

Return of Organization Exempt From Income Tax

2016

Department of the Treasury
Internal Revenue Service

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.

Open to Public Inspection

A For the 2016 calendar year, or tax year beginning and ending

| | | |
|--|---|---|
| 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 P.O. 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, DOWNINGTOWN, PA 19335 | D Employer identification number 52-2122720 E Telephone number 484-879-6160 G Gross receipts \$ 7,021,269. H(a) Is this a group return for subordinates? -- Yes ^X No H(b) Are all subordinates included? Yes No If "No," attach a list. (see instructions) H(c) Group exemption number |
| I Tax-exempt status: ^X 501(c)(3) 501(c) () § (insert no.) 4947(a)(1) or 527 | | |
| J Website: WWW.CUREFA.ORG | | |
| K Form of organization: ^X Corporation Trust Association Other | | L Year of formation: 1998 M State of legal domicile: VA |

Part I Summary

| Activities & Governance | 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 <input type="checkbox"/> 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) ~~~~~ 3 18 4 Number of independent voting members of the governing body (Part VI, line 1b) ~~~~~ 4 17 5 Total number of individuals employed in calendar year 2016 (Part V, line 2a) ~~~~~ 5 7 6 Total number of volunteers (estimate if necessary) ~~~~~ 6 500 7 a Total unrelated business revenue from Part VIII, column (C), line 12 ~~~~~ 7a 0. b Net unrelated business taxable income from Form 990-T, line 34 7b 0. | | | | | | | | | | | | | | | | | | | | | | |
|------------------------------------|--|---|----|---------------------------|--------------|----|------------|------------|----|----------|----------|-----|------------|------------|----|----------|----------|----|------------|------------|----|---------|-----------|
| Revenue | 8 Contributions and grants (Part VIII, line 1h) ~~~~~ 9 Program service revenue (Part VIII, line 2g) ~~~~~ 10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) ~~~~~ 11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) ~~~~~ 12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) ... | <table border="1" style="width:100%; border-collapse: collapse;"> <thead> <tr> <th style="width:30%;"></th> <th style="width:35%;">Prior Year</th> <th style="width:35%;">Current Year</th> </tr> </thead> <tbody> <tr> <td>8</td> <td style="text-align: right;">5,701,123.</td> <td style="text-align: right;">5,388,847.</td> </tr> <tr> <td>9</td> <td style="text-align: right;">0.</td> <td style="text-align: right;">0.</td> </tr> <tr> <td>10</td> <td style="text-align: right;">19,427.</td> <td style="text-align: right;">47,576.</td> </tr> <tr> <td>11</td> <td style="text-align: right;">-2,405.</td> <td style="text-align: right;">-54,930.</td> </tr> <tr> <td>12</td> <td style="text-align: right;">5,718,145.</td> <td style="text-align: right;">5,381,493.</td> </tr> </tbody> </table> | | Prior Year | Current Year | 8 | 5,701,123. | 5,388,847. | 9 | 0. | 0. | 10 | 19,427. | 47,576. | 11 | -2,405. | -54,930. | 12 | 5,718,145. | 5,381,493. | | | |
| | Prior Year | Current Year | | | | | | | | | | | | | | | | | | | | | |
| 8 | 5,701,123. | 5,388,847. | | | | | | | | | | | | | | | | | | | | | |
| 9 | 0. | 0. | | | | | | | | | | | | | | | | | | | | | |
| 10 | 19,427. | 47,576. | | | | | | | | | | | | | | | | | | | | | |
| 11 | -2,405. | -54,930. | | | | | | | | | | | | | | | | | | | | | |
| 12 | 5,718,145. | 5,381,493. | | | | | | | | | | | | | | | | | | | | | |
| Expenses | 13 Grants and similar amounts paid (Part IX, column (A), lines 1-3) ~~~~~ 14 Benefits paid to or for members (Part IX, column (A), line 4) ~~~~~ 15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) ~~~ 16a Professional fundraising fees (Part IX, column (A), line 11e) ~~~~~ b Total fundraising expenses (Part IX, column (D), line 25) 99,383. 17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) ~~~~~ 18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) ~~~~~ 19 Revenue less expenses. Subtract line 18 from line 12 | <table border="1" style="width:100%; border-collapse: collapse;"> <tbody> <tr> <td>13</td> <td style="text-align: right;">4,750,666.</td> <td style="text-align: right;">4,852,904.</td> </tr> <tr> <td>14</td> <td style="text-align: right;">0.</td> <td style="text-align: right;">0.</td> </tr> <tr> <td>15</td> <td style="text-align: right;">503,463.</td> <td style="text-align: right;">463,198.</td> </tr> <tr> <td>16a</td> <td style="text-align: right;">0.</td> <td style="text-align: right;">0.</td> </tr> <tr> <td>17</td> <td style="text-align: right;">367,667.</td> <td style="text-align: right;">237,062.</td> </tr> <tr> <td>18</td> <td style="text-align: right;">5,621,796.</td> <td style="text-align: right;">5,553,164.</td> </tr> <tr> <td>19</td> <td style="text-align: right;">96,349.</td> <td style="text-align: right;">-171,671.</td> </tr> </tbody> </table> | 13 | 4,750,666. | 4,852,904. | 14 | 0. | 0. | 15 | 503,463. | 463,198. | 16a | 0. | 0. | 17 | 367,667. | 237,062. | 18 | 5,621,796. | 5,553,164. | 19 | 96,349. | -171,671. |
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| 14 | 0. | 0. | | | | | | | | | | | | | | | | | | | | | |
| 15 | 503,463. | 463,198. | | | | | | | | | | | | | | | | | | | | | |
| 16a | 0. | 0. | | | | | | | | | | | | | | | | | | | | | |
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| 18 | 5,621,796. | 5,553,164. | | | | | | | | | | | | | | | | | | | | | |
| 19 | 96,349. | -171,671. | | | | | | | | | | | | | | | | | | | | | |
| Balance or Fund Balances | 20 Total assets (Part X, line 16) ~~~~~ 21 Total liabilities (Part X, line 26) ~~~~~ 22 Net assets or fund balances. Subtract line 21 from line 20 | <table border="1" style="width:100%; border-collapse: collapse;"> <thead> <tr> <th style="width:30%;"></th> <th style="width:35%;">Beginning of Current Year</th> <th style="width:35%;">End of Year</th> </tr> </thead> <tbody> <tr> <td>20</td> <td style="text-align: right;">4,057,130.</td> <td style="text-align: right;">4,110,033.</td> </tr> <tr> <td>21</td> <td style="text-align: right;">289,961.</td> <td style="text-align: right;">484,966.</td> </tr> <tr> <td>22</td> <td style="text-align: right;">3,767,169.</td> <td style="text-align: right;">3,625,067.</td> </tr> </tbody> </table> | | Beginning of Current Year | End of Year | 20 | 4,057,130. | 4,110,033. | 21 | 289,961. | 484,966. | 22 | 3,767,169. | 3,625,067. | | | | | | | | | |
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| 22 | 3,767,169. | 3,625,067. | | | | | | | | | | | | | | | | | | | | | |

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 JENNIFER FARMER, EXECUTIVE DIRECTOR Type or print name and title | Date |
| Paid Preparer Use Only | Print/Type preparer's name EDWARD FRONCZKOWSKI CPA Preparer's signature Date Check if self-employed PTIN P01259092 Firm's name 9 MAILLIE LLP Firm's EIN 9 23-1518888 Firm's address 624 WILLOWBROOK LANE 9 WEST CHESTER, PA 19382 Phone no. (610)696-4353 | |

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

Part III Statement of Program Service Accomplishments

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

X

1 Briefly describe the organization's mission: TO MARSHAL AND FOCUS THE RESOURCES AND RELATIONSHIPS NEEDED TO CURE FA BY RAISING FUNDS FOR RESEARCH, PROMOTING PUBLIC AWARENESS AND ALIGNING SCIENTISTS, PATIENTS, CLINICIANS, GOV'T AGENCIES AND PHARMACEUTICAL COMPANIES DEDICATED TO CURING FA AND RELATED DISORDERS.

2 Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? Yes No X

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

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 \$ 4,629,368. including grants of \$ 4,455,203.) (Revenue \$) RESEARCH & GRANT PROGRAM:IN 2016, 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 >\$4.8M 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, 38 NEW LETTERS OF INTENT FOR FUNDING REQUESTS WERE SUBMITTED, 25 RESEARCHERS WERE INVITED TO APPLY FOR GRANT FUNDING, AND AFTER RIGOROUS PEER REVIEW, 15 WERE DETERMINED MERITORIOUS AND AWARDED FUNDING IN 2016. IN ADDITION, BASED ON EXCELLENT PROGRESS, CONTINUATION FUNDING WAS PROVIDED FOR 12 PROJECTS, FOR A TOTAL OF 27 RESEARCH GRANTS AWARDED. FARA ALSO AWARDED CONFERENCE GRANTS TO SUPPORT SCIENTIFIC

4b (Code:) (Expenses \$ 100,504. including grants of \$ 15,700.) (Revenue \$) 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.

