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Form **990**

Department of the Treasury
Internal Revenue Service

# Return of Organization Exempt From Income Tax

**Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)**

▶ Do not enter social security numbers on this form as it may be made public
▶ Information about Form 990 and its instructions is at *www IRS gov/form990*

OMB No 1545-0047

**2016**

**Open to Public Inspection**

**A For the 2016 calendar year, or tax year beginning 01-01-2016 , and ending 12-31-2016**

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

**C** Name of organization
FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Doing business as

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

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

**D Employer identification number**
52-2122720

E Telephone number
(484) 879-6160

**G** Gross receipts $ 7,021,269

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

**H(a)** Is this a group return for subordinates? ☐ Yes ☑ No

**H(b)** Are all subordinates included? ☐ Yes ☐ No
If "No," attach a list (see instructions)

**H(c)** Group exemption number ▶

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

**J Website:** ▶ WWW CUREFA ORG

**K** Form of organization ☑ Corporation ☐ Trust ☐ Association ☐ Other ▶

**L** Year of formation 1998

**M** State of legal domicile VA

## Part I Summary

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

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

| | | | |
|---|---|---|---|
| **3** | Number of voting members of the governing body (Part VI, line 1a) | **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 |
| **7a** | 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 |

| | | Prior Year | Current Year |
|---|---|---|---|
| **8** | Contributions and grants (Part VIII, line 1h) | 5,701,123 | 5,388,847 |
| **9** | Program service revenue (Part VIII, line 2g) | 0 | 0 |
| **10** | Investment income (Part VIII, column (A), lines 3, 4, and 7d ) | 19,427 | 47,576 |
| **11** | Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) | -2,405 | -54,930 |
| **12** | Total revenue—add lines 8 through 11 (must equal Part VIII, column (A), line 12) | 5,718,145 | 5,381,493 |
| **13** | Grants and similar amounts paid (Part IX, column (A), lines 1–3 ) | 4,750,666 | 4,852,904 |
| **14** | Benefits paid to or for members (Part IX, column (A), line 4) | 0 | 0 |
| **15** | Salaries, other compensation, employee benefits (Part IX, column (A), lines 5–10) | 503,463 | 463,198 |
| **16a** | Professional fundraising fees (Part IX, column (A), line 11e) | 0 | 0 |
| **b** | Total fundraising expenses (Part IX, column (D), line 25) ▶99,383 | | |
| **17** | Other expenses (Part IX, column (A), lines 11a–11d, 11f–24e) | 367,667 | 237,062 |
| **18** | Total expenses Add lines 13–17 (must equal Part IX, column (A), line 25) | 5,621,796 | 5,553,164 |
| **19** | Revenue less expenses Subtract line 18 from line 12 | 96,349 | -171,671 |

| | | Beginning of Current Year | End of Year |
|---|---|---|---|
| **20** | Total assets (Part X, line 16) | 4,057,130 | 4,110,033 |
| **21** | Total liabilities (Part X, line 26) | 289,961 | 484,966 |
| **22** | Net assets or fund balances Subtract line 21 from line 20 | 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**

****** 2017-05-10
Signature of officer Date

JENNIFER FARMER EXECUTIVE DIRECTOR
Type or print name and title

**Paid Preparer Use Only**

| Print/Type preparer's name | Preparer's signature | Date | Check ☐ if self-employed | PTIN |
|---|---|---|---|---|
| EDWARD FRONCZKOWSKI CPA | EDWARD FRONCZKOWSKI CPA | | | P01259092 |

