

Form **990**
Department of the Treasury
Internal Revenue Service

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

OMB No 1545-0047
2017
Open to Public Inspection

A For the 2017 calendar year, or tax year beginning 01-01-2017, and ending 12-31-2017

- B** Check if applicable:
 Address change
 Name change
 Initial return
 Final return/terminated
 Amended return
 Application pending

C Name of organization
FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Doing business as

Number and street (or P O box if mail is not delivered to street address) Room/suite
PO BOX 1537

City or town, state or province, country, and ZIP or foreign postal code
SPRINGFIELD, VA 22151

F Name and address of principal officer
JENNIFER FARMER
533 W UWCHLAN AVENUE
DOWNTOWN, PA 19335

D Employer identification number
52-2122720

E Telephone number
(484) 879-6160

G Gross receipts \$ 8,646,430

I Tax-exempt status 501(c)(3) 501(c) () ◀ (insert no) 4947(a)(1) or 527

J Website: WWW.CUREFA.ORG

H(a) Is this a group return for subordinates? Yes No
H(b) Are all subordinates included? Yes No
If "No," attach a list (see instructions)
H(c) Group exemption number ▶

L Year of formation 1998 **M** State of legal domicile VA

K Form of organization Corporation Trust Association Other ▶

Part I Summary

1 Briefly describe the organization's mission or most significant activities
TO TREAT AND CURE FRIEDREICH'S ATAXIA BY ADVANCING RESEARCH, AWARENESS AND PARTNERSHIPS

2 Check this box if the organization discontinued its operations or disposed of more than 25% of its net assets

3 Number of voting members of the governing body (Part VI, line 1a)	19
4 Number of independent voting members of the governing body (Part VI, line 1b)	18
5 Total number of individuals employed in calendar year 2017 (Part V, line 2a)	11
6 Total number of volunteers (estimate if necessary)	500
7a Total unrelated business revenue from Part VIII, column (C), line 12	0
7b Net unrelated business taxable income from Form 990-T, line 34	0

	Prior Year	Current Year
8 Contributions and grants (Part VIII, line 1h)	5,388,847	7,518,776
9 Program service revenue (Part VIII, line 2g)	0	0
10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	47,576	53,104
11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	-54,930	-38,343
12 Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12)	5,381,493	7,533,537
13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	4,852,904	5,824,049
14 Benefits paid to or for members (Part IX, column (A), line 4)	0	0
15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	463,198	605,722
16a Professional fundraising fees (Part IX, column (A), line 11e)	0	0
b Total fundraising expenses (Part IX, column (D), line 25) ▶101,785		
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	237,062	382,043
18 Total expenses Add lines 13-17 (must equal Part IX, column (A), line 25)	5,553,164	6,811,814
19 Revenue less expenses Subtract line 18 from line 12	-171,671	721,723

	Beginning of Current Year	End of Year
20 Total assets (Part X, line 16)	4,110,033	4,852,978
21 Total liabilities (Part X, line 26)	484,966	323,194
22 Net assets or fund balances Subtract line 21 from line 20	3,625,067	4,529,784

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

Sign Here
Signature of officer: ***** Date: 2018-05-15
JENNIFER FARMER EXECUTIVE DIRECTOR
Type or print name and title

Paid Preparer Use Only
Print/Type preparer's name: EDWARD FRONCZKOWSKI CPA
Preparer's signature: EDWARD FRONCZKOWSKI CPA
Date: _____
Check if self-employed PTIN: P01259092
Firm's name: MAILLIE LLP Firm's EIN: 23-1518888
Firm's address: 624 WILLOWBROOK LANE
WEST CHESTER, PA 19382 Phone no: (610) 696-4353

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
If "Yes," describe these new services on Schedule O

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? [] Yes [X] No
If "Yes," describe these changes on Schedule O

4 Describe the organization's program service accomplishments for each of its three largest program services, 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 \$ 5,363,415 including grants of \$ 5,171,280) (Revenue \$)
See Additional Data

4b (Code) (Expenses \$ 280,759 including grants of \$ 26,512) (Revenue \$)
See Additional Data

4c (Code) (Expenses \$ 244,313 including grants of \$) (Revenue \$)
See Additional Data

(Code) (Expenses \$ 715,107 including grants of \$ 626,257) (Revenue \$)
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 PATIENT REGISTRY THE ONLY INTERNATIONAL FRIEDREICH ATAXIA PATIENT REGISTRY WITH MORE THAN 3000 INDIVIDUALS ENROLLED THIS REGISTRY CAPTURES DEMOGRAPHIC AND CLINICAL INFORMATION ON INDIVIDUALS WITH FA AND IS USED TO RECRUIT INDIVIDUALS FOR CLINICAL TRIALS WORLDWIDE IN 2017, THE PATIENT REGISTRY WAS USED TO RECRUIT FOR 5 CLINICAL TRIALS AND SEVERAL OTHER CLINICAL RESEARCH STUDIES FA PATIENT REGISTRY WWW CUREFA NET/REGISTRY COLLABORATIVE CLINICAL RESEARCH NETWORK IN FA (CCRN IN FA) AN INTERNATIONAL NETWORK OF 10 CLINICAL RESEARCH CENTERS THAT WORK TOGETHER TO ADVANCE TREATMENTS AND CLINICAL CARE FOR INDIVIDUALS WITH FRIEDREICH'S ATAXIA HAVING SUCH A NETWORK MEANS THAT THERE ARE TRAINED PHYSICIANS AND RESEARCH COORDINATORS READY TO DO CLINICAL RESEARCH STUDIES AND TRIALS ALSO, THIS NETWORK IS BACKED BY A DATA COORDINATION CENTER THAT FACILITATES ALL ASPECTS OF DATA COLLECTION, DATABASE MANAGEMENT, AND STATISTICAL ANALYSIS OF STUDY DATA TO LEARN MORE, VISIT WWW 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, 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 ELEVEN YEARS OF NATURAL HISTORY DATA (ONGOING) IN MORE THAN 950 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 MORE THAN \$XXX,000 IN 2017 TO CLINICAL RESEARCH INFRASTRUCTURE IN DIRECT FUNDING TO THE CCRN IN FA CENTERS AND RELATED CLINICAL RESEARCH ACTIVITIES SELECTED CCRN IN FA PUBLICATION IMPACT OF DIABETES IN THE FRIEDREICH ATAXIA CLINICAL OUTCOME MEASURES STUDY MCCORMICK A, FARMER J, PERLMAN S, DELATYCKI M, WILMOT G, MATTHEWS K, YOON G, HOYLE C, SUBRAMONY SH, ZESIEWICZ T, LYNCH DR, MCCORMACK SE ANN CLIN TRANSL NEUROL 2017 JUL 26;4(9) 622-631 DOI 10.1002/ACN3.439 ECOLLECTION 2017 SEP OBJECTIVE FRIEDREICH ATAXIA (FA) IS A PROGRESSIVE NEUROMUSCULAR DISORDER CAUSED BY GAA TRIPLET REPEAT EXPANSIONS OR POINT MUTATIONS IN THE FXN GENE FA IS ASSOCIATED WITH INCREASED RISK OF DIABETES MELLITUS (DM) THIS STUDY ASSESSED THE AGE-SPECIFIC PREVALENCE OF FA-ASSOCIATED DM AND ITS IMPACT ON NEUROLOGIC OUTCOMES RESEARCH DESIGN AND METHODS PARTICIPANTS WERE 811 INDIVIDUALS WITH FA FROM 12 INTERNATIONAL SITES IN A PROSPECTIVE NATURAL HISTORY STUDY (FA CLINICAL OUTCOME MEASURES STUDY, FACOMS) PHYSICAL FUNCTION WAS ASSESSED, USING VALIDATED INSTRUMENTS MULTIVARIABLE REGRESSION ANALYSES EXAMINED THE INDEPENDENT ASSOCIATION OF DM WITH OUTCOMES RESULTS MEAN AGE OF PARTICIPANTS WAS 30.1 YEARS (SD 15.3, RANGE 7-82), 50% WERE FEMALE, AND 94% WERE NON-HISPANIC WHITE 9% (42/459) OF ADULTS AND 3% (10/352) OF CHILDREN HAD DM INDIVIDUALS WITH FA-ASSOCIATED DM WERE OLDER (P < 0.001), HAD LONGER GAA REPEAT LENGTH ON THE LEAST AFFECTED FXN ALLELE (P = 0.037), AND MORE SEVERE FA (P = 0.0001) OF INDIVIDUALS WITH DM, 65% (34/52) WERE TAKING INSULIN EVEN AFTER ACCOUNTING STATISTICALLY FOR BOTH AGE AND GAA REPEAT LENGTH, DM WAS INDEPENDENTLY ASSOCIATED WITH GREATER FA SYMPTOM BURDEN (P = 0.010), REDUCED CAPACITY TO PERFORM ACTIVITIES OF DAILY LIVING (P = 0.021), AND A DECREASE OF 0.33 SDS ON A COMPOSITE PERFORMANCE MEASURE (95% CI -0.56-0.11, P = 0.004), THE RELATIVE IMPACT OF DM WAS MOST APPARENT IN YOUNGER INDIVIDUALS CONCLUSIONS DM-ASSOCIATED FA HAS AN INDEPENDENT ADVERSE IMPACT ON WELL-BEING IN AFFECTED INDIVIDUALS, PARTICULARLY AT YOUNGER AGES IN FUTURE, EVIDENCE-BASED APPROACHES FOR IDENTIFICATION AND MANAGEMENT OF FA-RELATED DM MAY IMPROVE BOTH HEALTH AND FUNCTION 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 THE PROJECT WILL ESTABLISH AN INTEGRATED DATABASE OF CLINICAL DATA FOR FA THAT CAN BE SHARED AND UTILIZED BY EXISTING FA RESEARCHERS IT WILL ENLIST 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 THREE DATASETS HAVE BEEN PROMISED FOR THE PROJECT, WITH THE FIRST PLACEBO-ARM DATASET EXPECTED TO BE SHARED IN THE NEXT FEW WEEKS SHARING ADDITIONAL DATASETS IS UNDER DISCUSSION THE DE-IDENTIFIED DATASETS WILL BE AGGREGATED INTO A SINGLE DATABASE IN A SCIENTIFICALLY RIGOROUS MANNER BY C-PATH'S DCC

4d Other program services (Describe in Schedule O)
(Expenses \$ 715,107 including grants of \$ 626,257) (Revenue \$)

4e Total program service expenses 6,603,594

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If "Yes," complete Schedule A	Yes	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?	Yes	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I		No
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II	Yes	
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III		No
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I		No
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II		No
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III		No
9 Did the organization report an amount in Part X, line 21 for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X, or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV		No
10 Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? If "Yes," complete Schedule D, Part V		No
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI	Yes	
b Did the organization report an amount for investments—other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII		No
c Did the organization report an amount for investments—program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII	Yes	
d Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX		No
e Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X		No
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X		No
12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII	Yes	
b Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional		No
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E		No
14a Did the organization maintain an office, employees, or agents outside of the United States?		No
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If "Yes," complete Schedule F, Parts I and IV	Yes	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? If "Yes," complete Schedule F, Parts II and IV	Yes	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts III and IV		No
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I (see instructions)		No
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II	Yes	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III		No

Part IV Checklist of Required Schedules (continued)

	Yes	No
20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		No
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	Yes	
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>		No
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>		No
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>		No
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>		No
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>		No
26 Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If "Yes," complete Schedule L, Part II</i>		No
27 Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>		No
28 Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions)		
a A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		No
b A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		No
c An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i>	Yes	
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	Yes	
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>		No
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		No
32 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>		No
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>		No
34 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>		No
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		No
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>		
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>		No
37 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>		No
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O	Yes	

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 []

Table with columns for question ID, question text, and Yes/No response boxes. Includes sections for backup withholding, employee reporting, foreign accounts, prohibited tax shelter transactions, deductible contributions, and 501(c)(7), (12), and (29) organizations.