MARCH 2016 ATAXIA INVESTIGATORS MEETING

FARA WAS A SPONSOR FOR AND PARTICIPANT IN THE NATIONAL ATAXIA FOUNDATION'S ATAXIA INVESTIGATORS MEETING. THE MEETING BROUGHT TOGETHER OVER 150 ATAXIA INVESTIGATORS TO EXPLORE COMMON DISEASE MECHANISMS AND THERAPEUTIC STRATEGIES.

MAY 2016 GENE THERAPY MEETING

4c (Code:) (Expenses \$ 197,035. including grants of \$) (Revenue \$) 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 FOUR PATIENT SYMPOSIUMS WITH CLINICAL RESEARCH NETWORK SITES, UCLA (JANUARY 21ST, 2016, LOS ANGELES, CA), CHILDREN'S

4d Other program services (Describe in Schedule O.) (Expenses \$ 451,781. including grants of \$ 582,000.) (Revenue \$)

4e Total program service expenses | 5,358,688.

Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Yes, No. Rows 1-19 contain various tax-related questions and their corresponding 'Yes' or 'No' status.

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> _____ | | X |
| 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> _____ | X | |
| 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> _____ | | X |
| 23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i> _____ | | X |
| 24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i> _____ | | X |
| 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> _____ | | X |
| b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i> _____ | | X |
| 26 Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If "Yes," complete Schedule L, Part II</i> _____ | | X |
| 27 Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i> _____ | | X |
| 28 Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions): | | |
| a A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i> _____ | | X |
| b A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i> _____ | | X |
| 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> _____ | | X |
| 29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> _____ | X | |
| 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> _____ | | X |
| 31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> _____ | | X |
| 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> _____ | | X |
| 33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i> _____ | | X |
| 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> _____ | | X |
| 35a Did the organization have a controlled entity within the meaning of section 512(b)(13)? _____ | | X |
| b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <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> _____ | | X |
| 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> _____ | | X |
| 38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? _____ | X | |

Note. All Form 990 filers are required to complete Schedule O

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

Table with columns for question numbers (1a-14b), Yes/No checkboxes, and numerical input fields. Contains questions about backup withholding, employee reporting, foreign accounts, and charitable contributions.

Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes 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 4 columns: Question, Yes, No, and a column for line numbers (1a, 1b, 2-9). Contains questions about governing body members, relationships, and documentation.

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

Table with 4 columns: Question, Yes, No, and a column for line numbers (10a-16b). Contains questions about local chapters, written policies, conflict of interest, whistleblower, and document retention.

Section C. Disclosure

AL, AK, AZ, AR, CA, CO, CT, FL, GA, IL, KS, KY

- 17 List the states with which a copy of this Form 990 is required to be filed
18 Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (Section 501(c)(3)s only) available for public inspection.
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 - 484-879-6160

533 W. UWCHLAN AVENUE, DOWNINGTOWN, PA 19335

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

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

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

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

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

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) | (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 |
|---|--|--|---|--|--|--|--|--|---|---|
| | | | | | | | | | | |
| (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) VINCENT R. GIANNINI 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 RITSCHER DIRECTOR | 0.00 | X | | | | | | 0. | 0. | 0. |
| (17) RONALD BARTEK PRESIDENT/DIRECTOR | 40.00 | X | X | | | | | 100,000. | 0. | 180. |

Part VIII Statement of Revenue

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

| | | | (A) | (B) | (C) | (D) | |
|--|---|---|---------------|------------------------------------|----------------------------|--|--|
| | | | Total revenue | Related or exempt function revenue | Unrelated business revenue | Revenue excluded from tax under sections 512 - 514 | |
| Amounts of Gifts | 1 a Federated campaigns ~~~~~ | 1a | | | | | |
| | b Membership dues ~~~~~ | 1b | | | | | |
| | c Fundraising events ~~~~~ | 1c | 3,196,185. | | | | |
| | e Government grants (contributions) <small>Government organizations</small> | 1e | | 5,388,841. | | | |
| | f All other contributions, gifts, grants, and similar amounts not included above ~ | 1f | 2,192,662. | | | | |
| | g Noncash contributions included in lines 1a-1f: \$ | | | | | | |
| | Business Code | | | | | | |
| | Other Service Programs | 2 a _____ | | | | | |
| | | b _____ | | | | | |
| c _____ | | | | | | | |
| d _____ | | | | | | | |
| e _____ | | | | | | | |
| f All other program service revenue ~~~~~ | | | | | | | |
| g Total. Add lines 2a-2f | | | | | | | |
| Revenue | 3 Investment income (including dividends, interest, and other similar amounts) ~~~~~ | | 29,213. | | | 29,213. | |
| | 4 Income from investment of tax-exempt bond proceeds | | | | | | |
| | 5 Royalties | | | | | | |
| | 6 a Gross rents ~~~~~ | (i) Real | | | | | |
| | | (ii) Personal | | | | | |
| | | b Less: rental expenses ~~~ | | | | | |
| | | c Rental income or (loss) ~~ | | | | | |
| | d Net rental income or (loss) | | | | | | |
| | 7 a Gross amount from sales of assets other than inventory | (i) Securities | 889,227. | | | | |
| | | (ii) Other | | | | | |
| | | b Less: cost or other basis and sales expenses ~~~ | 870,864. | | | | |
| | | c Gain or (loss) ~~~~~ | 18,363. | | | | |
| | d Net gain or (loss) | | 18,363. | | | 18,363. | |
| | 8 a Gross income from fundraising events (not including \$3,196,185. of contributions reported on line 1c). See Part IV, line 18 ~~~~~ | a | 713,982. | | | | |
| b Less: direct expenses ~~~~~ | | 768,912. | | | | | |
| c Net income or (loss) from fundraising events | | | -54,930. | | | -54,930. | |
| 9 a Gross income from gaming activities. See Part IV, line 19 ~~~~~ | a | | | | | | |
| | b Less: direct expenses ~~~~~ | b | | | | | |
| | c Net income or (loss) from gaming activities | | | | | | |
| 10 a Gross sales of inventory, less returns and allowances ~~~~~ | a | | | | | | |
| | b Less: cost of goods sold ~~~~~ | b | | | | | |
| | c Net income or (loss) from sales of inventory | | | | | | |
| Miscellaneous Revenue | | | | | | | |
| Other | 11 a _____ | | | | | | |
| | b _____ | | | | | | |
| | c _____ | | | | | | |
| | d All other revenue ~~~~~ | | | | | | |
| | e Total. Add lines 11a-11d | | | | | | |
| 12 Total revenue. See instructions. | | | 5,381,493. | 0. | | 0. -7,354. | |

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 ~ | 3,863,542. | 3,863,542. | | |
| 2 Grants and other assistance to domestic individuals. See Part IV, line 22 ~~~~~ | | | | |
| 3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16 ~~~ | 989,362. | 989,362. | | |
| 4 Benefits paid to or for members ~~~~~ | | | | |
| 5 Compensation of current officers, directors, trustees, and key employees ~~~~~ | 216,699. | 177,023. | 17,351. | 22,325. |
| 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 ~~~~~ | 246,499. | 191,152. | 14,107. | 41,240. |
| 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 ~~~~~ | 429. | | 429. | |
| c Accounting ~~~~~ | 12,400. | | 12,400. | |
| d Lobbying ~~~~~ | | | | |
| e Professional fundraising services. See Part IV, line 17 | | | | |
| f Investment management fees ~~~~~ | 11,557. | | 11,557. | |
| g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O.) | 8,809. | | 2,000. | 6,809. |
| 12 Advertising and promotion ~~~~~ | | | | |
| 13 Office expenses ~~~~~ | 21,271. | 10,266. | 9,064. | 1,941. |
| 14 Information technology ~~~~~ | | | | |
| 15 Royalties ~~~~~ | | | | |
| 16 Occupancy ~~~~~ | 28,853. | 16,487. | 4,123. | 8,243. |
| 17 Travel ~~~~~ | 106,902. | 88,904. | 16,992. | 1,006. |
| 18 Payments of travel or entertainment expenses for any federal, state, or local public officials | | | | |
| 19 Conferences, conventions, and meetings ~ | 9,866. | 7,648. | 2,218. | |
| 20 Interest ~~~~~ | | | | |
| 21 Payments to affiliates ~~~~~ | | | | |
| 22 Depreciation, depletion, and amortization ~ | 1,298. | | 1,298. | |
| 23 Insurance ~~~~~ | 5,513. | | 2,816. | 2,697. |
| 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 & | 12,271. | 5,827. | 481. | 5,963. |
| b CREDIT CARD & BANK FEES | 6,055. | 310. | 100. | 5,645. |
| c FACILITIES & EQUIPMENT | 4,876. | 4,876. | | |
| d BUSINESS REGISTRATION F | 3,660. | 400. | 50. | 3,210. |
| e All other expenses | 3,302. | 2,891. | 107. | 304. |
| 25 Total functional expenses. Add lines 1 through 24e | 5,553,164. | 5,358,688. | 95,093. | 99,383. |
| 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 if following SOP 98-2 (ASC 958-720)