Firm's name ▶ MAILLIE LLP — Firm's EIN ▶ 23-1518888

Firm's address ▶ 624 WILLOWBROOK LANE
WEST CHESTER, PA 19382

Phone no (610) 696-4353

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

**Part III** **Statement of Program Service Accomplishments**

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

**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

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

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

If "Yes," describe these changes on Schedule O

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

**4a** (Code ) (Expenses $ 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 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 PATHE FA CENTER OF EXCELLENCE (COE) IS A TRANSLATIONAL RESEARCH AND CLINICAL CARE CENTER DEVOTED TO FRIEDREICH ATAXIA EXPEDITING BASIC SCIENCE AND DRUG DISCOVERY FINDINGS TO NEW TREATMENTS AND DEDICATING RESOURCES TO CLINICAL RESEARCH AND CARE TO FURTHER UNDERSTAND THE DISEASE, INFORM DRUG DEVELOPMENT AND IMPROVE OUTCOMES FOR INDIVIDUALS LIVING WITH FA THE CENTER WAS ESTABLISHED IN MARCH 2014 , WITH A GIFT OF $3 25 MILLION (OVER 3 YEARS) TO PENN MEDICINE/ CHILDREN'S HOSPITAL OF PHILADELPHIA, PRESENTED BY FARA IN PARTNERSHIP WITH THE HAMILTON AND FINNERAN FAMILIES 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 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 INITIATIVEBIOMARKERS ARE BIOLOGICAL MEASURES THAT INDICATE CHANGE IN A DISEASE, AND THEY HAVE THE POTENTIAL TO SHORTEN THE LENGTH OF CLINICAL TRIALS FARA LAUNCHED AN INITIATIVE TO LOOK FOR NOVEL BIOMARKERS FOR FA, STARTING WITH A NOVEMBER 2014 MEETING WHERE EXPERTS CAME TOGETHER TO PRIORITIZE POSSIBLE MARKERS THEY DETERMINED THAT WE NEED BIOMARKERS TO - MEASURE DISEASE PROGRESSION (PARTICULARLY AT EARLY STAGES OF DISEASE)- MEASURE DRUG EFFECTIVENESS IN TERMS OF AFFECT ON PRIMARY MECHANISMS OF DISEASE OR A SPECIFIC TARGET- MEASURE DRUG EFFECTIVENESS AT TREATING SPECIFIC GROUPS OF SYMPTOMS, SUCH AS CARDIAC AND NEUROLOGICAL SYMPTOMS- IDENTIFY SUBSETS OF PATIENTS WITH IDENTIFIABLE GENOTYPIC OR PHENOTYPIC PROFILES LIKELY TO BENEFIT FROM SPECIFIC THERAPEUTIC APPROACHES IN A GIVEN PERIOD OF TIME THERE ARE 4 MAIN AREAS OF INVESTIGATION WITH PROJECTS UNDERWAY (DESCRIBED BELOW) - FRATAXIN-PROTEIN, GENE EXPRESSION AND EPIGENETICS- NEUROLOGICAL-SENSORY/PERIPHERAL AND BRAIN- CARDIAC-METABOLICPROJECTS 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 MINNESOTATITLE NEUROPHYSIOLOGIC BIOMARKERS IN FRIEDREICH'S ATAXIA HOPITAL ERASME, BRUSSELS AND CHILDREN'S HOSPITAL OF PHILADELPHIA, PATITLE IN-VIVO CONFOCAL IMAGING OF MEISSNER'S CORPUSCLES AS A BIOMARKER IN FRIEDREICH'S ATAXIA UNIVERSITY OF ROCHESTER, NYTITLE 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, PATITLE LONGITUDINAL MEASUREMENT OF GAIT AND BALANCE IN FRIEDREICH ATAXIA MURDOCH CHILDRENS RESEARCH INSTITUTE, AUSTRALIA AND UNIVERSITY OF SOUTH FLORIDA, TAMPA, FLNEWLY AWARDED PROJECTS IN 2016TITLE CLINICAL OUTCOME MEASURES OF EFFICACY IN TREATMENT OF FRIEDREICH'S ATAXIA UNIVERSITY OF FLORIDA, FLTITLE PROTEIN BIOMARKERS IN FRDA CARDIOMYOPATHY TO MONITOR DISEASE PROGRESSION AND THERAPEUTIC EFFICACY DUKE UNIVERSITY, NCA 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 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

**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 MEETINGFARA 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 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 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 MEETINGFARA'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

**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 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 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

(Code ) (Expenses $ 431,781 including grants of $ 382,000 ) (Revenue $ )