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

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

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a (19), 1b (18), 2, 3, 4, 5, 6, 7a, 7b, 8a, 8b, 9.

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

Table with 3 columns: Question, Yes, No. Rows include: 10a, 10b, 11a, 11b, 12a, 12b, 12c, 13, 14, 15a, 15b, 16a, 16b.

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, ME, MD, MS, MI, MN, MO, NH, NJ, NM, NY, NC, ND, OH, OK, OR, PA, RI, SC, TN, UT, VA, WA, WI, MA
18 Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (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 in Schedule O)
19 Describe in 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 533 W UWCHLAN AVENUE DOWNINGTOWN, PA 19335 (484) 879-6160

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, or 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

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

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 dotted 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	0 00	X		X				0	0	0
(3) RUTH DEWITT TREASURER	0 00	X		X				0	0	0
(4) JENNIFER GOOD DIRECTOR	0 00	X						0	0	0
(5) PAUL AVERY CHAIRMAN	0 00	X		X				0	0	0
(6) PETER CRISP DIRECTOR	0 00	X						0	0	0
(7) DR HOLLY HEDRICK DIRECTOR	0 00	X						0	0	0
(8) GEOFFREY LEVITT DIRECTOR	0 00	X						0	0	0
(9) DR STEVE KLASKO DIRECTOR	0 00	X						0	0	0
(10) THOMAS HAMILTON DIRECTOR	0 00	X						0	0	0
(11) BERNARD RAVINA SCIENTIFIC DIRECTOR	0 00	X						0	0	0
(12) DR SANJAY BIDICHANDANI SCIENTIFIC DIRECTOR	0 00	X						0	0	0
(13) DEREK G HENNECKE DIRECTOR	0 00	X						0	0	0
(14) DR JAMES MCARTHUR SCIENTIFIC DIRECTOR	0 00	X						0	0	0
(15) TONY PLOHOROS DIRECTOR	0 00	X						0	0	0
(16) PAT RITSCHEL DIRECTOR	0 00	X						0	0	0
(17) RONALD BARTEK PRESIDENT/DIRECTOR	40 00	X		X				100,000	0	3,669

Part VII Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (continued)

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted 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			
(18) BRIGID BRENNAN DIRECTOR	0 00	X						0	0	0
(19) DR JAMES R RUSCHE DIRECTOR	0 00	X						0	0	0
(20) JENNIFER FARMER EXECUTIVE DIRECTOR	40 00			X				110,000	0	4,294
1b Sub-Total										
c Total from continuation sheets to Part VII, Section A										
d Total (add lines 1b and 1c)							210,000	0		7,963

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization ▶ **1**

	Yes	No
3 Did the organization list any former officer, director or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		No
4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>		No
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		No

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization Report compensation for the calendar year ending with or within the organization's tax year

(A) Name and business address	(B) Description of services	(C) Compensation

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization ▶ **0**

Part VIII Statement of Revenue

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

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
Contributions, Gifts, Grants and Other Similar Amounts	1a Federated campaigns	1a					
	b Membership dues	1b					
	c Fundraising events	1c	3,756,127				
	d Related organizations	1d					
	e Government grants (contributions)	1e					
	f All other contributions, gifts, grants, and similar amounts not included above	1f	3,762,649				
	g Noncash contributions included in lines 1a-1f \$ _____						
	h Total. Add lines 1a-1f			7,518,776			
Program Service Revenue	2a _____	Business Code					
	b _____						
	c _____						
	d _____						
	e _____						
	f All other program service revenue						
	g Total. Add lines 2a-2f						
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		37,283			37,283	
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
	6a Gross rents	(i) Real	(ii) Personal				
		b Less rental expenses					
		c Rental income or (loss)					
		d Net rental income or (loss)					
	7a Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other				
		b Less cost or other basis and sales expenses		290,409			
		c Gain or (loss)		15,821			
		d Net gain or (loss)			15,821		15,821
	8a Gross income from fundraising events (not including \$ 3,756,127 of contributions reported on line 1c) See Part IV, line 18	a					
		b Less direct expenses		784,141			
		c Net income or (loss) from fundraising events			-38,343		-38,343
	9a Gross income from gaming activities See Part IV, line 19	a					
b Less direct expenses							
c Net income or (loss) from gaming activities							
10a Gross sales of inventory, less returns and allowances	a						
	b Less cost of goods sold						
	c Net income or (loss) from sales of inventory						
Miscellaneous Revenue	Business Code						
11a _____							
b _____							
c _____							
d All other revenue							
e Total. Add lines 11a-11d							
12 Total revenue. See Instructions			7,533,537	0	0	14,761	

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	4,953,825	4,953,825		
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, line 15 and 16	870,224	870,224		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	222,848	182,082	17,878	22,888
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	382,874	320,390	20,911	41,573
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 (non-employees)				
a Management				
b Legal	338		338	
c Accounting	12,700		12,700	
d Lobbying				
e Professional fundraising services See Part IV, line 17				
f Investment management fees	13,318		13,318	
g Other (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	73,190	64,752	1,987	6,451
12 Advertising and promotion	16,101	16,000		101
13 Office expenses	25,019	13,557	7,903	3,559
14 Information technology				
15 Royalties				
16 Occupancy	31,785	18,163	4,540	9,082
17 Travel	128,903	115,102	13,530	271
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	39,472	35,469	4,003	
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	834		834	
23 Insurance	5,390	1,250	3,197	943
24 Other expenses Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O)				
a BOOKS, SUBSCRIPTIONS &	10,329	3,740	1,891	4,698
b BUSINESS REGISTRATION F	7,744	900	544	6,300
c CREDIT CARD & BANK FEES	6,545	560	272	5,713
d FACILITIES & EQUIPMENT	6,522	4,182	2,340	
e All other expenses	3,853	3,398	249	206
25 Total functional expenses. Add lines 1 through 24e	6,811,814	6,603,594	106,435	101,785
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation				
Check here <input type="checkbox"/> 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 IX

		(A) Beginning of year		(B) End of year
Assets	1 Cash—non-interest-bearing	844,839	1	1,459,689
	2 Savings and temporary cash investments	376,754	2	230,051
	3 Pledges and grants receivable, net	269,394	3	358,567
	4 Accounts receivable, net		4	
	5 Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees Complete Part II of Schedule L		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instructions) Complete Part II of Schedule L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	34,261	9	8,402
	10a Land, buildings, and equipment cost or other basis Complete Part VI of Schedule D	7,135		
	b Less accumulated depreciation	6,129		
		1,840	10c	1,006
	11 Investments—publicly traded securities	1,491,445	11	1,703,763
	12 Investments—other securities See Part IV, line 11		12	
	13 Investments—program-related See Part IV, line 11	1,091,500	13	1,091,500
	14 Intangible assets		14	
15 Other assets See Part IV, line 11		15		
16 Total assets. Add lines 1 through 15 (must equal line 34)	4,110,033	16	4,852,978	
Liabilities	17 Accounts payable and accrued expenses	484,966	17	323,194
	18 Grants payable		18	
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability Complete Part IV of Schedule D		21	
	22 Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons Complete Part II of Schedule L		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 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		25	
	26 Total liabilities. Add lines 17 through 25	484,966	26	323,194
Net Assets or Fund Balances	27 Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34. Unrestricted net assets	3,597,092	27	4,208,302
	28 Temporarily restricted net assets	27,975	28	321,482
	29 Permanently restricted net assets		29	
	30 Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34. Capital stock or trust principal, or current funds		30	
	31 Paid-in or capital surplus, or land, building or equipment fund		31	
	32 Retained earnings, endowment, accumulated income, or other funds		32	
	33 Total net assets or fund balances	3,625,067	33	4,529,784
	34 Total liabilities and net assets/fund balances	4,110,033	34	4,852,978

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	7,533,537
2	Total expenses (must equal Part IX, column (A), line 25)	2	6,811,814
3	Revenue less expenses Subtract line 2 from line 1	3	721,723
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	3,625,067
5	Net unrealized gains (losses) on investments	5	182,994
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0
10	Net assets or fund balances at end of year Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	4,529,784

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	2a	No
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	2b	Yes
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 in Schedule O	2c	Yes
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?	3a	No
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 in Schedule O and describe any steps taken to undergo such audits	3b	

Software ID:**Software Version:****EIN:** 52-2122720**Name:** FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Form 990 (2017)

Form 990, Part III, Line 4a:

RESEARCH AND GRANT PROGRAM IN 2017, FARA CONTINUED TO ACCELERATE THE PACE OF RESEARCH WITH A COMMITMENT TO FUNDING HIGH QUALITY RESEARCH PROJECTS TO MOVE US CLOSER TO EFFECTIVE TREATMENTS. IN TOTAL, FARA PROVIDED >\$5.8M IN BASIC AND TRANSLATIONAL AND CLINICAL RESEARCH GRANTS, THE FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE, SCIENTIFIC CONFERENCE SUPPORT AND CLINICAL RESEARCH INFRASTRUCTURE FUNDING. OVER THE PAST YEAR, 50 NEW LETTERS OF INTENT AND 25 GRANT APPLICATIONS WERE SUBMITTED TO FARA WITH A REQUEST FOR FUNDING. AFTER RIGOROUS PEER REVIEW, 15 GRANTS WERE DETERMINED MERITORIOUS AND AWARDED FUNDING IN 2017. IN ADDITION, BASED ON EXCELLENT PROGRESS, CONTINUATION FUNDING WAS PROVIDED FOR 14 PROJECTS, FOR A TOTAL OF 29 RESEARCH GRANTS AWARDED. THESE FUNDED PROJECTS ADDRESS NUMEROUS IMPORTANT RESEARCH QUESTIONS THAT DIRECTLY TARGET FARA'S STRATEGIC RESEARCH INITIATIVES, INCLUDING EVALUATING OF MECHANISMS OF DISEASE, DRUG DISCOVERY, PRE-CLINICAL AND CLINICAL STUDIES OF LEAD CANDIDATES IN THE TREATMENT PIPELINE, ADVANCES IN GENE AND CELL THERAPY APPROACHES, ADVANCES IN DIFFERENTIATION OF INDUCED PLURIPOTENT STEM (IPS) CELL LINES FROM FA PATIENTS INTO SENSORY NEURONS AND CARDIOMYOCYTES, DEVELOPMENT OF NEW ANIMAL MODELS, CARDIAC RESEARCH AND EVALUATION OF NOVEL BIOMARKERS. SEVERAL ARE CO-FUNDED WITH OUR FRIEDREICH'S ATAXIA ADVOCACY GROUP PARTNERS, THIS COLLABORATIVE APPROACH BOTH INCREASES THE NUMBER OF AVAILABLE RESEARCH DOLLARS AND HELPS TO MINIMIZE DUPLICATION OF EFFORT. 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. 2017 FUNDED RESEARCH INITIATIVES: FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE, PHILADELPHIA PATHE 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 GIFT 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. PROJECTS AND INVESTIGATORS BEING FUNDED INCLUDE DR. ROB WILSON- DRUG DISCOVERY, DR. DAVID LYNCH- TRANSLATIONAL AND CLINICAL NEUROSCIENCE RESEARCH, DR. IAN BLAIR- METABOLIC BIOMARKERS, DR. KIM LIN- CARDIAC RESEARCH AND DR. SHANA MCCORMACK- ENDOCRINOLOGIST. 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 FOUR 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. SOME BRIEF HIGHLIGHTS OF RESEARCH OCCURRING AT THE CENTER ARE PROVIDED BELOW. CREATED A CARDIAC RESEARCH AND CLINICAL CARE CORE AND RECRUITED 3 CARDIAC STUDIES (CARDIAC MRI, SERUM BIOMARKERS AND EXERCISE TOLERANCE) WITH INTERNATIONAL COLLABORATION. CREATED A BIOMARKER CORE AND IDENTIFIED 3 NEW BLOOD BASED BIOMARKERS. CREATED A PATIENT-DERIVED CELL REPOSITORY IN COLLABORATION WITH DR. NAPIERLA AT UNIVERSITY OF ALABAMA BIRMINGHAM, > 50 CELL LINES ARE AVAILABLE AND BEING SHARED WITH THE RESEARCH COMMUNITY, > 8 COMPANIES AND >6 ACADEMICS SOURCING CELLS FOR DRUG DISCOVERY AND RESEARCH. ESTABLISHED 2 FA MOUSE MODEL COLONIES CURRENTLY TESTING DRUG CANDIDATES WITH >3 INDUSTRY AND 2 ACADEMIC PARTNERS. ESTABLISHED A DRUG DISCOVERY CORE THAT ADVANCES INTERNALLY LED DRUG DISCOVERY AS WELL AS COLLABORATIONS WITH EXTERNAL PARTNERS. 3 NOVEL THERAPEUTIC DISCOVERIES HELPED INFORM EARLY STAGE WORK AND CLINICAL DEVELOPMENT STRATEGY (TRIALS IN FA PATIENTS) FOR 3 DRUG DEVELOPMENT PARTNERS BY SHARING INSIGHTS FROM FA PATIENT STUDIES OF CARDIAC OUTCOMES, METABOLIC AND MUSCLE METABOLISM AND THE LONGITUDINAL NATURAL HISTORY STUDY COMPLETED TWO COE FUNDED CLINICAL TRIALS- A STATIN STUDY AND A STEROID STUDY. THE STATIN STUDY COMES OUT OF BIOMARKER WORK IN DR. BLAIR'S LAB. THE STEROID STUDY COMES FROM CLINICAL OBSERVATIONS THAT TREATMENT WITH STEROIDS HAS IMPROVED FUNCTION IN PATIENTS. PUBLICATIONS FROM CENTER OF EXCELLENCE RESEARCH: LIQUID CHROMATOGRAPHY-HIGH RESOLUTION MASS SPECTROMETRY ANALYSIS OF PLATELET FRAXIN AS A PROTEIN BIOMARKER FOR THE RARE DISEASE FRIEDREICH'S ATAXIA. GUO L, WANG Q, WENG L, HAUSER LA, STRAWSER CJ, ROCHA AG, DANCIS A, MESAROS C, LYNCH DR, BLAIR IA. ANAL CHEM 2018 FEB 6,90(3) 2216-2223. DOI 10.1021/ACS.ANALCHEM.7B04590. Epub 2018 Jan 11. EARLY VGLUT1-SPECIFIC PARALLEL FIBER SYNAPTIC DEFICITS AND DYSREGULATED CEREBELLAR CIRCUIT IN THE KIKO MOUSE MODEL OF FRIEDREICH ATAXIA. LIN H, MAGRANE J, CLARK EM, HALAWANI SM, WARREN N, RATTELLE A, LYNCH DR. DIS MODEL MECH 2017 DEC 19,10(12) 1529-1538. DOI 10.1242/DMM.030049. EARLY CEREBELLAR DEFICITS IN MITOCHONDRIAL BIOGENESIS AND RESPIRATORY CHAIN COMPLEXES IN THE KIKO MOUSE MODEL OF FRIEDREICH ATAXIA. LIN H, MAGRANE J, RATTELLE A, STEPANOVA A, GALKIN A, CLARK EM, DONG YN, HALAWANI SM, LYNCH DR. DIS MODEL MECH 2017 NOV 1,10(11) 1343-1352. DOI 10.1242/DMM.030502. BIOMARKER INITIATIVE: BIOMARKERS ARE BIOLOGICAL MEASURES THAT INDICATE CHANGE IN A DISEASE, AND THEY HAVE THE POTENTIAL TO SHORTEN THE LENGTH OF CLINICAL TRIALS. FARA LAUNCHED AN INITIATIVE TO LOOK FOR NOVEL BIOMARKERS FOR FA, STARTING WITH A NOVEMBER 2014 MEETING WHERE EXPERTS CAME TOGETHER TO PRIORITIZE POSSIBLE MARKERS. THEY DETERMINED THAT WE NEED BIOMARKERS TO MEASURE DISEASE PROGRESSION (PARTICULARLY AT EARLY STAGES OF DISEASE) MEASURE DRUG EFFECTIVENESS IN TERMS OF AFFECT ON PRIMARY MECHANISMS OF DISEASE OR A SPECIFIC TARGET. MEASURE DRUG EFFECTIVENESS AT TREATING SPECIFIC GROUPS OF SYMPTOMS, SUCH AS CARDIAC AND NEUROLOGICAL SYMPTOMS. IDENTIFY SUBSETS OF PATIENTS WITH IDENTIFIABLE GENOTYPIC OR PHENOTYPIC PROFILES LIKELY TO BENEFIT FROM SPECIFIC THERAPEUTIC APPROACHES IN A GIVEN PERIOD OF TIME. THERE ARE 4 MAIN AREAS OF INVESTIGATION WITH PROJECTS UNDERWAY (DESCRIBED BELOW): FRAXIN-PROTEIN, GENE EXPRESSION AND EPIGENETICS. NEUROLOGICAL-SENSORY/PERIPHERAL AND BRAIN. CARDIAC. METABOLIC. PROJECTS ONGOING AND COLLECTING DATA IN 2017 INCLUDE: TITLE: EARLY AND LONGITUDINAL ASSESSMENT OF NEURODEGENERATION IN THE BRAIN AND SPINAL CORD IN FRIEDREICH'S ATAXIA. UNIVERSITY OF MINNESOTA. TITLE: NEUROPHYSIOLOGIC BIOMARKERS IN FRIEDREICH'S ATAXIA. HOPITAL ERASME, BRUSSELS AND CHILDREN'S HOSPITAL OF PHILADELPHIA, PATITILE. IN-VIVO CONFOCAL IMAGING OF MEISSNER'S CORPUSCLES AS A BIOMARKER IN FRIEDREICH'S ATAXIA. UNIVERSITY OF ROCHESTER, NY. TITLE: INTERSTITIAL FIBROSIS, THE RENIN-ANGIOTENSIN-ALDOSTERONE SYSTEM AND BIOMARKERS IN THE CARDIAC DISEASE OF FRIEDREICH ATAXIA. MURDOCH CHILDRENS RESEARCH INSTITUTE, AUSTRALIA AND CHILDREN'S HOSPITAL OF PHILADELPHIA, PATITILE. LONGITUDINAL MEASUREMENT OF GAIT AND BALANCE IN FRIEDREICH ATAXIA. MURDOCH CHILDRENS RESEARCH INSTITUTE, AUSTRALIA AND UNIVERSITY OF SOUTH FLORIDA, TAMPA, FL. TITLE: CLINICAL OUTCOME MEASURES OF EFFICACY IN TREATMENT OF FRIEDREICH'S ATAXIA. UNIVERSITY OF FLORIDA, FL. TITLE: PROTEIN BIOMARKERS IN FRDA. CARDIOMYOPATHY TO MONITOR DISEASE PROGRESSION AND THERAPEUTIC EFFICACY. DUKE UNIVERSITY, NC. NEWLY AWARDED PROJECTS IN 2017. TITLE: MEASUREMENT OF THE TCA CYCLE RATE IN THE DENTATE NUCLEUS IN FRIEDREICH'S ATAXIA. UNIVERSITY OF MINNESOTA. TITLE: DEFINING THE MOLECULAR SIGNATURE OF FA TO IDENTIFY NOVEL BIOMARKERS. UNIVERSITY OF ALABAMA. FEW HIGHLIGHTED NEW RESEARCH GRANTS 2017. BRONYA J. KEATS INTERNATIONAL RESEARCH COLLABORATION AWARD. TITLE: SPEECH TREATMENT IN FRIEDREICH ATAXIA INVESTIGATORS. ADAM VOGEL, PHD-UNIVERSITY OF MELBOURNE, AUSTRALIA AND MATTHIS SYNOFZIK, PHD-UNIVERSITY OF TUBINGEN, GERMANY. DISORDERED SPEECH IS A DEVASTATING AND INEVITABLE CONSEQUENCE OF MANY HEREDITARY ATAXIAS, PARTICULARLY IN FRIEDREICH ATAXIA (FRDA). DR. VOGEL AND SYNOFZIK'S RESEARCH IN SPEECH AND ATAXIA HAS DESCRIBED THE INSIDIOUS FUNCTIONAL DECLINE, LOSS OF ABILITY TO CARRY OUT BASIC TASKS AND DIMINISHED QUALITY OF LIFE IN FRDA. THEIR SUCCESSFUL PILOT TRIAL OF A SPEECH TREATMENT IN HEREDITARY ATAXIAS USING PRINCIPLES OF MOTOR LEARNING (PML), NEUROPLASTICITY, AND BIOFEEDBACK, AS WELL AS INTERVENTIONS BY SYNOFZIK/SCHLTS DELIVERED VIA PHYSIOTHERAPY OR HIGHLY MOTIVATING EXERCISE VIDEO-GAMING HAVE NOW PAVED THE WAY FOR FIRST EVIDENCE-BASED THERAPIES IN FRDA.

Form 990, Part III, Line 4b:

RESEARCH CONFERENCES FARA ORGANIZES AND SUPPORTS A NUMBER OF SCIENTIFIC CONFERENCES TO IMPROVE SHARING OF KNOWLEDGE, INSIGHTS AND ADVANCES AND BUILD COLLABORATIONS AND SYNERGISTIC CONNECTIONS BETWEEN FA RESEARCHERS. GENE THERAPY MEETING WITH CBERIN FOLLOW-UP TO FARA'S 2016 GENE THERAPY MEETING, FARA, ALONG WITH THE FOUR COMPANIES AND TWO UNIVERSITIES THAT ARE EACH ADVANCING AGGRESSIVE GENE THERAPY PROGRAMS IN FA, MET WITH THE CENTER FOR BIOLOGICS EVALUATION AND RESEARCH (CBER) OF THE FDA. IN ADDITION TO FULL REPRESENTATION FROM CBER, MANY OTHER FDA OFFICES VERY IMPORTANT TO THE FA COMMUNITY SENT THEIR LEADERS AND STAFF - E.G., THE OFFICES OF RARE DISEASE PROGRAMS, ORPHAN PRODUCT DEVELOPMENT, HEALTH AND CONSTITUENT AFFAIRS, BIOMARKER VALIDATION, AND ELSEWHERE THROUGHOUT THE FDA. THE CBER STAFF INDICATED THAT THIS WAS THE LARGEST MEETING OF ITS KIND THEY HAVE HAD. THE MEETING HELPED SET THE STAGE FOR CONTINUED DIALOGUE WITH THE FDA ABOUT FA GENE THERAPY PROGRAMS AND ACCELERATION OF THOSE PROGRAMS INTO CLINICAL TRIALS THAT WOULD LATER BE REVIEWED BY FDA PERSONNEL WITH A MUCH BETTER UNDERSTANDING OF FA AND OUR PATIENTS.