Part X Balance Sheet

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

| | | (A) Beginning of year | | (B) End of year |
|--|---|--------------------------|-----------|--------------------|
| 1 | Cash - non-interest-bearing ~~~~~ | 1,004,180. | 1 | 844,839. |
| 2 | Savings and temporary cash investments ~~~~~ | 484,112. | 2 | 376,754. |
| 3 | Pledges and grants receivable, net ~~~~~ | 138,397. | 3 | 269,394. |
| 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 instr). Complete Part II of Sch L ~~~ | | 6 | |
| 7 | Notes and loans receivable, net ~~~~~ | | 7 | |
| 8 | Inventories for sale or use ~~~~~ | | 8 | |
| 9 | Prepaid expenses and deferred charges ~~~~~ | 9,411 | 9 | 34,261. |
| 10a | Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D ~~~ | 10a 7,135. | | |
| b | Less: accumulated depreciation ~~~~~ | 10b 5,295. | 10c 3,138 | 1,840. |
| 11 | Investments - publicly traded securities ~~~~~ | 1,326,392 | 11 | 1,491,445. |
| 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) | 4,057,130 | 16 | 4,110,033. |
| 17 | Accounts payable and accrued expenses ~~~~~ | 289,961 | 17 | 484,966. |
| 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 | 289,961 | 26 | 484,966. |
| Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34. | | | | |
| 27 | Unrestricted net assets ~~~~~ | 3,604,380. | 27 | 3,597,092. |
| 28 | Temporarily restricted net assets ~~~~~ | 162,789. | 28 | 27,975. |
| 29 | Permanently restricted net assets ~~~~~ | | 29 | |
| Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34. | | | | |
| 30 | 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 ~~~~~ | 3,767,169. | 33 | 3,625,067. |
| 34 | Total liabilities and net assets/fund balances | 4,057,130. | 34 | 4,110,033. |

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 | 5,381,493. |
| 2 | Total expenses (must equal Part IX, column (A), line 25) ~~~~~ | 2 | 5,553,164. |
| 3 | Revenue less expenses. Subtract line 2 from line 1 ~~~~~ | 3 | -171,671. |
| 4 | Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A)) ~~~~~ | 4 | 3,767,169. |
| 5 | Net unrealized gains (losses) on investments ~~~~~ | 5 | 29,569. |
| 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 | | 3,625,067. |

Part XII Financial Statements and Reporting

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

| | | X | |
|----|--|-----|----|
| | | Yes | No |
| 1 | Accounting method used to prepare the Form 990: Cash <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: Separate basis Consolidated basis Both consolidated and separate basis | | X |
| b | Were the organization's financial statements audited by an independent accountant? ~~~~~ If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input checked="" type="checkbox"/> Separate basis Consolidated basis Both consolidated and separate basis | X | |
| c | If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? ~~~~~ If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O. | X | |
| 3a | As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? ~~~~~ | | X |
| b | If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits | | |

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.
| Attach to Form 990 or Form 990-EZ.
www.irs.gov/form990.

Information about Schedule A (Form 990 or 990-EZ) and its instructions is at

OMB No. 1545-0047

2016

Open to Public
Inspection

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

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

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

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

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

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

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

Section A. Public Support

| Calendar year (or fiscal year beginning in) | (a) 2012 | (b) 2013 | (c) 2014 | (d) 2015 | (e) 2016 | (f) Total |
|---|------------|------------|------------|------------|------------|-------------|
| 1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") ~ | 3,174,652. | 4,460,547. | 5,572,073. | 5,701,123. | 5,388,847. | 24,297,242. |
| 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 ~ | 3,174,652. | 4,460,547. | 5,572,073. | 5,701,123. | 5,388,847. | 24,297,242. |
| 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) ~ | | | | | | 2,820,287. |
| 6 Public support. Subtract line 5 from line 4. | | | | | | 21,476,955. |

Section B. Total Support

| Calendar year (or fiscal year beginning in) | (a) 2012 | (b) 2013 | (c) 2014 | (d) 2015 | (e) 2016 | (f) Total |
|--|------------|------------|------------|------------|------------|-------------|
| 7 Amounts from line 4 ~ | 3,174,652. | 4,460,547. | 5,572,073. | 5,701,123. | 5,388,847. | 24,297,242. |
| 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources ~ | 21,555. | 9,955. | 14,051. | 19,755. | 29,213. | 94,529. |
| 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 | | | | | | 24,391,771. |
| 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 2016 (line 6, column (f) divided by line 11, column (f)) ~ | 14 | 88.05 % |
| 15 Public support percentage from 2015 Schedule A, Part II, line 14 ~ | 15 | 90.30 % |
| 16a 33 1/3% support test - 2016. 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 ~ | | X |
| b 33 1/3% support test - 2015. 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 - 2016. 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 - 2015. 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) 2012 | (b) 2013 | (c) 2014 | (d) 2015 | (e) 2016 | (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) 2012 | (b) 2013 | (c) 2014 | (d) 2015 | (e) 2016 | (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 2016 (line 8, column (f) divided by line 13, column (f)) ~~~~~ | 15 | % |
| 16 Public support percentage from 2015 Schedule A, Part III, line 15 | 16 | % |

Section D. Computation of Investment Income Percentage

| | | |
|---|-----------|---|
| 17 Investment income percentage for 2016 (line 10c, column (f) divided by line 13, column (f)) ~~~~~ | 17 | % |
| 18 Investment income percentage from 2015 Schedule A, Part III, line 17 ~~~~~ | 18 | % |

19a 33 1/3% support tests - 2016. 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 - 2015. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization ~~~~~ |

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

Part IV Supporting Organizations

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

Section A. All Supporting Organizations

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

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? | | |
| 11a | | |
| b A family member of a person described in (a) above? | | |
| 11b | | |
| 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> | | |
| 11c | | |

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> | | |
| 1 | | |
| 2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <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> | | |
| 2 | | |

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> | | |
| 1 | | |

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? | | |
| 1 | | |
| 2 Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? <i>If "NO," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i> | | |
| 2 | | |
| 3 By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i> | | |
| 3 | | |

Section E. Type III Functionally Integrated Supporting Organizations

| | | |
|--|-----|----|
| 1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions). Complete line 2 below. | | |
| a The organization satisfied the Activities Test. Complete line 3 below. | | |
| b The organization is the parent of each of its supported organizations. | | |
| c The organization supported a governmental entity. <i>Describe in Part VI how you supported a government entity (see instructions).</i> | | |
| 2 Activities Test. Answer (a) and (b) below. | Yes | No |
| 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> | | |
| 2a | | |
| b Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <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> | | |
| 2b | | |
| 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> | | |
| 3a | | |
| 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> | | |
| 3b | | |

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

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

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

Schedule A (Form 990 or 990-EZ) 2016

| 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 2016 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-2016 | (iii) Distributable Amount for 2016 |
| 1 Distributable amount for 2016 from Section C, line 6 | | | |
| 2 Underdistributions, if any, for years prior to 2016 (reasonable cause required- explain in Part VI). See instructions | | | |
| 3 Excess distributions carryover, if any, to 2016: | | | |
| a | | | |
| b | | | |
| c From 2013 | | | |
| d From 2014 | | | |
| e From 2015 | | | |
| f Total of lines 3a through e | | | |
| g Applied to underdistributions of prior years | | | |
| h Applied to 2016 distributable amount | | | |
| i Carryover from 2011 not applied (see instructions) | | | |
| j Remainder. Subtract lines 3g, 3h, and 3i from 3f. | | | |
| 4 Distributions for 2016 from Section D, line 7: \$ | | | |
| a Applied to underdistributions of prior years | | | |
| b Applied to 2016 distributable amount | | | |
| c Remainder. Subtract lines 4a and 4b from 4 | | | |
| 5 Remaining underdistributions for years prior to 2016, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions | | | |
| 6 Remaining underdistributions for 2016. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions | | | |
| 7 Excess distributions carryover to 2017. Add lines 3j and 4c | | | |
| 8 Breakdown of line 7: | | | |
| a | | | |
| b Excess from 2013 | | | |
| c Excess from 2014 | | | |
| d Excess from 2015 | | | |
| e Excess from 2016 | | | |

SCHEDULE C
(Form 990 or 990-EZ)

Political Campaign and Lobbying Activities

OMB No. 1545-0047

2016

Department of the Treasury
Internal Revenue Service

For Organizations Exempt From Income Tax Under section 501(c) and section 527
J Complete if the organization is described below. J Attach to Form 990 or Form 990-EZ.