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/REGISTRYCOLLABORATIVE 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 HTMLNATURAL HISTORY STUDY LONGITUDINAL DATA (USUALLY ABOUT 10 YEARS) ON INDIVIDUALS WITH A DISEASE THAT DESCRIBES AND QUANTIFIES THE PROGRESSION OF THE DISEASE ALONG WITH THE SYMPTOMS AND MANIFESTATIONS OF THE DISEASE NATURAL HISTORY CAN SOMETIMES SERVE AS THE BASIS FROM WHICH MEASUREMENTS CAN BE MADE TO DETERMINE EFFECTS OF NEW TREATMENTS, DRUGS OR INTERVENTIONS CLINICAL OUTCOME MEASURES FUNCTIONAL PERFORMANCE TESTS (E G , TIMED PEGBOARD OR WALK TESTS, VISION, HEARING OR SPEECH TESTS) THAT QUANTIFY HOW MUCH CHANGE TAKES PLACE IN A SPECIFIC AMOUNT OF TIME AND ARE USED IN CLINICAL TRIALS TO MEASURE WHETHER A DRUG IS ALTERING THE COURSE OF THE DISEASE BIOMARKERS ANYTHING THAT CAN BE USED AS AN INDICATOR OF A PARTICULAR DISEASE STATE - USUALLY PROTEINS, ENZYMES, GENETIC VARIANTS, IMAGING (MRI, CT OR PET SCANS) BIOMARKERS CAN BE USED TO ASSESS RISK OF DISEASE, DIAGNOSIS, OR OUTCOMES USE OF BIOMARKERS IN DRUG DEVELOPMENT IS OF GREAT INTEREST BECAUSE BIOMARKERS CAN PROVIDE EVIDENCE OF BIOLOGICAL ACTIVITY, POTENTIALLY DEMONSTRATING THERAPEUTIC BENEFIT MORE QUICKLY THAN TRADITIONAL OUTCOME MEASURES BIOREPOSITORY A REPOSITORY OR BANK OF STORED BIOLOGICAL MATERIALS SUCH AS BLOOD SAMPLES, DNA, ORGANS, AND TISSUES (SUCH AS SKIN, MUSCLE, HEART) THAT CAN BE USED FOR RESEARCH THROUGH THE CCRN IN FA WE HAVE COLLECTED ELEVEN YEARS OF NATURAL HISTORY DATA (ONGOING) IN MORE THAN 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 SELECTED CCRN IN FA PUBLICATIONSPROGRESSION 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

**4d** Other program services (Describe in Schedule O )
(Expenses $ 431,781 including grants of $ 382,000 ) (Revenue $ )

**4e** **Total program service expenses ▶** 5,358,688

**Part IV Checklist of Required Schedules**

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

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

| | | | Yes | No |
|---|---|---|---|---|
| **20a** | Did the organization operate one or more hospital facilities? *If "Yes," complete Schedule H* | **20a** | | No |
| **b** | If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? | **20b** | | |
| **21** | Did the organization report more than $5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? *If "Yes," complete Schedule I, Parts I and II* | **21** | Yes | |
| **22** | Did the organization report more than $5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? *If "Yes," complete Schedule I, Parts I and III* | **22** | | No |
| **23** | Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? *If "Yes," complete Schedule J* | **23** | | No |
| **24a** | Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than $100,000 as of the last day of the year, that was issued after December 31, 2002? *If "Yes," answer lines 24b through 24d and complete Schedule K If "No," go to line 25a* | **24a** | | No |
| **b** | Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? | **24b** | | |
| **c** | Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? | **24c** | | |
| **d** | Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? | **24d** | | |
| **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? *If "Yes," complete Schedule L, Part I* | **25a** | | No |
| **b** | Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? *If "Yes," complete Schedule L, Part I* | **25b** | | No |
| **26** | Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? *If "Yes," complete Schedule L, Part II* | **26** | | No |
| **27** | Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? *If "Yes," complete Schedule L, Part III* | **27** | | No |
| **28** | Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions) | | | |
| **a** | A current or former officer, director, trustee, or key employee? *If "Yes," complete Schedule L, Part IV* | **28a** | | No |
| **b** | A family member of a current or former officer, director, trustee, or key employee? *If "Yes," complete Schedule L, Part IV* | **28b** | | No |
| **c** | An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? *If "Yes," complete Schedule L, Part IV* | **28c** | | No |
| **29** | Did the organization receive more than $25,000 in non-cash contributions? *If "Yes," complete Schedule M* | **29** | Yes | |
| **30** | Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? *If "Yes," complete Schedule M* | **30** | | No |
| **31** | Did the organization liquidate, terminate, or dissolve and cease operations? *If "Yes," complete Schedule N, Part I* | **31** | | No |
| **32** | Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? *If "Yes," complete Schedule N, Part II* | **32** | | No |
| **33** | Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301 7701-2 and 301 7701-3? *If "Yes," complete Schedule R, Part I* | **33** | | No |
| **34** | Was the organization related to any tax-exempt or taxable entity? *If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1* | **34** | | No |
| **35a** | Did the organization have a controlled entity within the meaning of section 512(b)(13)? | **35a** | | No |
| **b** | If 'Yes' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? *If "Yes," complete Schedule R, Part V, line 2* | **35b** | | |
| **36** | **Section 501(c)(3) organizations.** Did the organization make any transfers to an exempt non-charitable related organization? *If "Yes," complete Schedule R, Part V, line 2* | **36** | | No |
| **37** | Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? *If "Yes," complete Schedule R, Part VI* | **37** | | No |
| **38** | Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? **Note.** All Form 990 filers are required to complete Schedule O | **38** | Yes | |