INTERNATIONAL ATAXIA RESEARCH CONFERENCE (IARC) THE INTERNATIONAL ATAXIA RESEARCH CONFERENCE 2017 TOOK PLACE IN PISA, ITALY ON THE 27TH- 30TH OF SEPTEMBER, 2017. IARC 2017 WAS A RESEARCH CONFERENCE FOR ACADEMICS AND INDUSTRY SCIENTISTS INTERESTED IN BASIC AND TRANSLATIONAL RESEARCH IN THE ATAXIAS. FARA WAS ABLE TO PARTNER WITH INTERNATIONAL ATAXIA RESEARCH ORGANIZATIONS TO COHOST THE LARGEST ATAXIA RESEARCH CONFERENCE TO DATE. IARC 2017 WAS CO-ORGANIZED BY GOFAR, ATAXIA UK AND FARA AND SIMPLY BY THE NUMBERS INCLUDED OVER 400 ATTENDEES- RESEARCHERS, CLINICIANS, PATIENTS, AND GOVERNMENT, REGULATORY, AND INDUSTRY REPRESENTATIVES. REPRESENTATIVES FROM 22 COUNTRIES >15 PHARMA/ BIOTECH COMPANIES >30 PLATFORM PRESENTATIONS ON FA OVER 95 POSTER PRESENTATIONS ON FA. THE FOCUS OF THE MEETING WAS A COMPREHENSIVE SCIENTIFIC REVIEW OF NEW RESEARCH FROM DISEASE DEFINITION TO THERAPEUTIC TREATMENTS. THE CONFERENCE INCLUDED FRIEDREICH'S ATAXIA AND OTHER RECESSIVE ATAXIAS (E.G. ATAXIA WITH OCULOMOTOR APRAXIA), DOMINANT ATAXIAS (E.G. SPINOCEREBELLAR ATAXIAS, DRPLA, EPISODIC ATAXIAS) AND AUTOIMMUNE ATAXIAS. I. MOLECULAR BASIS OF DISEASE. II. DIAGNOSIS AND IDENTIFICATION OF DISEASE PATHWAYS ASSOCIATED WITH DISEASE. III. TRANSLATIONAL MODELS OF DISEASE. CELL AND ANIMAL MODELS OF ATAXIAS. DRUG DISCOVERY. IV. TOOLS FOR DISCOVERY. V. RECENT COMPOUNDS. VI. NATURAL HISTORY, BIOMARKERS, AND ENDPOINTS. DEFINING DISEASE MEASURES FOR USE IN ADVANCING TREATMENT DEVELOPMENT. VII. THERAPEUTICS, INTERVENTIONS AND CLINICAL DEVELOPMENT. THERAPEUTIC APPROACHES TO ATAXIAS, INCLUDING GENE THERAPY. REGULATORY CONSIDERATIONS IN TREATMENT TRIALS. PATIENT FOCUSED DRUG DEVELOPMENT MEETING AND VOICE OF THE PATIENT REPORT. IN 2017, FARA RELEASED THE FRIEDREICH'S ATAXIA "VOICE OF THE PATIENT" REPORT (LINK BELOW), A UNIQUE SUMMARY OF DIRECT TESTIMONY AND SURVEY RESPONSES FROM INDIVIDUALS LIVING WITH FRIEDREICH'S ATAXIA (FA). THIS REPORT IS BASED ON THE PROCEEDINGS SURROUNDING THE EXTERNALLY LED PATIENT FOCUSED DRUG DEVELOPMENT MEETING HELD ON JUNE 2, 2017 IN HYATTSVILLE, MD. THE GOAL OF THE MEETING WAS TO GIVE FA PATIENTS, AND THEIR FAMILIES, FRIENDS AND CAREGIVERS A FORUM TO DISCUSS THEIR PERSPECTIVES ON LIVING WITH THE DISEASE. WHAT SYMPTOMS PATIENTS EXPERIENCE, HOW IT AFFECTS THEIR LIVES, WHAT CONCERNS THEM ABOUT THE DISEASE, THEIR OPINIONS ON CURRENT AND FUTURE TREATMENT OPTIONS, AND EXPERIENCES WITH RESEARCH STUDIES AND CLINICAL TRIALS. THIS MEETING, AND THE REPORT, REPRESENT IMPORTANT ACCOMPLISHMENTS AND MILESTONES FOR OUR COMMUNITY. THIS WAS THE LARGEST FA MEETING EVER HELD WITH MORE THAN 400 PEOPLE PARTICIPATING IN PERSON OR ONLINE, INCLUDING >20 FDA REPRESENTATIVES, 25 DRUG COMPANY REPRESENTATIVES AND >350 FA PATIENT AND FAMILY PARTICIPANTS. IT WAS THE FIRST TIME FA PATIENTS AND OTHER MEMBERS OF THE FA COMMUNITY HAD AN OPPORTUNITY TO COMMUNICATE DIRECTLY WITH REPRESENTATIVES OF THE FOOD AND DRUG ADMINISTRATION. IMPORTANT THEMES AND INSIGHTS EMERGED THAT CAN INFORM DRUG DEVELOPMENT AND REGULATORY DECISION MAKING, SUCH AS THE CONCLUSION THAT "WHILE THE MAJORITY OF PATIENTS NOTED THAT BALANCE, DEXTERITY AND FATIGUE AFFECTED THEIR LIVES THE MOST NOW, MOST PATIENTS' GREATEST CONCERN FOR THEIR FUTURE IS THE DEVELOPMENT/ PROGRESSION OF CARDIOMYOPATHY IN THE FUTURE, BECAUSE IT IS LIFE SHORTENING". THIS DOCUMENT FAITHFULLY SUMMARIZES THE TESTIMONY, COMMENTS AND SURVEY RESPONSES SHARED BY INDIVIDUALS LIVING WITH FA AND THEIR FAMILY MEMBERS AND CAREGIVERS. THE REPORT CAN BE READ AT [HTTP://CUREFA.ORG/PDF/NEWS/FA-VOICE-OF-THE-PATIENT](http://curefa.org/pdf/news/fa-voice-of-the-patient). PDF A RECORDING OF THE MEETING IN ITS ENTIRETY CAN BE FOUND AT [HTTPS://WWW.YOUTUBE.COM/WATCH?V=VA1D4SQR5FW](https://www.youtube.com/watch?v=VA1D4SQR5FW).

Form 990, Part III, Line 4c:

EDUCATION, AWARENESS & OUTREACH PROGRAMS FRIEDREICH'S ATAXIA (FA) IS A RARE DISEASE, AFFECTING 1 IN 50,000 INDIVIDUALS. FARA IS DEDICATED TO 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 WEBINARS TO INFORM THE COMMUNITY ABOUT THE LATEST DEVELOPMENTS IN FA RESEARCH AND SOME OF THE RESULTS OF FUNDED GRANTS. FARA CO-ORGANIZED TWO PATIENT SYMPOSIUMS WITH CLINICAL RESEARCH NETWORK SITES, UNIVERSITY OF IOWA (MARCH 3RD) AND CHILDREN'S HOSPITAL OF PHILADELPHIA (OCTOBER 16TH, 2016, KING OF PRUSSIA, PA). 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 SYMPOSIA ACCOMMODATED MORE THAN 250 ATTENDEES. THE FARA AMBASSADOR PROGRAM WHICH WAS LAUNCHED IN 2011 WITH >20 PARTICIPANTS HAD A YEAR OF CONTINUED GROWTH AND ACTIVITY IN 2017. THE PROGRAM NOW INCLUDES 55 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 2017, FARA FACILITATED FORMAL TRAINING FOR THE AMBASSADOR LEADERSHIP TEAM AND AMBASSADORS. THE FOCUS FOR THE TRAINING WAS ON GENE THERAPY FOR FA- POSSIBLE APPROACHES, ROUTES OF ADMINISTRATION, AND ASSESSING RISK/ BENEFIT. THE AMBASSADOR BLOG FEATURED POSTS SUCH AS COMMUNITY EVENT SUMMARIES, MEET THE COMMUNITY INTERVIEWS WITH PEOPLE LIVING WITH FA, AND PATIENT PERSPECTIVES ON PARTICIPATING IN RESEARCH. IN 2017, THEY ACHIEVED >50 POSTS WITH OVER 14,500 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 20 CARDS PER MONTH. ANOTHER PROJECT FACILITATED BY THE AMBASSADOR GROUP ARE MONTHLY PEER GOOGLE HANGOUT GROUPS FOR THE GREATER FA COMMUNITY TO ATTEND AND CONNECT WITH ONE ANOTHER ONLINE. IN 2017, THE AMBASSADORS EXPANDED THIS EFFORT TO INCLUDE A HANG-OUT GROUP SPECIFICALLY FOR TEENS. FINALLY, THE AMBASSADORS HAVE CONTINUED IMPORTANT OUTREACH IN VISITING ACADEMIC LABORATORIES AND BIOPHARMACEUTICAL COMPANIES TO PROVIDE THE PATIENT PERSPECTIVE OF FA, AND SHARING THEIR PERSONAL EXPERIENCES AT FA SYMPOSIA.

SCHEDULE A
(Form 990 or 990EZ)

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.

2017

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

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 **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		
Total						

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

(Complete only if you checked the box on line 5, 7, 8, or 9 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) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
1	Gifts, grants, contributions, and membership fees received (Do not include any "unusual grant.")	4,460,547	5,572,073	5,701,123	5,388,847	7,518,776	28,641,366
2	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3	The value of services or facilities furnished by a governmental unit to the organization without charge						
4	Total. Add lines 1 through 3	4,460,547	5,572,073	5,701,123	5,388,847	7,518,776	28,641,366
5	The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						3,413,212
6	Public support. Subtract line 5 from line 4						25,228,154

Section B. Total Support

	Calendar year (or fiscal year beginning in) ▶	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
7	Amounts from line 4	4,460,547	5,572,073	5,701,123	5,388,847	7,518,776	28,641,366
8	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	9,955	14,051	19,755	29,213	37,283	110,257
9	Net income from unrelated business activities, whether or not the business is regularly carried on						
10	Other income (Do not include gain or loss from the sale of capital assets (Explain in Part VI))						
11	Total support. Add lines 7 through 10						28,751,623

12 Gross receipts from related activities, etc. (see instructions) **12**

13 **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

14	Public support percentage for 2017 (line 6, column (f) divided by line 11, column (f))	14	87.750%
15	Public support percentage for 2016 Schedule A, Part II, line 14	15	88.050%

16a **33 1/3% support test—2017.** If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and **stop here.** The organization qualifies as a publicly supported organization ▶

b **33 1/3% support test—2016.** 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 **stop here.** The organization qualifies as a publicly supported organization ▶

17a **10%-facts-and-circumstances test—2017.** 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 **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ▶

b **10%-facts-and-circumstances test—2016.** 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 **stop here.** Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization ▶

18 **Private foundation.** If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions ▶