Open to Public Inspection

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 organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE | Employer identification number 52-2122720 |
|--|---|

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

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

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

- 1 Enter the amount of any excise tax incurred by the organization under section 4955 ~~~~~ J \$ _____ 0.
- 2 Enter the amount of any excise tax incurred by organization managers under section 4955 ~~~~~ J \$ _____ 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 ~~~~ J \$ _____
- 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities ~~~~~ J \$ _____
- 3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL, line 17b ~~~~~ J \$ _____
- 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-. |
|----------|-------------|---------|---|--|
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

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 **J** 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 **J** 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 | | | | | | | | | | | | |
|---|--|---|------------------------------------|--------------------|-------------------------------|---|--|---|--|--|---|-------------------|--------------|--|--|
| 1 a Total lobbying expenditures to influence public opinion (grass roots lobbying) ~~~~~ | | 3,700. | | | | | | | | | | | | | |
| b Total lobbying expenditures to influence a legislative body (direct lobbying) ~~~~~ | | 2,500. | | | | | | | | | | | | | |
| c Total lobbying expenditures (add lines 1a and 1b) ~~~~~ | | 6,200. | | | | | | | | | | | | | |
| d Other exempt purpose expenditures ~~~~~ | | 6,304,319. | | | | | | | | | | | | | |
| e Total exempt purpose expenditures (add lines 1c and 1d) ~~~~~ | | 6,310,519. | | | | | | | | | | | | | |
| f Lobbying nontaxable amount. Enter the amount from the following table in both columns. | | 465,526. | | | | | | | | | | | | | |
| <table border="1" style="width: 100%; border-collapse: collapse;"> <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) ~~~~~ | | 116,382. | | | | | | | | | | | | | |
| 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? | | Yes | 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) 2013 | (b) 2014 | (c) 2015 | (d) 2016 | (e) Total |
| 2 a Lobbying nontaxable amount | 350,101. | 423,349. | 458,529. | 465,526. | 1,697,505. |
| b Lobbying ceiling amount (150% of line 2a, column(e)) | | | | | 2,546,258. |
| c Total lobbying expenditures | 9,100. | 9,100. | 8,106. | 6,200. | 32,506. |
| d Grassroots nontaxable amount | 87,525. | 105,837. | 114,632. | 116,382. | 424,376. |
| e Grassroots ceiling amount (150% of line 2d, column (e)) | | | | | 636,564. |
| f Grassroots lobbying expenditures | 5,100. | 5,100. | 4,731. | 3,700. | 18,631. |

Schedule C (Form 990 or 990-EZ) 2016

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

| For 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 ~~~~~ | | | |
| 2 a 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 campaign activity 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.

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

2016

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.

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate values, and compliance questions.

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

Table with 3 columns: Question, Held at the End of the Tax Year (2a-2d), Yes/No. Rows include purpose of easements, monitoring, and reporting requirements.

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.

Table with 3 columns: Question, Revenue included, Assets included. Rows include reporting requirements for art and historical treasures.

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:

- c Beginning balance
- d Additions during the year
- e Distributions during the year
- f Ending balance

| | Amount |
|----|--------|
| 1c | |
| 1d | |
| 1e | |
| 1f | |

2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? **Yes** **No**

b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided on Part XIII

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

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

2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

- a Board designated or quasi-endowment | _____ %
- b Permanent endowment | _____ %
- c 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:

- (i) unrelated organizations
- (ii) related organizations

b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?

| | Yes | No |
|--------|-----|----|
| 3a(i) | | |
| 3a(ii) | | |
| 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. | 5,295. | 1,840. |
| Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.) | | | | 1,840. |

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. (Col. (b) must equal Form 990, Part X, col. (B) line 12.) | | |

Part VIII Investments - Program Related.

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

| (a) Description of investment | (b) Book value | (c) Method of valuation: Cost or end-of-year market value |
|---|----------------|---|
| (1) INVESTMENT IN EDISON | | |
| (2) PHARMACEUTICALS, INC. | 1,091,500. | COST |
| (3) | | |
| (4) | | |
| (5) | | |
| (6) | | |
| (7) | | |
| (8) | | |
| (9) | | |
| Total. (Col. (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.

| 1. (a) Description of liability | (b) Book value |
|---|----------------|
| (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 | 6,168,417. |
| 2 | Amounts included on line 1 but not on Form 990, Part VIII, line 12: | | | |
| a | Net unrealized gains (losses) on investments | 2a | 29,569. | |
| b | Donated services and use of facilities | 2b | | |
| c | Recoveries of prior year grants | 2c | | |
| d | Other (Describe in Part XIII.) | 2d | 768,912. | |
| e | Add lines 2a through 2d | 2e | | 798,481. |
| 3 | Subtract line 2e from line 1 | 3 | | 5,369,936. |
| 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 | 11,557. | |
| c | Add lines 4a and 4b | 4c | | 11,557. |
| 5 | Total revenue. Add lines 3 and 4c. <i>(This must equal Form 990, Part I, line 12.)</i> | 5 | | 5,381,493. |

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 | 6,310,519. |
| 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 | 768,912. | |
| e | Add lines 2a through 2d | 2e | | 768,912. |
| 3 | Subtract line 2e from line 1 | 3 | | 5,541,607. |
| 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 | 11,557. | |
| c | Add lines 4a and 4b | 4c | | 11,557. |
| 5 | Total expenses. Add lines 3 and 4c. <i>(This must equal Form 990, Part I, line 18.)</i> | 5 | | 5,553,164. |

Part XIII Supplemental Information.

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

PART XI, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENTS EXPENSE

PART XI, LINE 4B - OTHER ADJUSTMENTS:

INVESTMENT MANAGEMENT FEES

PART XII, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENTS EXPENSE

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" on Form 990, Part IV, line 14b, 15, or 16.

| Attach to Form 990.

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

OMB No. 1545-0047

2016

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" on Form 990, Part IV, line 14b.

- 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**
- For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.
- Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.)

| (a) Region | (b) Number of offices in the region | (c) Number of employees, agents, and independent contractors in the region | (d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region) | (e) If activity listed in (d) is a program service, describe specific type of service(s) in the region | (f) Total expenditures for and investments in the region |
|---|-------------------------------------|--|--|--|--|
| EUROPE | 0 | 0 | GRANTS TO RECIPIENTS LOCATED IN REGION | RESEARCH AND GRANT PROGRAM | 608,810. |
| EAST ASIA AND THE PACIFIC | 0 | 0 | GRANTS TO RECIPIENTS LOCATED IN REGION | RESEARCH AND GRANT PROGRAM | 381,814. |
| | | | | | |
| | | | | | |
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| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| 3 a Sub-total ~~~~~ | 0 | 0 | | | 990,624. |
| b Total from continuation sheets to Part I ~~~ | 0 | 0 | | | 0. |
| c Totals (add lines 3a and 3b) | 0 | 0 | | | 990,624. |

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

| 1 (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of noncash assistance | (h) Description of noncash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
|-------------------------------|--|---------------------------|----------------------|--------------------------|---------------------------------|----------------------------------|---------------------------------------|---|
| | | EAST ASIA AND THE PACIFIC | MEDICAL RESEARCH | 164,621. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 155,706. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 90,000. | WIRE | 0. | | |
| | | EAST ASIA AND THE PACIFIC | MEDICAL RESEARCH | 100,311. | WIRE | 0. | | |
| | | EAST ASIA AND THE PACIFIC | MEDICAL RESEARCH | 116,882. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 87,709. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 7,200. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 20,000. | WIRE | 0. | | |

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

3 Enter total number of other organizations or entities

_____ 11

| Part II Continuation of Grants and Other Assistance to Organizations or Entities Outside the United States. (Schedule F (Form 990), Part II, line 1) | | | | | | | | |
|---|---|-------------------|-----------------------------|---------------------------------|--|--|---|--|
| 1 (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of non-cash assistance | (h) Description of non-cash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
| | | EUROPE | RESEARCH CONFERENCE | 10,700. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 87,500. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 149,995. | WIRE | 0. | | |
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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.

PART I, LINE 2:

GRANTS ARE REVIEWED BY INDEPENDENT SCIENTIFIC ADVISORS AND APPROVED BY BOARD.

Multiple horizontal lines for supplemental information.