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

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

| | | | | Yes | No |
|---|---|---|---|---|---|
| **1a** | Enter the number reported in Box 3 of Form 1096 Enter -0- if not applicable . . | **1a** | 4 | | |
| **b** | Enter the number of Forms W-2G included in line 1a *Enter -0-* if not applicable | **1b** | 0 | | |
| **c** | Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? . . . . . | **1c** | | Yes | |
| **2a** | Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return . . . . . | **2a** | 7 | | |
| **b** | If at least one is reported on line 2a, did the organization file all required federal employment tax returns? **Note.** If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions) | **2b** | | Yes | |
| **3a** | Did the organization have unrelated business gross income of $1,000 or more during the year? . . . | **3a** | | | No |
| **b** | If "Yes," has it filed a Form 990-T for this year? *If "No" to line 3b, provide an explanation in Schedule O* . . . | **3b** | | | |
| **4a** | At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)? . . | **4a** | | | No |
| **b** | If "Yes," enter the name of the foreign country ▶ _____ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR) | | | | |
| **5a** | Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? . . | **5a** | | | No |
| **b** | Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? | **5b** | | | No |
| **c** | If "Yes," to line 5a or 5b, did the organization file Form 8886-T? . . . . . | **5c** | | | |
| **6a** | Does the organization have annual gross receipts that are normally greater than $100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions? . . . | **6a** | | | No |
| **b** | If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible? . . . . . | **6b** | | | |
| **7** | **Organizations that may receive deductible contributions under section 170(c).** | | | | |
| **a** | Did the organization receive a payment in excess of $75 made partly as a contribution and partly for goods and services provided to the payor? . . . . . | **7a** | | Yes | |
| **b** | If "Yes," did the organization notify the donor of the value of the goods or services provided? . . . . . | **7b** | | Yes | |
| **c** | Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282? . . . . . | **7c** | | | No |
| **d** | If "Yes," indicate the number of Forms 8282 filed during the year . . . . | **7d** | | | |
| **e** | Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? | **7e** | | | No |
| **f** | Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? . . | **7f** | | | No |
| **g** | If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required? . . . . . | **7g** | | | |
| **h** | If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C? . . . . . | **7h** | | | |
| **8** | **Sponsoring organizations maintaining donor advised funds.** Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year? . . . . . | **8** | | | |
| **9a** | Did the sponsoring organization make any taxable distributions under section 4966? . . . | **9a** | | | |
| **b** | Did the sponsoring organization make a distribution to a donor, donor advisor, or related person? . . . | **9b** | | | |
| **10** | **Section 501(c)(7) organizations.** Enter | | | | |
| **a** | Initiation fees and capital contributions included on Part VIII, line 12 . . . | **10a** | | | |
| **b** | Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities | **10b** | | | |
| **11** | **Section 501(c)(12) organizations.** Enter | | | | |
| **a** | Gross income from members or shareholders . . . . . | **11a** | | | |
| **b** | Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them ) . . . . . | **11b** | | | |
| **12a** | **Section 4947(a)(1) non-exempt charitable trusts.** Is the organization filing Form 990 in lieu of Form 1041? | **12a** | | | |
| **b** | If "Yes," enter the amount of tax-exempt interest received or accrued during the year | **12b** | | | |
| **13** | **Section 501(c)(29) qualified nonprofit health insurance issuers.** | | | | |
| **a** | Is the organization licensed to issue qualified health plans in more than one state? **Note.** See the instructions for additional information the organization must report on Schedule O | **13a** | | | |
| **b** | Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans . . . . | **13b** | | | |
| **c** | Enter the amount of reserves on hand . . . . . | **13c** | | | |
| **14a** | Did the organization receive any payments for indoor tanning services during the tax year? . . . . . | **14a** | | | No |
| **b** | If "Yes," has it filed a Form 720 to report these payments? *If "No," provide an explanation in Schedule O* . . | **14b** | | | |