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) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
1	Gifts, grants, contributions, and membership fees received (Do not include any "unusual grants.")						
2	Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3	Gross receipts from activities that are not an unrelated trade or business under section 513						
4	Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5	The value of services or facilities furnished by a governmental unit to the organization without charge						
6	Total. Add lines 1 through 5						
7a	Amounts included on lines 1, 2, and 3 received from disqualified persons						
b	Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c	Add lines 7a and 7b						
8	Public support. (Subtract line 7c from line 6)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ►		(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
9	Amounts from line 6						
10a	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b	Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c	Add lines 10a and 10b						
11	Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13	Total support. (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

15	Public support percentage for 2017 (line 8, column (f) divided by line 13, column (f))	15	
16	Public support percentage from 2016 Schedule A, Part III, line 15	16	

Section D. Computation of Investment Income Percentage

17	Investment income percentage for 2017 (line 10c, column (f) divided by line 13, column (f))	17	
18	Investment income percentage from 2016 Schedule A, Part III, line 17	18	

19a 33 1/3% support tests—2017. 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—2016. 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 on line 12 of 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
1	Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.		
	1		
2	Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).		
	2		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer (b) and (c) below.		
	3a		
b	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in Part VI when and how the organization made the determination.		
	3b		
c	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.		
	3c		
4a	Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes" and if you checked 12a or 12b in Part I, answer (b) and (c) below.		
	4a		
b	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.		
	4b		
c	Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.		
	4c		
5a	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer (b) and (c) below (if applicable). Also, provide detail in Part VI , including (i) the names and EIN numbers of the supported organizations added, substituted, or removed, (ii) the reasons for each such action, (iii) the authority under the organization's organizing document authorizing such action, and (iv) how the action was accomplished (such as by amendment to the organizing document).		
	5a		
b	Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
	5b		
c	Substitutions only. Was the substitution the result of an event beyond the organization's control?		
	5c		
6	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in Part VI .		
	6		
7	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
	7		
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).		
	8		
9a	Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in Part VI .		
	9a		
b	Did one or more disqualified persons (as defined in line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in Part VI .		
	9b		
c	Did a disqualified person (as defined in line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI .		
	9c		
10a	Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.		
	10a		
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.)		
	10b		

Part IV Supporting Organizations (continued)

		Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?		
a	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	A family member of a person described in (a) above?		
c	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>		

Section B. Type I Supporting Organizations

		Yes	No
1	Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <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>		
2	Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <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>		

Section C. Type II Supporting Organizations

		Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <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>		

Section D. All Type III Supporting Organizations

		Yes	No
1	Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
2	Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization (s) or (ii) serving on the governing body of a supported organization? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
3	By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally-Integrated Supporting Organizations

1	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions)		
a	<input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
b	<input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
c	<input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).		
2	Activities Test Answer (a) and (b) below.		
a	Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <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	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>		
3	Parent of Supported Organizations Answer (a) and (b) below.		
a	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>Provide details in Part VI.</i>		
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>		

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

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

Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	1	
2	Recoveries of prior-year distributions	2	
3	Other gross income (see instructions)	3	
4	Add lines 1 through 3	4	
5	Depreciation and depletion	5	
6	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6	
7	Other expenses (see instructions)	7	
8	Adjusted Net Income (subtract lines 5, 6 and 7 from line 4)	8	
Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year)	1	
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	Total (add lines 1a, 1b, and 1c)	1d	
e	Discount claimed for blockage or other factors (explain in detail in Part VI)		
2	Acquisition indebtedness applicable to non-exempt use assets	2	
3	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	Minimum Asset Amount (add line 7 to line 6)	8	
Section C - Distributable Amount			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	Distributable Amount. 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 Total annual distributions. 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 2017 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-2017	(iii) Distributable Amount for 2017
1 Distributable amount for 2017 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2017 (reasonable cause required-- explain in Part VI) See instructions			
3 Excess distributions carryover, if any, to 2017			
a			
b From 2013.			
c From 2014.			
d From 2015.			
e From 2016.			
f Total of lines 3a through e			
g Applied to underdistributions of prior years			
h Applied to 2017 distributable amount			
i Carryover from 2012 not applied (see instructions)			
j Remainder Subtract lines 3g, 3h, and 3i from 3f			
4 Distributions for 2017 from Section D, line 7			
a Applied to underdistributions of prior years			
b Applied to 2017 distributable amount			
c Remainder Subtract lines 4a and 4b from 4			
5 Remaining underdistributions for years prior to 2017, if any Subtract lines 3g and 4a from line 2 If the amount is greater than zero, explain in Part VI See instructions			
6 Remaining underdistributions for 2017 Subtract lines 3h and 4b from line 1 If the amount is greater than zero, explain in Part VI See instructions			
7 Excess distributions carryover to 2018. Add lines 3j and 4c			
8 Breakdown of line 7			
a Excess from 2013.			
b Excess from 2014.			
c Excess from 2015.			
d Excess from 2016.			
e Excess from 2017.			

Part VI **Supplemental Information.** Provide the explanations required by Part II, line 10, Part II, line 17a or 17b, Part III, line 12, Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c, Part IV, Section B, lines 1 and 2, Part IV, Section C, line 1, Part IV, Section D, lines 2 and 3, Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b, Part V, line 1, Part V, Section B, line 1e, Part V Section D, lines 5, 6, and 8, and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.)

Facts And Circumstances Test

SCHEDULE C
(Form 990 or 990-EZ)

Political Campaign and Lobbying Activities

OMB No 1545-0047

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

2017

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

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 the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE	Employer identification number 52-2122720
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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 (see instructions for definition of "political campaign activities")
- 2 Political campaign activity expenditures (see instructions) ▶ \$ _____
- 3 Volunteer hours for political campaign activities (see instructions) _____

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 ▶ \$ _____ 0
- 2 Enter the amount of any excise tax incurred by organization managers under section 4955 ▶ \$ _____ 0
- 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-
1				
2				
3				
4				
5				
6				

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

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals												
1a	Total lobbying expenditures to influence public opinion (grass roots lobbying)	3,879													
b	Total lobbying expenditures to influence a legislative body (direct lobbying)	2,621													
c	Total lobbying expenditures (add lines 1a and 1b)	6,500													
d	Other exempt purpose expenditures	7,620,980													
e	Total exempt purpose expenditures (add lines 1c and 1d)	7,627,480													
f	Lobbying nontaxable amount Enter the amount from the following table in both columns	531,374													
<table border="1" style="width: 100%;"> <thead> <tr> <th style="width: 50%;">If the amount on line 1e, column (a) or (b) is:</th> <th style="width: 50%;">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														
g	Grassroots nontaxable amount (enter 25% of line 1f)	132,844													
h	Subtract line 1g from line 1a If zero or less, enter -0-	0													
i	Subtract line 1f from line 1c If zero or less, enter -0-	0													
j	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) 2014	(b) 2015	(c) 2016	(d) 2017	(e) Total
2a Lobbying nontaxable amount	423,349	458,529	465,526	531,374	1,878,778
b Lobbying ceiling amount (150% of line 2a, column(e))					2,818,167
c Total lobbying expenditures	9,100	8,106	6,200	6,500	29,906
d Grassroots nontaxable amount	105,837	114,632	116,382	132,844	469,695
e Grassroots ceiling amount (150% of line 2d, column (e))					704,543
f Grassroots lobbying expenditures	5,100	4,731	3,700	3,879	17,410

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
1 During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of			
a Volunteers?			
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?			
c Media advertisements?			
d Mailings to members, legislators, or the public?			
e Publications, or published or broadcast statements?			
f Grants to other organizations for lobbying purposes?			
g Direct contact with legislators, their staffs, government officials, or a legislative body?			
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?			
i Other activities?			
j Total Add lines 1c through 1i			
2a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?			
b If "Yes," enter the amount of any tax incurred under section 4912			
c If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

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
1 Were substantially all (90% or more) dues received nondeductible by members?	1	
2 Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2	
3 Did the organization agree to carry over lobbying and political expenditures from the prior year?	3	

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No" OR (b) Part III-A, line 3, is answered "Yes."

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

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

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

OMB No 1545-0047
2017
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 (e g , recreation or education) Preservation of an 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 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 8/17/06, 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 SFAS 116 (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 SFAS 116 (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 SFAS 116 (ASC 958) relating to these items

a Revenue included on Form 990, Part VIII, line 1 ► \$ _____

b Assets included in Form 990, Part X ► \$ _____

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 are a 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 programs
 - 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 | |
| d Additions during the year | |
| e Distributions during the year | |
| f Ending balance | |
- 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 in 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** Temporarily restricted 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 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	6,129	1,006
Total. Add lines 1a through 1e (Column (d) must equal Form 990, Part X, column (B), line 10(c)) . . . ▶				1,006

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)		
Total. (Column (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) INVESTMENT IN EDISON PHARMACEUTICALS, INC	1,091,500	C
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
Total. (Column (b) must equal Form 990, Part X, col (B) line 13.) ▶	1,091,500	

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)	
Total. (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.

(a) Description of liability	(b) Book value
1. (1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (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 FIN 48 (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	8,525,697
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12		
a	Net unrealized gains (losses) on investments	2a	182,994
b	Donated services and use of facilities	2b	
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII)	2d	822,484
e	Add lines 2a through 2d	2e	1,005,478
3	Subtract line 2e from line 1	3	7,520,219
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	13,318
c	Add lines 4a and 4b	4c	13,318
5	Total revenue Add lines 3 and 4c . (This must equal Form 990, Part I, line 12)	5	7,533,537

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	7,620,980
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	
d	Other (Describe in Part XIII)	2d	822,484
e	Add lines 2a through 2d	2e	822,484
3	Subtract line 2e from line 1	3	6,798,496
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	13,318
c	Add lines 4a and 4b	4c	13,318
5	Total expenses Add lines 3 and 4c . (This must equal Form 990, Part I, line 18)	5	6,811,814

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

Return Reference	Explanation
See Additional Data Table	

Part XIII Supplemental Information *(continued)*

Return Reference	Explanation

Additional Data

Software ID:

Software Version:

EIN: 52-2122720

Name: FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Supplemental Information

Return Reference	Explanation
PART XI, LINE 2D - OTHER ADJUSTMENTS	SPECIAL EVENTS EXPENSE

Supplemental Information

Return Reference	Explanation
PART XI, LINE 4B - OTHER ADJUSTMENTS	INVESTMENT MANAGEMENT FEES

Supplemental Information

Return Reference	Explanation
PART XII, LINE 2D - OTHER ADJUSTMENTS	SPECIAL EVENTS EXPENSE

Supplemental Information

Return Reference	Explanation
PART XII, LINE 4B - OTHER ADJUSTMENTS	INVESTMENT MANAGEMENT FEES

**SCHEDULE F
(Form 990)**

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

▶ Complete if the organization answered "Yes" to Form 990, Part IV, line 14b, 15, or 16.
▶ Attach to Form 990.
▶ Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047
2017
Open to Public Inspection

Name of the organization
FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number
52-2122720

Part I **General Information on Activities Outside the United States.** Complete if the organization answered "Yes" to 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 region	(d) Activities conducted in region (by type) (e g , 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 region	(f) Total expenditures for and investments in region
See Add'l Data					
3a Sub-total	0	0			870,224
b Total from continuation sheets to Part I					0
c Totals (add lines 3a and 3b)	0	0			870,224

Part II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" to 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 non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
See Add'l Data								

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 ▶ _____

3 Enter total number of other organizations or entities ▶ _____

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, do not 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, do not file with Form 990)* Yes No