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

| | (a) Event #1 | (b) Event #2 | (c) Other events | (d) Total events |
|---|------------------------------|--------------|------------------|---------------------------------|
| | FARA ENERGY RIDE ATAXIA BALL | PHILADELPHIA | 62 | (add col. (a) through col. (c)) |
| | (event type) | (event type) | (total number) | |
| Revenue | | | | |
| 1 Gross receipts ~~~~~ | 1,719,078. | 433,358. | 1,757,731. | 3,910,167. |
| 2 Less: Contributions ~~~~~ | 1,254,547. | 410,878. | 1,530,760. | 3,196,185. |
| 3 Gross income (line 1 minus line 2) **** | 464,531. | 22,480. | 226,971. | 713,982. |
| Direct Expenses | | | | |
| 4 Cash prizes ~~~~~ | | | | |
| 5 Noncash prizes ~~~~~ | | | | |
| 6 Rent/facility costs ~~~~~ | | | | |
| 7 Food and beverages ~~~~~ | | | | |
| 8 Entertainment ~~~~~ | | | | |
| 9 Other direct expenses ~~~~~ | 339,948. | 51,573. | 377,391. | 768,912. |
| 10 Direct expense summary. Add lines 4 through 9 in column (d) ~~~~~ | | | | 768,912. |
| 11 Net income summary. Subtract line 10 from line 3, column (d) | | | | -54,930. |

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 | | | | |
| 2 Cash prizes ~~~~~ | | | | |
| 3 Noncash prizes ~~~~~ | | | | |
| 4 Rent/facility costs ~~~~~ | | | | |
| 5 Other direct expenses | | | | |
| 6 Volunteer labor ~~~~~ | Yes _____ % No | Yes _____ % No | Yes _____ % 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 ~~~~~ | 13a | % |
| b An outside facility ~~~~~ | 13b | % |

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

Name | FELICIA DEROSA _____

Address | 533 W. UWCHLAN AVENUE - DOWNINGTOWN, 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 to be 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

SCHEDULE I

(Form 990)

Department of the Treasury
Internal Revenue Service

**Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States**
Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.
| Attach to Form 990.

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

OMB No. 1545-0047

2016

**Open to Public
Inspection**

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

Part I General Information on Grants and Assistance

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ----- Yes No
- 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

| 1 (a) Name and address of organization or government | (b) EIN | (c) IRC section (if applicable) | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of noncash assistance | (h) Purpose of grant or assistance |
|--|------------|---------------------------------|--------------------------|-----------------------------------|---|---------------------------------------|------------------------------------|
| ARIZONA STATE UNIVERSITY 1711 S. RURAL ROAD TEMPE, AZ 85287 | 86-0196696 | 501(C)(3) | 150,000. | 0. | | | MEDICAL RESEARCH |
| CALIFORNIA INSTITUTE OF TECHNOLOGY 1200 EAST CALIFORNIA BLVD 123-15 PASADENA, CA 91125 | 95-1643307 | 501(C)(3) | 150,000. | 0. | | | MEDICAL RESEARCH |
| DUKE UNIVERSITY 2200 W. MAIN ST SUITE 710 DURHAM, NC 27705-4677 | 56-0532129 | 501(C)(3) | 200,000. | 0. | | | MEDICAL RESEARCH |
| CHILDREN'S HOSPITAL OF PHILADELPHIA - 34TH ST & CIVIC CENTER BLVD - PHILADELPHIA, PA 19104 | 23-1352166 | 501(C)(3) | 407,553. | 0. | | | MEDICAL RESEARCH |
| EMORY UNIVERSITY 201 DOWMAN DR ATLANTA, GA 30322 | 58-0566256 | 501(C)(3) | 24,200. | 0. | | | MEDICAL RESEARCH |
| UNIVERSITY OF OKLAHOMA 865 RESEARCH PARKWAY STE 540 OKLAHOMA CITY, OK 73104 | 73-1377584 | 501(C)(3) | 66,015. | 0. | | | MEDICAL RESEARCH |

- 2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ----- | 26.
- 3 Enter total number of other organizations listed in the line 1 table | 1.

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

Schedule I (Form 990) (2016)

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

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|---|------------|-------------------------------|--------------------------|-----------------------------------|---|--|------------------------------------|
| OHIO STATE UNIVERSITY 333 W. 10TH AVE COLUMBUS, OH 43210 | 31-6025986 | 501(C)(3) | 6,700. | 0. | | | MEDICAL RESEARCH |
| PFIZER, INC 235 EAST 42ND STREET NEW YORK, NY 10017 | 13-5315170 | | 150,000. | 0. | | | MEDICAL RESEARCH |
| REGENTS OF THE UNIVERSITY OF MINNESOTA - 200 SE OAK ST #600 - MINNEAPOLIS, MN 55455 | 41-6007513 | 501(C)(3) | 36,870. | 0. | | | MEDICAL RESEARCH |
| SCRIPPS RESEARCH INSTITUTE 10550 NORTH TORREY PINES ROAD, OSP- LA JOLLA, CA 92037 | 33-0435954 | 501(C)(3) | 67,455. | 0. | | | MEDICAL RESEARCH |
| THE JACKSON LABORATORY 600 MAIN STREET BAR HARBOR, ME 04609 | 01-0211513 | 501(C)(3) | 21,360. | 0. | | | MEDICAL RESEARCH |
| THE REGENTS OF THE UNIVERSITY OF CALIFORNIA LOS ANGELES - 10920 WILSHIRE BLVD, 5TH FLOOR - LOS ANGELES, CA 90024 | 95-6006143 | 501(C)(3) | 41,800. | 0. | | | MEDICAL RESEARCH |
| THE TRUSTEES OF THE UNIVERSITY OF PENNSYLVANIA - 3451 WALNUT STREET, RM P 221, FRANKLIN BLDG - PHILADELPHIA, PA 19104 | 23-1352685 | 501(C)(3) | 1,083,618. | 0. | | | MEDICAL RESEARCH |
| THE UNIVERSITY OF ALABAMA BIRMINGHAM - 701 20TH STREET SOUTH - BIRMINGHAM, AL 35294 | 63-6005396 | 501(C)(3) | 140,000. | 0. | | | MEDICAL RESEARCH |
| UNIVERSITY OF FLORIDA DEPT OF NEUROLOGY, L3-100 MCKNIGHT BRAIN INSTITUTE, NEWELL DRIVE - GAINESVIL | 59-6002052 | 501(C)(3) | 220,230. | 0. | | | MEDICAL RESEARCH |

Schedule I (Form 990)

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

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|--|------------|-------------------------------|--------------------------|-----------------------------------|---|--|------------------------------------|
| UNIVERSITY OF IOWA, DEPT OF PEDIATRICS - 200 HAWKINS DRIVE - IOWA CITY, IA 52242 | 42-6004813 | 501(C)(3) | 17,400. | 0. | | | MEDICAL RESEARCH |
| UNIVERSITY OF ROCHESTER 515 HYLAN BUILDING, RC BOX 270140 ROCHESTER, NY 14627 | 16-0743209 | 501(C)(3) | 157,782. | 0. | | | MEDICAL RESEARCH |
| UNIVERSITY OF SOUTH FLORIDA FOUNDATION - 4202 EAST FOWLER AVENUE - TAMPA, FL 33620 | 59-0879015 | 501(C)(3) | 150,000. | 0. | | | MEDICAL RESEARCH |
| WEILL MEDICAL COLLEGE OF CORNELL UNIVERSITY - 445 E 69TH ST - NEW YORK, NY 10021 | 13-1623978 | 501(C)(3) | 150,000. | 0. | | | MEDICAL RESEARCH |
| ALBANY RESEARCH INSTITUTE 113 HOLLAND AVE ALBANY, NY 12208 | 14-1716021 | 501(C)(3) | 35,200. | 0. | | | MEDICAL RESEARCH |
| HARVARD MEDICAL SCHOOL 1033 MASSACHUSETTS AVENUE CAMBRIDGE, MA 02138 | 04-2103580 | 501(C)(3) | 54,740. | 0. | | | MEDICAL RESEARCH |
| INDIANA UNIVERSITY 107 S INDIANA AVE BLOOMINGTON, IN 47405 | 35-6001673 | 501(C)(3) | 75,000. | 0. | | | MEDICAL RESEARCH |
| NATIONAL ATAXIA FOUNDATION 2600 FERNBROOK LANE MINNEAPOLIS, MN 55447 | 41-0832903 | 501(C)(3) | 5,000. | 0. | | | RESEARCH CONFERENCE |
| THE REGENTS OF THE UNIVERSITY OF CALIFORNIA DAVIS - 1850 RESEARCH PARK DRIVE - DAVIS, CA 95618 | 94-6036494 | 501(C)(3) | 90,000. | 0. | | | MEDICAL RESEARCH |

Schedule I (Form 990)

| Part II Continuation of Grants and Other Assistance to Governments and Organizations in the United States (Schedule I (Form 990), Part II.) | | | | | | | |
|--|------------|-------------------------------|--------------------------|-----------------------------------|---|--|------------------------------------|
| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
| THOMAS JEFFERSON UNIVERSITY 1020 WALNUT STREET PHILADELPHIA, PA 19107 | 23-2829095 | 501(C)(3) | 150,000. | 0. | | | MEDICAL RESEARCH |
| THE UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER - 5323 HARRY HINES BLVD - DALLAS, TX 75390 | 75-6002868 | 501(C)(3) | 123,360. | 0. | | | MEDICAL RESEARCH |
| UNIVERSITY OF SOUTH FLORIDA 4202 EAST FOWLER AVENUE TAMPA, FL 33620 | 59-3102112 | 501(C)(3) | 87,997. | 0. | | | MEDICAL RESEARCH |
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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 (d) cash grant | Amount of non-cash assistance | (e) Method of valuation (book, FMV, appraisal, other) | (f) Description of noncash assistance |
|---------------------------------|--------------------------|------------------------------|-------------------------------|---|---------------------------------------|
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Part IV Supplemental Information. Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

PART I, LINE 2:

GRANTS ARE REVIEWED BY INDEPENDENT SCIENTIFIC ADVISORS AND APPROVED BY BOARD.