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

Check if Schedule O contains a response or note to any line in this Part VI . . . . . ☑

## Section A. Governing Body and Management

| | | | | Yes | No |
|---|---|---|---|---|---|
| **1a** | Enter the number of voting members of the governing body at the end of the tax year | **1a** | 18 | | |
| | If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O | | | | |
| **b** | Enter the number of voting members included in line 1a, above, who are independent | **1b** | 17 | | |
| **2** | Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee? | | **2** | | No |
| **3** | Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors or trustees, or key employees to a management company or other person? | | **3** | | No |
| **4** | Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? | | **4** | Yes | |
| **5** | Did the organization become aware during the year of a significant diversion of the organization's assets? | | **5** | | No |
| **6** | Did the organization have members or stockholders? | | **6** | | No |
| **7a** | Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? | | **7a** | | No |
| **b** | Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? | | **7b** | | No |
| **8** | Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following | | | | |
| **a** | The governing body? | | **8a** | Yes | |
| **b** | Each committee with authority to act on behalf of the governing body? | | **8b** | Yes | |
| **9** | Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? *If "Yes," provide the names and addresses in Schedule O* | | **9** | | No |

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

| | | | Yes | No |
|---|---|---|---|---|
| **10a** | Did the organization have local chapters, branches, or affiliates? | **10a** | | No |
| **b** | If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? | **10b** | | |
| **11a** | Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? | **11a** | Yes | |
| **b** | Describe in Schedule O the process, if any, used by the organization to review this Form 990 | | | |
| **12a** | Did the organization have a written conflict of interest policy? *If "No," go to line 13* | **12a** | Yes | |
| **b** | Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? | **12b** | Yes | |
| **c** | Did the organization regularly and consistently monitor and enforce compliance with the policy? *If "Yes," describe in Schedule O how this was done* | **12c** | Yes | |
| **13** | Did the organization have a written whistleblower policy? | **13** | Yes | |
| **14** | Did the organization have a written document retention and destruction policy? | **14** | Yes | |
| **15** | Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? | | | |
| **a** | The organization's CEO, Executive Director, or top management official | **15a** | Yes | |
| **b** | Other officers or key employees of the organization | **15b** | Yes | |
| | If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions) | | | |
| **16a** | Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? | **16a** | | No |
| **b** | If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements? | **16b** | | |

## Section C. Disclosure

**17** List the States with which a copy of this Form 990 is required to be filed▶ AL , AK , AZ , AR , CA , CO , CT , FL , GA , IL , KS , KY , ME , MD , MS , MI , MN , MS , MO , NH , NJ , NM , NY , NC , ND , OH , OK , OR , PA , RI , SC , TN , UT , VA , WA , WV , WI , MA

**18** Section 6104 requires an organization to make its Form 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection Indicate how you made these available Check all that apply

☑ Own website ☑ Another's website ☑ Upon request ☐ Other (explain in Schedule O)

**19** Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year

**20** State the name, address, and telephone number of the person who possesses the organization's books and records ▶JENNIFER FARMER 533 W UWCHLAN AVENUE DOWNINGTOWN, PA 19335 (484) 879-6160

