AND OTHER PATIENT ADVOCATES WERE INVOLVED WITH  
 FA PANEL PRESENTATIONS AT PHARMACEUTICAL COMPANIES WITH ACTIVE FA DRUG  
 OR GENE THERAPY DEVELOPMENT PIPELINES. EACH PANEL IS COMPRISED OF  
 PATIENTS AT VARIOUS AGES AND STAGES OF PROGRESSION FOR A COMPREHENSIVE  
 PICTURE OF LIFE WITH FA. FEEDBACK FROM PHARMACEUTICAL PARTNERS HAS  
 BEEN POSITIVE, AS THE INTERACTION WITH PATIENTS ALLOWS RESEARCHERS TO  
 TANGIBLY UNDERSTAND THE URGENCY FOR TREATMENTS AND A CURE. IN 2019,  
 FARA WAS HOSTED FOR PATIENT PANELS AT SEVEN PHARMACEUTICAL COMPANIES  
 PURSUING THERAPY FOR FA. FOR MORE INFORMATION VISIT  
 CUREFA.ORG/AMBASSADORS.

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

CLINICAL RESEARCH INFRASTRUCTURE

IN ADDITION TO RESEARCH GRANTS, FARA FUNDS THE ONGOING DEVELOPMENT 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 CAN INCLUDE THINGS LIKE:

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FRIEDREICH'S ATAXIA GLOBAL PATIENT REGISTRY: THE ONLY INTERNATIONAL FRIEDREICH ATAXIA PATIENT REGISTRY WITH MORE THAN 3500 INDIVIDUALS ENROLLED. THIS REGISTRY CAPTURES DEMOGRAPHIC AND CLINICAL INFORMATION ON INDIVIDUALS WITH FA AND IS USED TO RECRUIT INDIVIDUALS FOR CLINICAL TRIALS WORLDWIDE. IN 2019, THE PATIENT REGISTRY WAS USED TO RECRUIT FOR 3 CLINICAL TRIALS AND SEVERAL OTHER CLINICAL RESEARCH STUDIES. TO LEARN MORE, VISIT CUREFA.NET/REGISTRY. AT THE END OF 2019, FARA LAUNCHED AN UPGRADED PATIENT REGISTRY PLATFORM WITH PULSE INFOFRAME THAT HAS EXPANDED RESEARCH AND ANALYTICS CAPABILITIES AND WILL OFFER MULTIPLE LANGUAGES.

COLLABORATIVE CLINICAL RESEARCH NETWORK IN FA (CCRN IN FA): THE CCRN IS AN INTERNATIONAL NETWORK OF 13 CLINICAL RESEARCH CENTERS THAT WORK TOGETHER TO ADVANCE TREATMENTS AND CLINICAL CARE FOR INDIVIDUALS WITH FRIEDREICH'S ATAXIA. THREE OF THOSE SITES WERE ADDED IN DENVER, CO, AUCKLAND, NZ, AND MONTREAL, CA, SUPPORTED BY FARA IN 2019. 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 TO RESEARCH PUBLICATIONS, VISIT CUREFA.ORG/NETWORK.HTML

NATURAL HISTORY STUDY: LONGITUDINAL DATA (USUALLY ABOUT 10 YEARS) ON INDIVIDUALS WITH A DISEASE THAT DESCRIBES AND QUANTIFIES THE PROGRESSION OF THE DISEASE ALONG WITH THE SYMPTOMS AND MANIFESTATIONS OF THE DISEASE. NATURAL HISTORY CAN SOMETIMES SERVE AS THE BASIS FROM WHICH MEASUREMENTS CAN BE MADE TO DETERMINE EFFECTS OF NEW TREATMENTS,

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

CLINICAL OUTCOME MEASURES: FUNCTIONAL PERFORMANCE TESTS (E.G., TIMED PEGBOARD OR WALK TESTS, VISION, HEARING OR SPEECH TESTS) THAT QUANTIFY HOW MUCH CHANGE TAKES PLACE IN A SPECIFIC AMOUNT OF TIME AND ARE USED IN CLINICAL TRIALS TO MEASURE WHETHER A DRUG IS ALTERING THE COURSE OF THE DISEASE.