SCHEDULE M
(Form 990)

Noncash Contributions

OMB No. 1545-0047

2016

Open To Public Inspection

Department of the Treasury
Internal Revenue Service

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

J Attach to Form 990.

J Information about Schedule M (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 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 | 9 | 268,107.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 J (_____) | | | | |
| 26 Other J (_____) | | | | |
| 27 Other J (_____) | | | | |
| 28 Other J (_____) | | | | |

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

30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least three years from the date of the initial contribution, and which isn't required to be used for exempt purposes for the entire holding period? ~~~~~

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 didn't report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II.

| | Yes | No |
|-----|-----|----|
| 30a | | X |
| 31 | | X |
| 32a | | X |
| 33 | | |

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

Schedule M (Form 990) (2016)

SCHEDULE O
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

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

| Attach to Form 990 or 990-EZ.

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

OMB No. 1545-0047

2016

Open to Public
Inspection

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number

52-2122720

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

MEETINGS WITH CONTENT FOCUSED ON FRIEDREICH'S ATAXIA.

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.

2016 FUNDED RESEARCH INITIATIVES:

FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE, PHILADELPHIA PA

THE FA CENTER OF EXCELLENCE (COE) IS A TRANSLATIONAL RESEARCH AND

CLINICAL CARE CENTER DEVOTED TO FRIEDREICH ATAXIA: EXPEDITING BASIC

SCIENCE AND DRUG DISCOVERY FINDINGS TO NEW TREATMENTS AND DEDICATING

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

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

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| Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE | Employer identification number 52-2122720 |
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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. PROJECTS AND INVESTIGATORS BEING FUNDED INCLUDE DR. ROB WILSON- DRUG DISCOVERY, DR. DAVID LYNCH- CLINICAL AND NEUROSCIENCE RESEARCH, DR, IAN BLAIR- METABOLIC BIOMARKERS, AND DR. KIM LIN- CARDIAC RESEARCH.

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 THREE 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. NAPIERALA AT UNIVERSITY OF ALABAMA BIRMINGHAM, CELL LINES ARE BEING SHARED WITH THE RESEARCH COMMUNITY, > 6 COMPANIES AND >3 ACADEMICS

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

SOURCING CELLS FOR DRUG DISCOVERY AND RESEARCH.

- ESTABLISHED 2 FA MOUSE MODEL COLONIES CURRENTLY TESTING DRUG

CANDIDATES

- 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

- INITIATED 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.

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

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|---|--|

- 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):

- FRATAXIN-PROTEIN, GENE EXPRESSION AND EPIGENETICS
- NEUROLOGICAL-SENSORY/PERIPHERAL AND BRAIN
- CARDIAC
- METABOLIC

PROJECTS ONGOING AND COLLECTING DATA IN 2016 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, PA

TITLE: 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, PA

TITLE: LONGITUDINAL MEASUREMENT OF GAIT AND BALANCE IN FRIEDREICH ATAXIA. MURDOCH CHILDRENS RESEARCH INSTITUTE, AUSTRALIA AND UNIVERSITY

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

OF SOUTH FLORIDA, TAMPA, FL

NEWLY AWARDED PROJECTS IN 2016

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

A FEW HIGHLIGHTED NEW RESEARCH GRANTS:

2016 BRONYA J KEATS INTERNATIONAL RESEARCH COLLABORATION AWARD

TITLE: DRUG RESCUE OF FRATAXIN-DEPENDENT NEURAL AND CARDIAC PATHOPHYSIOLOGY IN FA MODELS INVESTIGATORS: DR. GINO CORTOPASSI (UNIVERSITY OF CALIFORNIA, DAVIS), DR. PAOLA GIUNTI (UNIVERSITY COLLEGE LONDON), AND DR. MARK POOK (BRUNEL UNIVERSITY).

THE OVERALL PROJECT OBJECTIVES ARE TO TEST SEVEN KNOWN DRUGS THAT HAVE BEEN THROUGH CLINICAL TRIALS IN HUMANS FOR THEIR ABILITY TO INCREASE FRATAXIN AND IMPROVE MITOCHONDRIAL FUNCTION IN THE CONTEXT OF FRATAXIN DEFICIENCY IN VITRO AND IN VIVO, TO DETERMINE THE MOST POTENT AS SINGLE DRUGS AND AS MIXTURES ON A COMMON PLATFORM. THIS WILL FACILITATE THE IDENTIFICATION OF POTENT SINGLE DRUGS ON A COMMON PLATFORM AND ALSO THE MOST EFFECTIVE COCKTAILS, WHICH COULD SPEED CLINICAL DEVELOPMENT. THE HYPOTHESIS IS THAT BY USING DRUGS THAT REVERSE MULTIPLE LEVELS OF FA PATHOPHYSIOLOGY, AN ADDITIVE OR SYNERGISTIC BENEFIT WILL BE OBTAINED IN TERMS OF MITOCHONDRIAL FUNCTION AND CLINICAL BENEFIT. THREE FUNCTIONAL CATEGORIES OF PROTECTIVE COMPOUNDS HAVE BEEN IDENTIFIED, INCLUDING THOSE THAT 1) INCREASE FRATAXIN EXPRESSION, 2) INCREASE MITOCHONDRIAL

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| Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE | Employer identification number 52-2122720 |
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NUMBER OR FUNCTION OR BOTH, AND 3) INCREASE MITOCHONDRIAL IRON-SULFUR CLUSTER BIOGENESIS. THE GOAL OF THE PROJECT IS TO IDENTIFY THE MOST POTENT IN EACH CATEGORY, AND TO DETERMINE WHETHER MIXTURES HAVE ADDITIVE EFFECT ON OVERALL MITOCHONDRIAL FUNCTION AND BENEFIT IN A RELEVANT MOUSE MODEL.

2016 KEITH MICHAEL ANDRUS MEMORIAL AWARDS (FOR CARDIAC RESEARCH)

TITLE: INVESTIGATION OF CARDIAC PATHOPHYSIOLOGICAL MECHANISM AND RELEVANT BIOMARKER IN THE CONTEXT OF FXN DEFICIENCY AND FXN OVEREXPRESSION INDUCED TOXICITY. INVESTIGATOR: DR. HELENE PUCCIO (IGBMC, UNIVERSITY OF STRASBOURG, FRANCE)

DR. PUCCIO AND DR. BRAHIM BELBELLAA, A POSTDOCTORAL FELLOW IN HER GROUP, ARE INVESTIGATING THE POTENTIAL ADVERSE EFFECTS OF OVEREXPRESSION OF CARDIAC FRATAXIN, GENERATING A NEW CARDIAC-SPECIFIC CONDITIONAL KNOCKOUT MOUSE MODEL, AND IDENTIFYING POTENTIAL BIOMARKERS OF CARDIAC FRATAXIN DEFICIENCY. THESE PRE-CLINICAL STUDIES ARE CRITICAL FOLLOW-UP STEPS TO DR. PUCCIO'S SUCCESSFUL CORRECTION OF FA CARDIOMYOPATHY USING GENE THERAPY IN A MOUSE MODEL AND THEY MUST BE DONE BEFORE A FA CARDIAC GENE THERAPY CLINICAL TRIAL CAN BEGIN.

TITLE: IMPACT OF FRATAXIN DEFICIENCY ON CARDIAC SUBSTRATE METABOLISM

INVESTIGATOR: DR. ERIN SEIFFERT (THOMAS JEFFERSON UNIVERSITY)

DR. SEIFFERT WILL INVESTIGATE THE HYPOTHESIS THAT FRATAXIN DEFICIENCY IS ASSOCIATED WITH DISTURBANCES IN MITOCHONDRIAL ATP PRODUCTION AND SUBSTRATE METABOLISM IN THE HEART, AND THAT THESE DISTURBANCE CAUSE OR WORSEN HEART FUNCTION. PROTEINS THAT MEDIATE HEART METABOLISM ARE CURRENTLY BEING TARGETED FOR TREATING CARDIOMYOPATHY OF VARIOUS

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| Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE | Employer identification number 52-2122720 |
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ORIGINS, WITH THE GOAL OF PREVENTING THE PROGRESSION TO HEART FAILURE.
 UNDERSTANDING HOW FXN DEFICIENCY ALTERS CARDIAC METABOLISM WOULD TELL
 US IF THESE DRUGS COULD BE USEFUL FOR FA PATIENTS. MOREOVER, METABOLIC
 DISTURBANCES IN SKELETAL MUSCLE WOULD PROVIDE A RATIONALE FOR TESTING
 FOR ALTERED METABOLITE PROFILES IN THE PLASMA THAT COULD SIGNAL THE
 WORSENING OF CARDIAC FUNCTION.