Part V Supplemental Information

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

Return Reference	Explanation
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

Additional Data

Software ID:

Software Version:

EIN: 52-2122720

Name: FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Form 990 Schedule F Part I - Activities Outside The United States

(a) Region	(b) Number of offices in the region	(c) Number of employees or agents in region	(d) Activities conducted in region (by type) (i.e., fundraising, program services, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for region
EUROPE			GRANTS TO RECIPIENTS LOCATED IN REGION	RESEARCH AND GRANT PROGRAM	518,419
EAST ASIA AND THE PACIFIC			GRANTS TO RECIPIENTS LOCATED IN REGION	RESEARCH AND GRANT PROGRAM	299,955

Form 990 Schedule F Part I - Activities Outside The United States

(a) Region	(b) Number of offices in the region	(c) Number of employees or agents in region	(d) Activities conducted in region (by type) (i.e., fundraising, program services, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for region
SOUTH AMERICA			GRANTS TO RECIPIENTS LOCATED IN REGION	RESEARCH AND GRANT PROGRAM	51,850

Form 990 Schedule F Part II - Grants or Entities Outside The United States

(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)
		EAST ASIA AND THE PACIFIC	MEDICAL RESEARCH	199,955	WIRE			
		EUROPE	MEDICAL RESEARCH	28,729	WIRE			

Form 990 Schedule F Part II - Grants or Entities Outside The United States

(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	20,000	WIRE			
		EUROPE	RESEARCH CONFERENCE	21,650	WIRE			

Form 990 Schedule F Part II - Grants or Entities Outside The United States

(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	87,000	WIRE			
		EUROPE	MEDICAL RESEARCH	47,540	WIRE			

Form 990 Schedule F Part II - Grants or Entities Outside The United States

(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	125,000	WIRE			
		SOUTH AMERICA	MEDICAL RESEARCH	51,850	WIRE			

Form 990 Schedule F Part II - Grants or Entities Outside The United States

(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	98,500	WIRE			
		EUROPE	MEDICAL RESEARCH	90,000	WIRE			

Form 990 Schedule F Part II - Grants or Entities Outside The United States								
(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)
		EAST ASIA AND THE PACIFIC	MEDICAL RESEARCH	100,000	WIRE			

SCHEDULE G (Form 990 or 990-EZ)

Supplemental Information Regarding Fundraising or Gaming Activities

OMB No 1545-0047

2017

Open to Public Inspection

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

Attach to Form 990 or Form 990-EZ.

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

Department of the Treasury Internal Revenue Service

Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number 52-2122720

Part I Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

- 1 Indicate whether the organization raised funds through any of the following activities. Check all that apply. a Mail solicitations, b Internet and email solicitations, c Phone solicitations, d In-person solicitations, e Solicitation of non-government grants, f Solicitation of government grants, g Special fundraising events. 2a Did the organization have a written or oral agreement with any individual... 2b If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements...

Table with 6 columns: (i) Name and address of individual or entity (fundraiser), (ii) Activity, (iii) Did fundraiser have custody or control of contributions?, (iv) Gross receipts from activity, (v) Amount paid to (or retained by) fundraiser listed in col (i), (vi) Amount paid to (or retained by) organization. Includes a Total row at the bottom.

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing

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)
		FARA ENERGY BALL (event type)	RIDE ATAXIA PHILADELPHIA (event type)	68 (total number)	Total events (add col (a) through col (c))
Revenue	1 Gross receipts	1,905,530	500,812	2,133,926	4,540,268
	2 Less Contributions	1,419,086	470,233	1,866,808	3,756,127
	3 Gross income (line 1 minus line 2)	486,444	30,579	267,118	784,141
Direct Expenses	4 Cash prizes				
	5 Noncash prizes				
	6 Rent/facility costs				
	7 Food and beverages				
	8 Entertainment				
	9 Other direct expenses	363,442	52,029	407,013	822,484
	10 Direct expense summary Add lines 4 through 9 in column (d) ▶				822,484
11 Net income summary Subtract line 10 from line 3, column (d) ▶				-38,343	

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))
		1 Gross revenue			
Direct Expenses	2 Cash prizes				
	3 Noncash prizes				
	4 Rent/facility costs				
	5 Other direct expenses				
6 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		
7 Direct expense summary Add lines 2 through 5 in column (d) ▶					
8 Net gaming income summary Subtract line 7 from line 1, column (d) ▶					

9 Enter the state(s) in which the organization conducts gaming activities _____

a Is the organization licensed to conduct gaming activities in each of these states? 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 _____

- 11** Does the organization conduct gaming activities with nonmembers? Yes No
- 12** Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? Yes No
- 13** Indicate the percentage of gaming activity conducted in
- | | | |
|----------|-----------------------------|---|
| a | The organization's facility | % |
| b | An outside facility | % |

14 Enter the name and address of the person who prepares the organization's gaming/special events books and records

Name ▶ FELICIA DEROSA

Address ▶ 533 W UWCHLAN AVENUE
DOWNTOWN, PA 19335

- 15a** Does the organization have a contract with a third party from whom the organization receives gaming revenue? Yes No
- b** If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ _____ and the amount of gaming revenue retained by the third party ▶ \$ _____
- c** If "Yes," enter name and address of the third party
- Name ▶ _____
- Address ▶ _____

16 Gaming manager information

Name ▶ _____

Gaming manager compensation ▶ \$ _____

Description of services provided ▶ _____

Director/officer Employee Independent contractor

- 17** Mandatory distributions
- a** Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? Yes No
- b** Enter the amount of distributions required under state law distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ _____

Part IV Supplemental Information. Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information (see instructions).

Return Reference	Explanation
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Schedule I (Form 990)

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

OMB No 1545-0047

2017

Open to Public Inspection

Department of the Treasury Internal Revenue Service

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

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

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...
2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States

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.

Table with 8 columns: (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, (g) Description of non-cash assistance, (h) Purpose of grant or assistance. Rows 1-12.

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

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 noncash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					
(7)					

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

Return Reference	Explanation
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

Additional Data

Software ID:
Software Version:
EIN: 52-2122720
Name: FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
CALIFORNIA INSTITUTE OF TECHNOLOGY 1200 EAST CALIFORNIA BLVD 123-15 PASADENA, CA 91125	95-1643307	501(C)(3)	150,000				MEDICAL RESEARCH
DUKE UNIVERSITY 2200 W MAIN ST SUITE 710 DURHAM, NC 277054677	56-0532129	501(C)(3)	100,000				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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)	1,931,202				MEDICAL RESEARCH
EMORY UNIVERSITY 201 DOWMAN DR ATLANTA, GA 30322	58-0566256	501(C)(3)	26,800				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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 OKLAHOMA 865 RESEARCH PARKWAY STE 540 OKLAHOMA CITY, OK 73104	73-1377584	501(C)(3)	63,958				MEDICAL RESEARCH
OHIO STATE UNIVERSITY 333 W 10TH AVE COLUMBUS, OH 43210	31-6025986	501(C)(3)	8,100				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
PFIZER INC 235 EAST 42ND STREET NEW YORK, NY 10017	13-5315170		25,000				MEDICAL RESEARCH
REGENTS OF THE UNIVERSITY OF MINNESOTA 200 SE OAK ST 600 MINNEAPOLIS, MN 55455	41-6007513	501(C)(3)	494,384				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
SCRIPPS RESEARCH INSTITUTE 10550 NORTH TORREY PINES ROAD OSP-TPC7 LA JOLLA, CA 92037	33-0435954	501(C)(3)	68,428				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)	151,228				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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 FLORIDA DEPT OF NEUROLOGY L3-100 MCKNIGHT BRAIN INSTITUTE NEWELL DRIVE GAINESVILLE, FL 32611	59-6002052	501(C)(3)	70,100				MEDICAL RESEARCH
UNIVERSITY OF IOWA DEPT OF PEDIATRICS 200 HAWKINS DRIVE IOWA CITY, IA 52242	42-6004813	501(C)(3)	9,600				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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 ROCHESTER 515 HYLAN BUILDING RC BOX 270140 ROCHESTER, NY 14627	16-0743209	501(C)(3)	107,826				MEDICAL RESEARCH
UNIVERSITY OF SOUTH FLORIDA FOUNDATION 4202 EAST FOWLER AVENUE TAMPA, FL 33620	59-0879015	501(C)(3)	150,000				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
WEILL MEDICAL COLLEGE OF CORNELL UNIVERSITY 445 E 69TH ST NEW YORK, NY 10021	13-1623978	501(C)(3)	150,000				MEDICAL RESEARCH
ALBANY RESEARCH INSTITUTE 113 HOLLAND AVE ALBANY, NY 12208	14-1716021	501(C)(3)	122,614				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
THE UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER 5323 HARRY HINES BLVD DALLAS, TX 75390	75-6002868	501(C)(3)	62,958				MEDICAL RESEARCH
UNIVERSITY OF SOUTH FLORIDA 4202 EAST FOWLER AVENUE TAMPA, FL 33620	59-3102112	501(C)(3)	16,380				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
BAYLOR COLLEGE OF MEDICINE 1 BAYLOR PLAZA HOUSTON, TX 77030	74-1613878	501(C)(3)	250,000				MEDICAL RESEARCH
CATABASIS PHARMACEUTICALS INC 1 KENDALL SQUARE B14202 CAMBRIDGE, MA 02139	26-3687168		79,000				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
CRITICAL PATH INSTITUTE 1730 E RIVER ROAD 200 TUCSON, AZ 85718	20-1991334	501(C)(3)	91,950				MEDICAL RESEARCH
Q-STATE BIOSCIENCES INC 179 SIDNEY ST CAMBRIDGE, MA 02139	46-2469775		100,734				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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
TRANSLATE BIO 29 HARTWELL AVE LEXINGTON, MA 02421	45-1858251		86,063				MEDICAL RESEARCH
UNIVERSITY OF CALIFORNIA LOS ANGELES 110 WESTWOOD PLAZA LOS ANGELES, CA 90095	95-6006143	501(C)(3)	91,500				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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 MASSACHUSETTS 1 CAMPUS CENTER WAY AMHERST, MA 01003	54-2084125	501(C)(3)	150,000				MEDICAL RESEARCH
UNIVERSITY OF VIRGINIA 580 MASSIE ROAD CHARLOTTESVILLE, VA 22901	54-6001796	501(C)(3)	150,000				MEDICAL RESEARCH

Form 990, Schedule I, Part II, Grants and Other Assistance to Domestic Organizations and Domestic Governments.