BIOMARKERS: ANYTHING THAT CAN BE USED AS AN INDICATOR OF A PARTICULAR DISEASE STATE - USUALLY PROTEINS, ENZYMES, GENETIC VARIANTS, IMAGING (MRI, CT OR PET SCANS). BIOMARKERS CAN BE USED TO ASSESS RISK OF DISEASE, DIAGNOSIS, OR OUTCOMES. USE OF BIOMARKERS IN DRUG DEVELOPMENT IS OF GREAT INTEREST BECAUSE BIOMARKERS CAN PROVIDE EVIDENCE OF BIOLOGICAL ACTIVITY, POTENTIALLY DEMONSTRATING THERAPEUTIC BENEFIT MORE QUICKLY THAN TRADITIONAL OUTCOME MEASURES.

BIOREPOSITORY: A REPOSITORY OR BANK OF STORED BIOLOGICAL MATERIALS SUCH AS BLOOD SAMPLES, DNA, ORGANS, AND TISSUES (SUCH AS SKIN, MUSCLE, HEART) THAT CAN BE USED FOR RESEARCH.

THROUGH THE CCRN IN FA WE HAVE COLLECTED NATURAL HISTORY DATA (ONGOING) IN MORE THAN 1,100 INDIVIDUALS WITH FA, 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 MULTIPLE CLINICAL TRIALS INCLUDING A FEW THAT WERE DESIGNED AND CONDUCTED SOLELY THROUGH NETWORK SITES. FARA CONTRIBUTED >\$750,000 IN 2019 TO CLINICAL RESEARCH

Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE	Employer identification number 52-2122720
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INFRASTRUCTURE IN DIRECT FUNDING TO THE CCRN IN FA CENTERS AND RELATED  
CLINICAL RESEARCH ACTIVITIES.

CRITICAL PATH INSTITUTE DATA COLLABORATION PROJECT

IN 2017, FARA INITIATED A PROJECT WITH CRITICAL PATH INSTITUTE'S  
(C-PATH) DATA COLLABORATION CENTER (DCC) TO DEVELOP AN AGGREGATED  
DATABASE OF CLINICAL DATA FOR FA. USE OF THIS DATABASE WILL PROMOTE  
COLLABORATIVE RESEARCH TO SUPPORT THE UNDERSTANDING OF NATURAL HISTORY,  
POTENTIAL BIOMARKERS, AND POTENTIAL CLINICAL ENDPOINTS FOR PATIENTS  
WITH FA, WHICH WILL HELP RESEARCHERS DEVELOP MORE EFFICIENT CLINICAL  
TRIAL PROTOCOLS TO TEST NEW THERAPIES MORE QUICKLY AND EFFECTIVELY.

IN 2018, THE PROJECT ESTABLISHED AN INTEGRATED DATABASE OF CLINICAL  
DATA FOR FA THAT CAN BE SHARED AND UTILIZED BY EXISTING FA RESEARCHERS.  
IT ENLISTED COMPANIES THAT HAVE CARRIED OUT CLINICAL TRIALS IN FA TO  
OBTAIN CONTRIBUTIONS OF CLINICAL DATA, AS WELL AS SHARING NATURAL  
HISTORY DATA COLLECTED BY FARA'S COLLABORATIVE CLINICAL RESEARCH  
NETWORK.

FOUR DE-IDENTIFIED DATASETS FROM PREVIOUS CLINICAL TRIALS AND  
FA-CLINICAL OUTCOME MEASURE DATASETS HAVE BEEN AGGREGATED INTO A SINGLE  
DATABASE IN A SCIENTIFICALLY RIGOROUS MANNER BY C-PATH'S DCC. IN 2019,  
THIS DATA WAS SHARED WITH >6 RESEARCH ORGANIZATIONS (ACADEMIC AND  
INDUSTRY) TO ASSIST IN DESIGNING CLINICAL TRIALS.

ADDITIONAL INFORMATION ABOUT FARA'S PROGRAMS IN 2019 CAN BE ACCESSED  
VIA THE ANNUAL REPORT AT: CUREFA.ORG/FINANCIALS  
EXPENSES \$ 844,106. INCLUDING GRANTS OF \$ 699,210. REVENUE \$ 0.

Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE	Employer identification number 52-2122720
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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 REQUIRED TO ANNUALLY COMPLETE A CONFLICT  
OF INTEREST STATEMENT

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 AND EXECUTIVE  
DIRECTOR.

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

AL, AK, AZ, AR, CA, CO, CT, FL, GA, IL, KS, KY, ME, MD, MS, MI, MN, 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 18:

FORM 990 IS AVAILABLE ON THE ORGANIZATION'S WEBSITE AS WELL AS  
GUIDESTAR.ORG AND CHARITYNAVIGATOR.ORG

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

FINANCIAL STATEMENTS ARE AVAILABLE ON THE ORGANIZATION'S WEBSITE. THE  
GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY AND FORM 1023 ARE  
AVAILABLE UPON REQUEST.

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

Name of the organization <b>FRIEDREICH'S ATAXIA RESEARCH ALLIANCE</b>	Employer identification number <b>52-2122720</b>
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<b>FOOD INVENTORY CONSUMED</b>	<b>-6,944.</b>
<b>IMPAIRMENT ON BIOELECTRON INVESTMENT</b>	<b>-1,080,585.</b>
<b>TOTAL TO FORM 990, PART XI, LINE 9</b>	<b>-1,087,529.</b>

FORM 990, PART XII, LINE 2C

FARA'S AUDIT COMMITTEE CONSISTS OF THE FINANCE COMMITTEE, EXECUTIVE DIRECTOR 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 AND 990 PRIOR TO SHARING WITH THE FULL BOARD FOR A VOTE.

FARA'S BOARD OF DIRECTORS RECEIVES THE FINANCIAL STATEMENTS AND 990 FOR REVIEW AND VOTES TO APPROVE PRIOR TO PUBLIC FILING.

**FORM HAS BEEN ELECTRONICALLY  
FILED - KEEP FOR YOUR RECORDS**

Form **8868**  
(Rev. January 2020)

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

OMB No. 1545-0047

Department of the Treasury  
Internal Revenue Service

▶ **File a separate application for each return.**  
▶ **Go to [www.irs.gov/Form8868](http://www.irs.gov/Form8868) for the latest information.**

**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](http://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.

<b>Type or print</b>	Name of exempt organization or other filer, see instructions. <b>FRIEDREICH'S ATAXIA RESEARCH ALLIANCE</b>	Taxpayer identification number (TIN) <b>52-2122720</b>
File by the due date for filing your return. See instructions.	Number, street, and room or suite no. If a P.O. box, see instructions. <b>P.O. BOX 1537</b>	
	City, town or post office, state, and ZIP code. For a foreign address, see instructions. <b>SPRINGFIELD, VA 22151</b>	

Enter the Return Code for the return that this application is for (file a separate application for each return) 0 1

Application Is For	Return Code	Application Is For	Return Code
Form 990 or Form 990-EZ	01	Form 990-T (corporation)	07
Form 990-BL	02	Form 1041-A	08
Form 4720 (individual)	03	Form 4720 (other than individual)	09
Form 990-PF	04	Form 5227	10
Form 990-T (sec. 401(a) or 408(a) trust)	05	Form 6069	11
Form 990-T (trust other than above)	06	Form 8870	12

**JENNIFER FARMER - 533 W. UWCHLAN AVENUE - DOWNTOWN,**

- The books are in the care of ▶ **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.

**1** I request an automatic 6-month extension of time until **NOVEMBER 15, 2020**, to file the exempt organization return for the organization named above. The extension is for the organization's return for:  
▶  calendar year **2019** or  
▶  tax year beginning \_\_\_\_\_, and ending \_\_\_\_\_.

**2** If the tax year entered in line 1 is for less than 12 months, check reason:  Initial return  Final return  
 Change in accounting period

<b>3a</b> If this application is for Forms 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions.	<b>3a</b>	<b>\$</b>	<b>0.</b>
<b>b</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.	<b>3b</b>	<b>\$</b>	<b>0.</b>
<b>c</b> <b>Balance due.</b> Subtract line 3b from line 3a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions.	<b>3c</b>	<b>\$</b>	<b>0.</b>

**Caution:** If you are going to make an electronic funds withdrawal (direct debit) with this Form 8868, see Form 8453-EO and Form 8879-EO for payment instructions.

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

Form **8868** (Rev. 1-2020)