2016 KYLE BRYANT TRANSLATIONAL RESEARCH AWARD

TITLE: A HUMAN IPSC-BASED CARDIAC MODEL OF FRIEDREICH'S ATAXIA FOR
 DRUG DISCOVERY AND PATIENT STRATIFICATION USING ALL-OPTICAL
 ELECTROPHYSIOLOGY. INVESTIGATORS: DR. JONATHAN CHERRY (RANA
 THERAPEUTICS) AND DR. GRAHAM DEMPSEY (Q-STATE BIOSCIENCES).
 A COLLABORATIVE STUDY BETWEEN RANA THERAPEUTICS AND Q-STATE BIOSCIENCES
 TO DEVELOP A NOVEL, HUMAN "DISEASE-IN-A-DISH" MODEL TO INVESTIGATE
 CARDIAC DYSFUNCTION IN FA. USING STEM CELL BIOLOGY, SKIN OR BLOOD FROM
 A FA PATIENT CAN BE REPROGRAMMED TO STEM CELLS, WHICH CAN THEN BE
 DIFFERENTIATED INTO PATIENT-SPECIFIC CARDIAC CELLS OR CARDIOMYOCYTES
 (CMS). THE FUNCTIONAL PROPERTIES OF THE DERIVED CMS CAN THEN BE STUDIED
 WITH Q-STATE'S PLATFORM TECHNOLOGY CALLED OPTOPATCH, WHERE SPECIFIC
 OPTOGENETIC PROTEINS CAN BE EXPRESSED IN CMS TO ALLOW FOR LIGHT-DRIVEN
 STIMULATION AND RECORDING OF ELECTRICAL ACTIVITY IN THOSE CELLS. THESE
 TYPES OF LIGHT-BASED ASSAYS CAN BE SCALED TO HIGH-THROUGHPUT
 CHARACTERIZATION OF DRUGS FOR DISCOVERY OF CANDIDATE TREATMENTS. OUR
 HYPOTHESIS IS THAT STEM CELL DERIVED CMS FROM FA PATIENTS WILL EXHIBIT
 A MEASURABLE ELECTROPHYSIOLOGICAL PHENOTYPE USING OPTOPATCH. THE
 PROPOSED RESEARCH WILL DEVELOP AND VALIDATE THE OPTOPATCH ASSAY ON
 PATIENT-DERIVED CMS PREPARED BY RANA SCIENTISTS. SUCCESSFUL COMPLETION
 OF THESE STUDIES WILL ESTABLISH THE REQUISITE TECHNOLOGY TO (1)

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| Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE | Employer identification number 52-2122720 |
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EVALUATE THE EFFECTS OF THERAPEUTICS DEVELOPED BY RANA AND (2) STUDY THE PHENOTYPE ACROSS A BROAD COHORT OF FA PATIENTS. BROADLY, THIS WILL OPEN THE OPPORTUNITY FOR PATIENT STRATIFICATION FOR CLINICAL TRIALS AND SCREENING OF THERAPEUTICS TO TREAT THIS DEVASTATING DISEASE.

2016 GENERAL GRANT HIGHLIGHTS

TITLE: DEVELOPMENT OF OLIGONUCLEOTIDE ACTIVATORS OF FXN EXPRESSION

INVESTIGATOR: DR. DAVID COREY (UT SOUTHWESTERN)

IN EARLY 2016, DR. COREY'S LABORATORY REPORTED THE DISCOVERY OF OLIGONUCLEOTIDES (SHORT MAN-MADE PIECES OF DNA OR RNA) THAT CAN ACTIVATE EXPRESSION OF FRATAXIN. IN THIS PROJECT, DR. COREY WILL TEST HIS COMPOUNDS IN A WIDER VARIETY OF PATIENT-DERIVED CELLS TO DETERMINE IF HIS FINDINGS CAN BE APPLIED WIDELY THROUGHOUT THE FRIEDREICH'S ATAXIA PATIENT POPULATION. HE WILL ALSO TEST MANY MORE COMPOUNDS TO IDENTIFY THE BEST ONES TO TAKE FORWARD AND TO PROVIDE INSIGHTS INTO HOW TO DESIGN THE NEXT GENERATION OF COMPOUNDS WITH IMPROVED PROPERTIES. AT THE END OF ONE YEAR HIS GOAL IS TO PROVIDE THE COMMUNITY WITH THE INFORMATION NEEDED TO CRITICALLY EVALUATE THE POTENTIAL OF OLIGONUCLEOTIDE-DIRECTED ACTIVATION OF FRATAXIN.

TITLE: EVALUATING NOVEL CAPSIDS ENGINEERED FOR EFFICIENT NERVOUS SYSTEM TRANSDUCTION AS FRATAXIN GENE DELIVERY VEHICLES INVESTIGATOR: DR. BEN DEVERMAN (CALIFORNIA INSTITUTE OF TECHNOLOGY)

DR. DEVERMAN WAS CO-FUNDED WITH FARA AUSTRALASIA AND FARA NZ. HIS RESEARCH IS FOCUSED ON DEVELOPING NOVEL VIRAL VECTORS FOR DELIVERY OF FRATAXIN TO THE NERVOUS SYSTEM AND OTHER SITES AFFECTED IN FRIEDREICH'S ATAXIA INCLUDING CARDIAC MUSCLE AND THE PANCREAS. RECENTLY, VOYAGER

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| Name of the organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE | Employer identification number 52-2122720 |
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THERAPEUTICS ENTERED INTO A LICENSING AGREEMENT WITH DR. DEVERMAN TO ADVANCE HIS VECTOR TECHNOLOGY.

TITLES AND SUMMARIES OF MOST OF THE PROJECTS PRESENTLY FUNDED BY FARA ARE AVAILABLE AT:

WWW.CUREFA.NET/RPMP/PUBLIC/PGGRANTLIST.ASPX AND COMPLETE LISTINGS OF GRANTS AWARDED BY YEAR CAN BE ACCESSED AT:
WWW.CUREFA.NET/GRANTS-AWARDED.HTML

RESULTS REPORTED FROM FARA AWARDED GRANTS - IN 2016, THERE WERE >20 MEDICAL AND SCIENTIFIC PUBLICATIONS THAT WERE DETAILED REPORTS OF FARA FUNDED RESEARCH.

SELECTED PUBLICATIONS
LOSS OF FRATAXIN ACTIVATES THE IRON/SPHINGOLIPID/PDK1/MEF2 PATHWAY IN MAMMALS. CHEN K, HO TS, LIN G, TAN KL, RASBAND MN, BELLEN HJ. ELIFE. 2016 NOV 30;5. PII: E20732. DOI: 10.7554/ELIFE.20732.

ALLEVIATING GAA REPEAT INDUCED TRANSCRIPTIONAL SILENCING OF THE FRIEDREICH'S ATAXIA GENE DURING SOMATIC CELL REPROGRAMMING. POLAK U, LI Y, BUTLER JS, NAPIERALA M. STEM CELLS DEV. 2016 DEC 1;25(23):1788-1800. EPUB 2016 OCT 17.

THE SIGNIFICANCE OF INTERCALATED DISCS IN THE PATHOGENESIS OF FRIEDREICH CARDIOMYOPATHY. KOEPPEN AH, BECKER AB, FEUSTEL PJ, GELMAN BB, MAZURKIEWICZ JE. J NEUROL SCI. 2016 AUG 15;367:171-6. DOI: 10.1016/J.JNS.2016.06.006. EPUB 2016 JUN 4.

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USING HUMAN PLURIPOTENT STEM CELLS TO STUDY FRIEDREICH ATAXIA

CARDIOMYOPATHY. CROMBIE DE, PERA MF, DELATYCKI MB, P BAY A. INT J

CARDIOL. 2016 JUN 1;212:37-43. DOI: 10.1016/J.IJCARD.2016.03.040.

ACTIVATING FRATAXIN EXPRESSION BY REPEAT-TARGETED NUCLEIC ACIDS. LI L,

MATSUI M, COREY DR.

NAT COMMUN. 2016 FEB 4;7:10606. DOI: 10.1038/NCOMMS10606.

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

FARA HELD A FRIEDREICH'S ATAXIA (FA) GENE THERAPY SYMPOSIUM IN

CONJUNCTION WITH THE AMERICAN SOCIETY OF GENE AND CELL THERAPY MEETING

IN WASHINGTON DC IN MAY OF 2016. THE FOCUS OF THE FARA SYMPOSIUM WAS

ON WHAT THE COMMUNITY COULD DO TOGETHER TO ADVANCE GENE THERAPIES FOR

FA. THE AGENDA WAS SPLIT INTO THREE SECTIONS: 1) EXPRESSION OF

FRATAXIN THROUGH GENE THERAPY, 2) TOOLS NEEDED TO DEVELOP GENE

THERAPIES FOR FA AND 3) BIOMARKERS AND ENDPOINTS FOR FA CLINICAL

TRIALS.