(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 WISCONSIN 1308 W DAYTON STREET MADISON, WI 53706	39-6006492	501(C)(3)	156,000				MEDICAL RESEARCH
UNIVERSITY OF CALIFORNIA DAVIS 1850 RESEARCH PARK DRIVE DAVIS, CA 95618	94-6036494	501(C)(3)	90,000				MEDICAL RESEARCH

Schedule L
(Form 990 or 990-EZ)

Transactions with Interested Persons

OMB No 1545-0047

▶ **Complete if the organization answered "Yes" on Form 990, Part IV, lines 25a, 25b, 26, 27, 28a, 28b, or 28c, or Form 990-EZ, Part V, line 38a or 40b.**
 ▶ **Attach to Form 990 or Form 990-EZ.**
 ▶ **Information about Schedule L (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.**

2017

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE	Employer identification number 52-2122720
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Part I Excess Benefit Transactions (section 501(c)(3), section 501(c)(4), and 501(c)(29) organizations only)
 Complete if the organization answered "Yes" on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b

1	(a) Name of disqualified person	(b) Relationship between disqualified person and organization	(c) Description of transaction	(d) Corrected?	
				Yes	No

2 Enter the amount of tax incurred by organization managers or disqualified persons during the year under section 4958 ▶ \$ _____

3 Enter the amount of tax, if any, on line 2, above, reimbursed by the organization ▶ \$ _____

Part II Loans to and/or From Interested Persons.
 Complete if the organization answered "Yes" on Form 990-EZ, Part V, line 38a, or Form 990, Part IV, line 26, or if the organization reported an amount on Form 990, Part X, line 5, 6, or 22

(a) Name of interested person	(b) Relationship with organization	(c) Purpose of loan	(d) Loan to or from the organization?		(e) Original principal amount	(f) Balance due	(g) In default?		(h) Approved by board or committee?		(i) Written agreement?	
			To	From			Yes	No	Yes	No	Yes	No
Total						▶	\$					

Part III Grants or Assistance Benefiting Interested Persons.
 Complete if the organization answered "Yes" on Form 990, Part IV, line 27.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of assistance	(d) Type of assistance	(e) Purpose of assistance

Part IV Business Transactions Involving Interested Persons.

Complete if the organization answered "Yes" on Form 990, Part IV, line 28a, 28b, or 28c.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of transaction	(d) Description of transaction	(e) Sharing of organization's revenues?	
				Yes	No
(1) THOMAS HAMILTON	BOARD MEMBER	1,149,883	CONTRIBUTIONS FROM BOARD MEMBER'S ORGANIZATION (CUREFA) TO FRIEDREICH'S ATAXIA RESEARCH ALLIANCE TO SUPPORT RESEARCH AND GRANT PROGRAMS		No

Part V Supplemental Information

Provide additional information for responses to questions on Schedule L (see instructions)

Return Reference	Explanation

**SCHEDULE M
(Form 990)**

Noncash Contributions

OMB No 1545-0047

2017

▶ **Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.**
 ▶ **Attach to Form 990.**
 ▶ **Information about Schedule M (Form 990) and its instructions is at www.irs.gov/form990**

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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	12	360,452	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				
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	
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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 is not required to be used for exempt purposes for the entire holding period?

	Yes	No
30a		No
31		No
32a		No

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?

32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?

b If "Yes," describe in Part II

33 If the organization did not report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II

Part II**Supplemental Information.**

Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.

Return Reference

Explanation

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Name of the organization
FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

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.

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

OMB No 1545-0047

2017

Open to Public Inspection

Employer identification number

52-2122720

990 Schedule O, Supplemental Information

Return Reference	Explanation
<p>FORM 990, PART III, LINE 4A</p>	<p>THE CLINICAL SPACE FOR FRDA NOW URGENTLY WARRANTS AN EVIDENCE BASED SPEECH REHABILITATION PROGRAM THAT CATERS TO THE PHYSICAL, SENSORY AND MOTOR LIMITATIONS OF PEOPLE WITH FRDA TO THAT END, THEY HAVE DESIGNED A HOME-BASED, INTENSIVE FOUR-WEEK SPEECH EXERCISE PROGRAM DESIGNED TO IMPROVE SPEECH IN PEOPLE WITH FRDA SPECIFICALLY, THEIR AIM IS TO EVALUATE THE HYPOTHESIS THAT INTENSIVE SPEECH REHABILITATION USING BIOFEEDBACK WILL LEAD TO IMPROVED SPEECH INTELLIGIBILITY (I.E., ABILITY TO BE UNDERSTOOD) IN FRDA COMPARED TO EXISTING CARE IF THIS HYPOTHESIS IS SUPPORTED, THEIR RESEARCH WILL CHANGE THE LANDSCAPE OF CLINICAL CARE FOR FRDA GLOBALLY BY INFLUENCING HEALTH POLICY AND IMPROVING PATIENT OUTCOMES IN THIS DISEASE GROUP AND LIKELY ALSO OTHER DEGENERATIVE ATAXIAS 2017 KYLE BRYANT TRANSLATIONAL RESEARCH AWARD TITLE CRISPR / CAS9 MEDIATED DELETION OF THE HUMAN FXN INTRONIC TRINUCLEOTIDE REPEAT AS A THERAPEUTIC APPROACH FOR FRIEDREICH'S ATAXIA INVESTIGATORS TONY HO, MD- CRISPR THERAPEUTICS AND MAREK NAPIERALA, PHD- UNIVERSITY OF ALABAMA AT BIRMINGHAM IN THIS GRANT, THE INVESTIGATORS PROPOSE TO USE THE CRISPR / CAS9 SYSTEM TO REMOVE THE EXPANDED REPEAT SEQUENCE FROM THE FXN GENE IN FA PATIENT-DERIVED STEM CELLS AND IN A FA MOUSE MODEL THEY WILL SCREEN FOR AND IDENTIFY CRISPR REAGENTS THAT EFFICIENTLY REMOVE THE EXPANDED REPEAT SEQUENCES AND WILL OPTIMIZE THE DELIVERY OF THESE REAGENTS TO PATIENT-DERIVED CELLS AND TO THE FA-MODEL MOUSE THEY WILL EXAMINE THE RESTORATION OF FRATAXIN PROTEIN FUNCTION AFTER REPEAT EXPANSION REMOVAL THIS PROOF OF CONCEPT STUDY WILL ENABLE THE GENERATION OF CRISPR-BASED THERAPEUTIC REAGENTS AND STRATEGIES TO DELIVER THESE REAGENTS TO PATIENT CELLS THEREBY POTENTIALLY SUPPORTING THE DEVELOPMENT OF AN EFFECTIVE THERAPY FOR FA 2017 GENERAL GRANT HIGHLIGHTS TITLE SUPPRESSING THE IRON/SPHINGOLIPID/PDK/MEF2 PATHWAY IMPLICATED IN FA FOR THERAPEUTIC EVALUATION INVESTIGATOR HUGO BELLEN, PHD- BAYLOR COLLEGE OF MEDICINE, TX MOST FRDA PATIENTS CARRY TRINUCLEOTIDE REPEAT EXPANSIONS IN BOTH ALLELES OF FRATAXIN (FXN) FXN IS EVOLUTIONARILY CONSERVED, WITH A SIMILAR GENE VERSION IN OTHER ANIMAL SPECIES, INCLUDING YEAST, PLANTS, AND FRUIT FLIES (3) DR BELLEN'S LAB STUDIES THE FRUIT FLY FRATAXIN GENE (FH) IN PHOTORECEPTORS (PRS) OF THE FRUIT FLY EYE THEY IDENTIFIED A LOSS OF FUNCTION MUTATION IN THE FH GENE THAT RESULTS IN LATE-PUPAL LETHALITY IN A FORWARD GENETIC SCREEN DESIGNED TO ISOLATE MUTATIONS THAT CAUSE NEURODEGENERATION THEY DISCOVERED THAT LOSS OF FH CAUSES A RAPID FUNCTIONAL AND MORPHOLOGICAL LOSS OF PR IN MUTANT EYE CLONES ADDITIONALLY, THEY OBSERVED AN ELEVATION OF IRON (I.E., FE2+ AND FE3+) IN NUMEROUS TISSUES IN FH MUTANTS THIS ACCUMULATION OF FE ACTIVATES SPHINGOLIPID SYNTHESIS-LIPID MOLECULES THAT SERVE TO PROMOTE CERTAIN CELLULAR SIGNALS WITHIN A CELL ACTIVATION OF SPHINGOLIPID SYNTHESIS IN TURN TRIGGERED THE PDK1/ MEF2 SIGNALING PATHWAY, A PATHWAY THAT IS REQUIRED IN MUSCLES DURING DEVELOPMENT (4) OVERACTIVA</p>

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART III, LINE 4A	<p>TION OF THE SPHINGOLIPID ACTIVATED PDK1/MEF2 PATHWAY CAUSES THE DEMISE OF NEURONS AND LEAD S TO THE ENHANCED TRANSCRIPTION OF MUSCLE GENES IN MANY TISSUES WHEN THEY REDUCE IRON TOXICITY, SUPPRESS SPHINGOLIPID BIOSYNTHESIS, OR DECREASE PDK1 OR MEF2 LEVELS, THEY CAN DELAY NEURODEGENERATION IN FH MUTANT CELLS SIMILARLY, MICE ENGINEERED TO HAVE REDUCED EXPRESSION OF FXN IN THE BRAIN, HAVE A REDUCED LIFESPAN (4 MONTHS INSTEAD OF 2 YEARS), DISPLAY A SEVERE NEURODEGENERATIVE PHENOTYPE, EXHIBIT IRON ACCUMULATION AND SHOW AN ACTIVATION OF PDK 1/MEF2 PATHWAY INTERESTINGLY, HEARTS OF FRDA PATIENTS EXHIBIT AN IRON ACCUMULATION AND INCREASED PDK1/MEF2 SIGNALING IN THE HEART, ACTIVATION OF THE MEF2 PATHWAY MAY UNDERLIE THE OBSERVED CARDIAC HYPERTROPHY, UNLIKE WHAT IS OBSERVED IN NEURONS INDEED, OVEREXPRESSION OF MEF2 ISOFORMS IN THE HEART HAS BEEN SHOWN TO CAUSE A CARDIAC HYPERTROPHY THESE DATA SUGGEST THAT THE IRON/SPHINGOLIPID/PDK1/MEF2 PATHWAY MAY PLAY AN IMPORTANT ROLE IN THE PATHOGENESIS OF FRDA AND PROVIDE AN AVENUE TO ATTENUATE OR DELAY SYMPTOMS IN PATIENTS AS THE PATHWAY IS EVOLUTIONARILY CONSERVED IN MAMMALS (5) CO-SPONSOR CURE FA FOUNDATION TITLE EVALUATING NOVEL CAPSID ENGINEERED FOR EFFICIENT CNS TRANSDUCTION, AS FRATAXIN GENE DELIVERY VEHICLES INVESTIGATOR BENJAMIN DEVERMAN, PHD- CALIFORNIA INSTITUTE OF TECHNOLOGY, CA) AA V-BASED FXN GENE THERAPY IS A PROMISING APPROACH FOR THE TREATMENT OF FRIEDREICH'S ATAXIA (FA), ESPECIALLY FOR THE PREVENTION AND/OR REVERSAL OF HEART ABNORMALITIES ASSOCIATED WITH THE DISEASE HOWEVER, TREATING THE PERIPHERAL AND CENTRAL NERVOUS SYSTEM ASPECTS OF FA WITH A GENE THERAPY HAS NOT BEEN POSSIBLE DUE TO THE UNSOLVED CHALLENGE OF ACHIEVING WIDESPREAD AND EFFICIENT GENE DELIVERY THROUGHOUT THE YOUNG ADULT CENTRAL AND PERIPHERAL NERVOUS SYSTEMS USING NOVEL ADENO-ASSOCIATED VIRUSES (AAV) DR DEVERMAN'S LAB RECENTLY EVOLVED FOR ENHANCED NONINVASIVE GENE TRANSFER TO BOTH THE CENTRAL AND PERIPHERAL NERVOUS SYSTEMS (1-2), THEY HAVE CREATED FRATAXIN (FXN) EXPRESSING VECTORS THAT CAN EFFICIENTLY RESTORE FXN EXPRESSION ACROSS MANY OF THE CELL TYPES THOUGHT TO BE MOST SENSITIVE TO REDUCED FXN LEVELS IN FA CNS NEURONS AND GLIA, PERIPHERAL SENSORY NEURONS, AND CARDIAC MUSCLE THEY ARE NOW TESTING WHETHER FXN EXPRESSION BY THESE VECTORS CAN AMELIORATE THE NEUROLOGICAL SYMPTOMS AND PATHOLOGIES IN THE FXN KIKO MODEL OF FA THERE OBJECTIVES ARE IN LINE WITH FARA'S PROGRAM PRIORITIES FOR ADVANCING DRUG DISCOVERY WITH THE AIM OF DEVELOPING APPROACHES FOR INCREASING FXN PROTEIN LEVELS CO-SPONSOR FARA AUSTRALIA TITLE SYSTEMATIC IDENTIFICATION OF PHARMACOLOGICAL ACTIVATORS OF THE REPRESSED FXN GENE TO TREAT FRIEDREICH ATAXIA INVESTIGATOR MICHAEL GREEN, MD, PHD - UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL, USA FRIEDREICH'S ATAXIA IS CAUSED BY A GAA/OTC TRIPLET REPEAT EXPANSION IN THE FIRST INTRON OF THE FXN GENE (HEREAFTER CALLED THE TRIPLET REPEAT EXPANSION (TRE)-FXN GENE), WHICH REPRESSES FXN TRANSCRIPTION REACTIVATION OF THE R</p>