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

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

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

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

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

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

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

| (A) Name and Title | (B) Average hours per week (list any hours for related organizations below dotted line) | (C) Position (do not check more than one box, unless person is both an officer and a director/trustee) | | | | | | (D) Reportable compensation from the organization (W- 2/1099-MISC) | (E) Reportable compensation from related organizations (W- 2/1099-MISC) | (F) Estimated amount of other compensation from the organization and related organizations |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Individual trustee or director | Institutional Trustee | Officer | Key employee | Highest compensated employee | Former | | | |
| (1) EDWARD RAMSEY<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (2) MARILYN E DOWNING<br>SECRETARY | 0 00 | X | | X | | | | 0 | 0 | 0 |
| (3) RUTH DEWITT<br>TREASURER | 0 00 | X | | X | | | | 0 | 0 | 0 |
| (4) JENNIFER GOOD<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (5) PAUL AVERY<br>CHAIRMAN | 0 00 | X | | X | | | | 0 | 0 | 0 |
| (6) PETER CRISP<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (7) DR HOLLY HEDRICK<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (8) GEOFFREY LEVITT<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (9) DR STEVE KLASKO<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (10) THOMAS HAMILTON<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (11) BERNARD RAVINA<br>SCIENTIFIC DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (12) DR SANJAY BIDICHANDANI<br>SCIENTIFIC DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (13) VINCENT R GIANNINI<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (14) DR JAMES MCARTHUR<br>SCIENTIFIC DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (15) TONY PLOHOROS<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (16) PAT RITSCHEL<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (17) RONALD BARTEK<br>PRESIDENT/DIRECTOR | 40 00 | X | | X | | | | 100,000 | 0 | 180 |

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

| (A) Name and Title | (B) Average hours per week (list any hours for related organizations below dotted line) | (C) Position (do not check more than one box, unless person is both an officer and a director/trustee) | | | | | | (D) Reportable compensation from the organization (W-2/1099-MISC) | (E) Reportable compensation from related organizations (W- 2/1099-MISC) | (F) Estimated amount of other compensation from the organization and related organizations |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Individual trustee or director | Institutional Trustee | Officer | Key employee | Highest compensated employee | Former | | | |
| (18) BRIGID BRENNAN<br>DIRECTOR | 0 00 | X | | | | | | 0 | 0 | 0 |
| (19) JENNIFER FARMER<br>EXECUTIVE DIRECTOR | 40 00 | | | X | | | | 110,000 | 0 | 180 |
| | | | | | | | | | | |
| | | | | | | | | | | |
| | | | | | | | | | | |
| | | | | | | | | | | |
| | | | | | | | | | | |
| | | | | | | | | | | |
| | | | | | | | | | | |
| **1b Sub-Total** ▶ | | | | | | | | | | |
| **c Total from continuation sheets to Part VII, Section A** ▶ | | | | | | | | | | |
| **d Total (add lines 1b and 1c)** ▶ | | | | | | | | 210,000 | 0 | 360 |

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

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

## Section B. Independent Contractors

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

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

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

**Part VIII Statement of Revenue**

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

| | | (A) Total revenue | (B) Related or exempt function revenue | (C) Unrelated business revenue | (D) Revenue excluded from tax under sections 512-514 |
|---|---|---|---|---|---|
| Contributions, Gifts, Grants and Other Similar Amounts | 1a Federated campaigns . . 1a | | | | |
| | b Membership dues . . 1b | | | | |
| | c Fundraising events . . 1c 3,196,185 | | | | |
| | d Related organizations 1d | | | | |
| | e Government grants (contributions) 1e | | | | |
| | f All other contributions, gifts, grants, and similar amounts not included above 1f 2,192,662 | | | | |
| | g Noncash contributions included in lines 1a-1f $ _____ | | | | |
| | h **Total.** Add lines 1a-1f . . . . . ▶ | 5,388,847 | | | |
| Program Service Revenue | | Business Code | | | |
| | 2a _____ | | | | |
| | b _____ | | | | |
| | c _____ | | | | |
| | d _____ | | | | |
| | e _____ | | | | |
| | f All other program service revenue | | | | |
| | g **Total.** Add lines 2a–2f . . . . ▶ | | | | |
| Other Revenue | 3 Investment income (including dividends, interest, and other similar amounts) . . . . . ▶ | 29,213 | | | 29,213 |
| | 4 Income from investment of tax-exempt bond proceeds ▶ | | | | |
| | 5 Royalties . . . . . ▶ | | | | |
| | | (i) Real / (ii) Personal | | | |
| | 6a Gross rents | | | | |
| | b Less rental expenses | | | | |
| | c Rental income or (loss) | | | | |
| | d Net rental income or (loss) . . . . . ▶ | | | | |
| | | (i) Securities / (ii) Other | | | |
| | 7a Gross amount from sales of assets other than inventory | 889,227 | | | |
| | 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 |
| | 8a 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 . . . b | 768,912 | | | |
| | c Net income or (loss) from fundraising events . . ▶ | -54,930 | | | -54,930 |
| | 9a Gross income from gaming activities See Part IV, line 19 . . . a | | | | |
| | b Less direct expenses . . . b | | | | |
| | c Net income or (loss) from gaming activities . . ▶ | | | | |
| | 10a 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 / Business Code | | | | |
| | 11a | | | | |
| | 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) Fundraisingexpenses |
|---|---|---|---|---|
| 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, line 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 Schedule 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 IX . . . . . ☐