THE GROUP DISCUSSED DATA GATHERED BY THE VARIOUS ACADEMICS AND

COMPANIES IN ATTENDANCE RELATED TO THE MINIMAL AND MAXIMAL AMOUNT OF

FRATAXIN THAT COULD BE PRODUCED AND BE EXPECTED TO BE THERAPEUTIC IN

DIFFERENT CELL TYPES AND ANIMAL MODELS. THEY ALSO DISCUSSED WHICH

TISSUES AND CELL TYPES IN THE BODY MIGHT NEED TO BE TARGETED BY GENE

THERAPIES TO HAVE THE MAXIMAL EFFECT ON PATIENT OUTCOMES. THEY

DISCUSSED SHARED PROTOCOLS, SHARED BANKED SERUM FOR TESTING

IMMUNOLOGICAL REACTIONS TO VECTORS AND OTHER POTENTIAL AREAS WHERE

COMPANIES COULD COLLABORATE, DESPITE BEING IN A COMPETITIVE SPACE.

FINALLY, THERE WAS DISCUSSION OF THE ENDPOINTS AND BIOMARKERS CURRENTLY

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

AVAILABLE AN IN DEVELOPMENT FOR FA.

THE GROUP CONCLUDED THAT IT WANTED TO WORK TOGETHER TO TRY AND HAVE A

MEETING WITH THE CENTER FOR BIOLOGICS EVALUATION AND RESEARCH (CBER) AT

FDA TO INTRODUCE THE CONCEPT OF FA GENE THERAPY, AND RECOMMENDED TO

FARA TO TRY AND HOLD AN EXTERNALLY LED PATIENT FOCUSED DRUG DEVELOPMENT

MEETING TO DISCUSS PATIENT PREFERENCE FOR PATIENTS WITH FA, AS WELL AS

FURTHER MEETINGS TO DIG MORE DEEPLY INTO BIOMARKERS AND ENDPOINTS.

SEPTEMBER 2016 BIOMARKER MEETING

FARA'S 2016 BIOMARKER MEETING WAS HELD IN TAMPA, FLORIDA, IN

CONJUNCTION WITH A PATIENT SYMPOSIUM AND FUNDRAISING EVENT. IT WAS

ATTENDED BY CLOSE TO 100 PEOPLE, REPRESENTING INDUSTRY AND ACADEMIA

FROM AROUND THE WORLD. UPDATES WERE PROVIDED BY BOTH FARA-FUNDED AND

NON-FARA-FUNDED RESEARCHERS, COVERING NEUROLOGICAL BIOMARKERS AND

ENDPOINTS, FRATAXIN EXPRESSION, EXERCISE RELATED OUTCOMES AND CARDIAC

AND METABOLIC OUTCOMES.

WITHIN EACH CATEGORY, SPECIFIC BIOMARKERS AND OUTCOME MEASURES WERE

IDENTIFIED AS PROMISING FOR SPECIFIC PURPOSES BY THOSE ATTENDING, AND

FURTHER WORK WAS RECOMMENDED. WHERE POTENTIAL BIOMARKERS WERE NOT

SUPPORTED BY DATA, THESE WERE DEPRIORITIZED, WHILE ADDITIONAL STUDIES

WERE RECOMMENDED FOR THOSE BIOMARKERS/ENDPOINTS THAT HELD THE MOST

PROMISE.

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

HOSPITAL OF PHILADELPHIA (OCTOBER 17TH, 2016, KING OF PRUSSIA, PA),

EMORY UNIVERSITY (MAY 14TH 2016, ALPHARETTA, GA) AND UNIVERSITY OF

SOUTH FLORIDA (SEPTEMBER 15TH 2016, TAMPA FL). THESE SYMPOSIUMS PROVIDE

AN OPPORTUNITY TO EDUCATE THE PATIENT/FAMILY COMMUNITY ON RESEARCH

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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 450 ATTENDEES.

THE FARA AMBASSADOR PROGRAM WHICH WAS LAUNCHED IN 2011 WITH >20 PARTICIPANTS HAD A YEAR OF CONTINUED GROWTH AND ACTIVITY IN 2016. THE PROGRAM NOW INCLUDES 44 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 2016, FARA FACILITATED FORMAL TRAINING FOR THE AMBASSADOR LEADERSHIP TEAM AND AMBASSADORS. THE FOCUS FOR THE TRAINING WAS ON THE PATIENT VOICE IN THE RESEARCH PROCESS. THE AMBASSADOR BLOG FEATURED POSTS SUCH AS COMMUNITY EVENT SUMMARIES, MEET THE COMMUNITY INTERVIEWS WITH PEOPLE LIVING WITH FA, AND COMMUNITY MEMBER SPOTLIGHTS. IN 2016, THEY ACHIEVED >70 POSTS WITH ALMOST 15,000 VIEWS. THE AMBASSADORS ALSO CONTINUED A CARD PROGRAM IN WHICH THEY DESIGNED CARDS TO SEND TO THE VARIOUS STAKEHOLDERS AND COMMUNITY MEMBERS THROUGHOUT THE YEAR TO SAY THANK YOU OR TO OFFER ENCOURAGEMENT. THEY ARE AVERAGING ABOUT 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. 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.

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

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CCRN AND PATIENT REGISTRY:

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 2016, 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,

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|---|--|

DRUGS OR INTERVENTIONS.

CLINICAL OUTCOME MEASURES : FUNCTIONAL PERFORMANCE TESTS (E.G., TIMED

PEGBBOARD 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 900 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 \$400,000 IN 2016 TO CLINICAL RESEARCH

INFRASTRUCTURE IN DIRECT FUNDING TO THE CCRN IN FA CENTERS AND RELATED

CLINICAL RESEARCH ACTIVITIES.

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SELECTED CCRN IN FA PUBLICATIONS

PROGRESSION OF FRIEDREICH ATAXIA: QUANTITATIVE CHARACTERIZATION OVER 5

YEARS. PATEL M, ISAACS CJ, SEYER L, BRIGATTI K, GELBARD S, STRAWSER C,

FOERSTER D, SHINNICK J, SCHADT K, YIU EM, DELATYCKI MB, PERLMAN S,

WILMOT GR, ZESIEWICZ T, MATHEWS K, GOMEZ CM, YOON G, SUBRAMONY SH,

BROCHT A, FARMER J, LYNCH DR. ANN CLIN TRANSL NEUROL. 2016 JUL

25;3(9):684-94. DOI: 10.1002/ACN3.332. ECOLLECTION 2016.

COMORBID MEDICAL CONDITIONS IN FRIEDREICH ATAXIA: ASSOCIATION WITH

INFLAMMATORY BOWEL DISEASE AND GROWTH HORMONE DEFICIENCY. SHINNICK JE,

SCHADT K, STRAWSER C, WILCOX N, PERLMAN SL, WILMOT GR, GOMEZ CM,

MATHEWS KD, YOON G, ZESIEWICZ T, HOYLE C, SUBRAMONY SH, YIU EM,

DELATYCKI MB, BROCHT AF, FARMER JM, LYNCH DR. J CHILD NEUROL. 2016

AUG;31(9):1161-5. DOI: 10.1177/0883073816643408. EPUB 2016 APR 12.

EFFECTS OF GENETIC SEVERITY ON GLUCOSE HOMEOSTASIS IN FRIEDREICH

ATAXIA. ISAACS CJ, BRIGATTI KW, KUCHERUK O, RATCLIFFE S, SCIASCIA T,

MCCORMACK SE, WILLI SM, LYNCH DR. MUSCLE NERVE. 2016

NOV;54(5):887-894. DOI: 10.1002/MUS.25136. EPUB 2016 AUG 30.

EXPENSES \$ 431,781. INCLUDING GRANTS OF \$ 382,000. REVENUE \$ 0.

FORM 990, PART VI, SECTION A, LINE 4:

THE POSITION OF VICE-CHAIR WAS REMOVED AND REFERENCE TO THE DEVELOPMENT

ADVISORY BOARD WAS REMOVED AS THESE WERE NOT FOUND TO BE ESSENTIAL.

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

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

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|---|--|
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PRIOR TO FILING.

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

ALL NEW AND EXISTING BOARD MEMBERS REQUIRED TO ANNUALLY COMPLETE A CONFLICT OF INTEREST STATEMENT

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

EVALUATION AND COMPENSATION COMMITTEE PERFORMS EMPLOYEE EVALUATIONS AND DETERMINES SALARY INCREASES ON A YEARLY BASIS FOR ALL EMPLOYEES. COMMITTEE EXAMINES BENCHMARK DATA IN DETERMINING SALARIES FOR PRESIDENT AND EXECUTIVE DIRECTOR.

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

AL,AK,AZ,AR,CA,CO,CT,FL,GA,IL,KS,KY,ME,MD,MS,MI,MN,MS,MO,NH,NJ,NM,NY,NC,ND
OH,OK,OR,PA,RI,SC,TN,UT,VA,WA,WV,WI,MA

FORM 990, PART VI, SECTION C, LINE 18:

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

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

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

FORM 990, PART VI LINE 17

THE ORGANIZATION IS ALSO REGISTERED TO SOLICIT CONTRIBUTIONS IN THE STATES LISTED.

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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.