990 Schedule O, Supplemental Information

Return Reference	Explanation
<p>FORM 990, PART III, LINE 4A</p>	<p>EPRESSED TRE-FXN GENE IS A POTENTIAL THERAPEUTIC APPROACH FOR FA THAT WOULD CORRECT THE ROOT CAUSE OF THE DISEASE RATHER THAN A SECONDARY, DOWNSTREAM CONSEQUENCE OF THE FRATAXIN DEFICIENCY DR GREEN HYPOTHESIZES THAT THERE ARE A NUMBER OF EPIGENETIC REPRESSORS WHOSE PHARMACOLOGICAL INHIBITION WILL LEAD TO UPREGULATED TRANSCRIPTION OF THE TRE-FXN GENE, RESULTING IN INCREASED FRATAXIN LEVELS AND DECREASED DISEASE SYMPTOMATOLOGY AS PROOF-OF-CONCEPT, HE PERFORMED A SMALL-SCALE CANDIDATE-BASED RNA INTERFERENCE (RNAI) SCREEN, WHICH IDENTIFIED 10 EPIGENETIC REGULATORS OF THE TRE-FXN GENE, FOR CONVENIENCE HE REFERS TO THESE EPIGENETIC REGULATORS AS FXN REPRESSING FACTORS (FXN-RFS) HE THEN SHOWED THAT SMALL MOLECULE INHIBITORS OF THESE FXN-RFS CAN ALSO UPREGULATE TRANSCRIPTION OF THE TRE-FXN GENE HIS PRELIMINARY RESULTS STRONGLY SUPPORT THE FEASIBILITY OF OUR APPROACH FOR IDENTIFYING SMALL MOLECULE FXN-RF INHIBITORS THAT UPREGULATE TRE-FXN TRANSCRIPTION EXPERIMENTS IN THIS APPLICATION ARE FOCUSED ON THE DISCOVERY OF NEW SMALL MOLECULE FXN-RF INHIBITORS, AND DETERMINATION OF WHETHER TRANSCRIPTIONAL UPREGULATION OF TRE-FXN CAN CORRECT WELL-CHARACTERIZED MITOCHONDRIAL ABNORMALITIES IN FA NEURONS AND CARDIOMYOCYTES, WHICH ARE THE CELL TYPES MOST RELEVANT TO FA THE RESULTS OF THE PROPOSED CELL-BASED EXPERIMENTS WILL IDENTIFY THE MOST EFFICACIOUS, LEAST CYTOTOXIC COMPOUNDS THAT IN FUTURE STUDIES CAN BE ANALYZED IN FA MOUSE MODELS IN THE LONG-TERM, THE RESULTS OF OUR STUDY ARE LIKELY TO HAVE A MAJOR IMPACT ON THE FIELD OF FA THERAPEUTICS AND HAVE THE POTENTIAL TO LEAD TO DEVELOPMENT OF A NEW CLASS OF DRUGS THAT CAN AMELIORATE THIS DEVASTATING DISEASE CO-SPONSOR FARA IRELAND TITLE ELUCIDATING THE MECHANISM BY WHICH SYNTHETIC MOLECULES STIMULATE FRATAXIN IN FRIEDREICH'S ATAXIA INVESTIGATOR ASEEM ANSARI, PHD - UNIVERSITY OF WISCONSIN-MADISON, USA DR ANSARI'S LAB HAS CREATED NOVEL BIFUNCTIONAL MOLECULES THAT SELECTIVELY BIND GAA REPEAT EXPANSIONS AND ACTIVELY ENABLE THE CELLULAR MACHINERY TO TRANSCRIBE ACROSS THE REPRESSIVE GAA REPEATS WITHIN FXN WHEN SCRUTINIZED WITH GENOMIC APPROACHES, OUR SYNTHETIC TRANSCRIPTION ELONGATION FACTORS (SYN-TEFS) DISPLAY THE ABILITY TO SPECIFICALLY OVERCOME THE REPRESSIVE ROADBLOCKS TO TRANSCRIPTION AT FXN WITHOUT PERTURBING THE FUNCTION OF OTHER CELLULAR GENES BASED ON THIS SPECIFICITY OF ACTION, WE PROPOSE TO UTILIZE SYN-TEFS TO EXAMINE UNDERLYING MOLECULAR MECHANISMS THAT CONTRIBUTE TO FXN SILENCING IN PATIENT CELLS DEEPER MECHANISTIC UNDERSTANDING WILL GUIDE THE DESIGN OF NEXT GENERATION SYN-TEFS THAT ARE PRECISION-TAILORED FOR INDIVIDUALS WITH THE DISEASE WE FURTHER PROPOSE TO TEST THE EFFICACY OF SYN-TEFS IN PATIENT-DERIVED NEURONS AND HEART CELLS - CELL TYPES IN WHICH FRATAXIN DEFICIENCY RESULTS IN ATAXIA AND MORBIDITY</p>

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART III, LINE 4A	<p>TAKEN TOGETHER, THE PROPOSED EXPERIMENTS WILL AID IN THE DEVELOPMENT OF THIS CLASS OF MOLECULES AS POTENTIAL INDIVIDUAL-TAILORED PRECISION THERAPEUTICS. TITLES AND SUMMARIES OF MOST OF THE PROJECTS PRESENTLY FUNDED BY FARA AS WELL AS COMPLETE LISTINGS OF GRANTS AWARDED BY YEAR ARE AVAILABLE AT HTTP://WWW.CUREFA.ORG/GRANT RESULTS REPORTED FROM FARA AWARDED GRANTS - IN 2017, THERE WERE >25 MEDICAL AND SCIENTIFIC PUBLICATIONS THAT WERE DETAILED REPORTS OF FARA FUNDED RESEARCH. SELECTED PUBLICATIONS:</p> <p>FRATAXIN DEFICIENCY IMPAIRS MITOCHONDRIAL BIOGENESIS IN CELLS, MICE AND HUMANS. JASOLIYA MJ, MCMACKIN MZ, HENDERSON CK, PERLMAN SL, CORTOPASSI GA. HUM MOL GENET. 2017 JUL 15;26(14):2627-2633. DOI: 10.1093/HMG/DDX141</p> <p>SOMATIC INSTABILITY OF THE EXPANDED GAA REPEATS IN FRIEDREICH'S ATAXIA. LONG A, NAPIERALA JS, POLAK U, HAUSER L, KOEPPEN AH, LYNCH DR, NAPIERALA M. PLOS ONE. 2017 DEC 19;12(12):E0189990. DOI: 10.1371/JOURNAL.PONE.0189990</p> <p>ECOLLECTION 2017 INDUCIBLE AND REVERSIBLE PHENOTYPES IN A NOVEL MOUSE MODEL OF FRIEDREICH'S ATAXIA. CHANDRAN V, GAO K, SWARUP V, VERSANO R, DONG H, JORDAN MC, GESCHWIND DH. ELIFE. 2017 DEC 19;6:PII E30054. DOI: 10.7554/ELIFE.30054</p> <p>COMPREHENSIVE ANALYSIS OF GENE EXPRESSION PATTERNS IN FRIEDREICH'S ATAXIA FIBROBLASTS BY RNA SEQUENCING REVEALS ALTERED LEVELS OF PROTEIN SYNTHESIS FACTORS AND SOLUTE CARRIERS. NAPIERALA JS, LI Y, LU Y, LIN K, HAUSER LA, LYNCH DR, NAPIERALA M. DIS MODEL MECH. 2017 NOV 1;10(11):1353-1369. DOI: 10.1242/DMM.030536</p> <p>ACTIVATION OF FRATAXIN PROTEIN EXPRESSION BY ANTISENSE OLIGONUCLEOTIDES TARGETING THE MUTANT EXPANDED REPEAT. LI L, SHEN X, LIU Z, NORRBOM M, PRAKASH TP, O'REILLY D, SHARMA VK, DAMHA MJ, WATTS JK, RIGO F, COREY DR. NUCLEIC ACID THER. 2018 FEB;28(1):23-33. DOI: 10.1089/NAT.2017.0703</p> <p>EPUB 2018 JAN 17. NICOTINAMIDE MONONUCLEOTIDE REQUIRES SIRT3 TO IMPROVE CARDIAC FUNCTION AND BIOENERGETICS IN A FRIEDREICH'S ATAXIA CARDIOMYOPATHY MODEL. MARTIN AS, ABRAHAM DM, HERSHBERGER KA, BHATT DP, MAO L, CUI H, LIU J, LIU X, MUEHLBAUER MJ, GRIMSRUD PA, LOCASALE JW, PAYNE RM, HIRSCHEY MD. JCI INSIGHT. 2017 JUL 20;2(14):PII 93885. DOI: 10.1172/JCI.INSIGHT.93885 [EPUB AHEAD OF PRINT]</p> <p>FRIEDREICH ATAXIA: HYPOPLASIA OF SPINAL CORD AND DORSAL ROOT GANGLIA. KOEPPEN AH, BECKER AB, QIAN J, FEUSTEL PJ. J NEUROPATHOL EXP NEUROL. 2017 FEB 1;76(2):101-108. DOI: 10.1093/JNEN/NLW111</p>

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 11B	COPIES OF 990 ARE DISTRIBUTED TO BOARD MEMBERS FOR REVIEW AND APPROVAL PRIOR TO FILING

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI, SECTION B, LINE 12C	ALL NEW AND EXISTING BOARD MEMBERS REQUIRED TO ANNUALLY COMPLETE A CONFLICT OF INTEREST STATEMENT

990 Schedule O, Supplemental Information

Return Reference	Explanation
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

990 Schedule O, Supplemental Information

Return Reference	Explanation
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

990 Schedule O, Supplemental Information

Return Reference	Explanation
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

990 Schedule O, Supplemental Information

Return Reference	Explanation
FORM 990, PART VI LINE 17	THE ORGANIZATION IS ALSO REGISTERED TO SOLICIT CONTRIBUTIONS IN THE STATES LISTED

990 Schedule O, Supplemental Information

Return Reference	Explanation
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