| | | | (A) Beginning of year | | (B) End of year |
|---|---|---|---|---|---|
| Assets | 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 instructions) Complete Part II of Schedule L | | 6 | |
| | 7 | Notes and loans receivable, net | | 7 | |
| | 8 | Inventories for sale or use | | 8 | |
| | 9 | Prepaid expenses and deferred charges | 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 | 3,138 | 10c | 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 |
| Liabilities | 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 |
| Net Assets or Fund Balances | | **Organizations that follow SFAS 117 (ASC 958), check here ▶ ☑ 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 ▶ ☐ 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 Reconcilliation 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 . . . . . ☑

| | | | Yes | No |
|---|---|---|---|---|
| 1 | Accounting method used to prepare the Form 990 ☐ Cash ☑ Accrual ☐ 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? | 2a | | No |
| | If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis | | | |
| b | Were the organization's financial statements audited by an independent accountant? | 2b | Yes | |
| | 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 ☑ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis | | | |
| 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? | 2c | Yes | |
| | If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O | | | |
| 3a | As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? | 3a | | No |
| b | If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits | 3b | | |

## Additional Data

**Software ID:**

**Software Version:**

**EIN:** 52-2122720

**Name:** FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

efile GRAPHIC print - DO NOT PROCESS | As Filed Data - | DLN: 93493131044367

# SCHEDULE A (Form 990 or 990EZ)

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.**

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

OMB No 1545-0047

**2016**

**Open to Public Inspection**

**Name of the organization**
FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

**Employer identification number**
52-2122720

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

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

1 ☐ A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i).**

2 ☐ A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E (Form 990 or 990-EZ))

3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**

4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state _____

5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170 (b)(1)(A)(iv).** (Complete Part II )

6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**

7 ☑ An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi).** (Complete Part II )

8 ☐ A community trust described in **section 170(b)(1)(A)(vi)** (Complete Part II )

9 ☐ An agricultural research organization described in **170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land grant college of agriculture See instructions Enter the name, city, and state of the college or university

_____

10 ☐ An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions—subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975 See **section 509(a)(2).** (Complete Part III )

11 ☐ An organization organized and operated exclusively to test for public safety See **section 509(a)(4).**

12 ☐ An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2).** See **section 509(a)(3).** Check the box in lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g

a ☐ **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization **You must complete Part IV, Sections A and B.**

b ☐ **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s) **You must complete Part IV, Sections A and C.**

c ☐ **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions) **You must complete Part IV, Sections A, D, and E.**

d ☐ **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions) **You must complete Part IV, Sections A and D, and Part V.**

e ☐ Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization

f Enter the number of supported organizations _____

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

| (i) Name of supported organization | (ii) EIN | (iii) Type of organization (described on lines 1- 10 above (see instructions)) | (iv) Is the organization listed in your governing document? Yes | (iv) No | (v) Amount of monetary support (see instructions) | (vi) Amount of other support (see instructions) |
|---|---|---|---|---|---|---|
| | | | | | | |
| | | | | | | |
| **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, 8, or 9 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

## Section A. Public Support

| Calendar year (or fiscal year beginning in) ▶ | (a)2012 | (b)2013 | (c)2014 | (d)2015 | (e)2016 | (f)Total |
|---|---|---|---|---|---|---|
| 1 Gifts, grants, contributions, and membership fees received (Do not include any "unusual grant ") | 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** | 88 050 % |
| 15 Public support percentage for 2015 Schedule A, Part II, line 14 | **15** | 90 300 % |

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 ▶ ☑

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

### Section A. All Supporting Organizations

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

## Part IV Supporting Organizations (continued)

| | | | Yes | No |
|---|---|---|---|---|
| 11 | Has the organization accepted a gift or contribution from any of the following persons? | | | |
| a | A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization? | 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? *If "Yes" to a, b, or c, provide detail in Part VI* | 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? *If "No," describe in* ***Part VI*** *how the supported organization(s) effectively operated, supervised, or controlled the organization's activities If the organization had more than one supported organization, describe how the powers to appoint and/or remove directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year* | 1 | | |
| 2 | Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? *If "Yes," explain in* ***Part VI*** *how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised or controlled the supporting organization* | 2 | | |

## 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)? *If "No," describe in* ***Part VI*** *how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s)* | 1 | | |

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

## Section E. Type III Functionally-Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year **(see instructions)**

- a ☐ The organization satisfied the Activities Test Complete **line 2** below
- b ☐ The organization is the parent of each of its supported organizations Complete **line 3** below
- c ☐ The organization supported a governmental entity Describe in **Part VI** how you supported a government entity (see instructions)

| | | | Yes | No |
|---|---|---|---|---|
| 2 | Activities Test **Answer (a) and (b) below.** | | | |
| a | Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? *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* | 2a | | |
| b | Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? *If "Yes," explain in* ***Part VI*** *the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement* | 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? *Provide details in* ***Part VI.*** | 3a | | |
| b | Did the organization exercise a substantial degree of direction over the policies, programs and activities of each of its supported organizations? *If "Yes," describe in* ***Part VI.*** *the role played by the organization in this regard* | 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 **See instructions.** All other Type III non-functionally integrated supporting organizations must complete Sections A through E

### Section A - Adjusted Net Income

| | | | (A) Prior Year | (B) Current Year (optional) |
|---|---|---|---|---|
| 1 | Net short-term capital gain | 1 | | |
| 2 | Recoveries of prior-year distributions | 2 | | |
| 3 | Other gross income (see instructions) | 3 | | |
| 4 | Add lines 1 through 3 | 4 | | |
| 5 | Depreciation and depletion | 5 | | |
| 6 | Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions) | 6 | | |
| 7 | Other expenses (see instructions) | 7 | | |
| 8 | **Adjusted Net Income** (subtract lines 5, 6 and 7 from line 4) | 8 | | |

### Section B - Minimum Asset Amount

| | | | (A) Prior Year | (B) Current Year (optional) |
|---|---|---|---|---|
| 1 | Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year) | 1 | | |
| a | Average monthly value of securities | 1a | | |
| b | Average monthly cash balances | 1b | | |
| c | Fair market value of other non-exempt-use assets | 1c | | |
| d | **Total** (add lines 1a, 1b, and 1c) | 1d | | |
| e | **Discount** claimed for blockage or other factors (explain in detail in Part VI) | | | |
| 2 | Acquisition indebtedness applicable to non-exempt use assets | 2 | | |
| 3 | Subtract line 2 from line 1d | 3 | | |
| 4 | Cash deemed held for exempt use Enter 1-1/2% of line 3 (for greater amount, see instructions) | 4 | | |
| 5 | Net value of non-exempt-use assets (subtract line 4 from line 3) | 5 | | |
| 6 | Multiply line 5 by 035 | 6 | | |
| 7 | Recoveries of prior-year distributions | 7 | | |
| 8 | **Minimum Asset Amount** (add line 7 to line 6) | 8 | | |

### Section C - Distributable Amount

| | | | | Current Year |
|---|---|---|---|---|
| 1 | Adjusted net income for prior year (from Section A, line 8, Column A) | 1 | | |
| 2 | Enter 85% of line 1 | 2 | | |
| 3 | Minimum asset amount for prior year (from Section B, line 8, Column A) | 3 | | |
| 4 | Enter greater of line 2 or line 3 | 4 | | |
| 5 | Income tax imposed in prior year | 5 | | |
| 6 | **Distributable Amount.** Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions) | 6 | | |

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

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

| **Section D - Distributions** | **Current Year** |
|---|---|
| **1** Amounts paid to supported organizations to accomplish exempt purposes | |
| **2** Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity | |
| **3** Administrative expenses paid to accomplish exempt purposes of supported organizations | |
| **4** Amounts paid to acquire exempt-use assets | |
| **5** Qualified set-aside amounts (prior IRS approval required) | |
| **6** Other distributions (describe in Part VI) See instructions | |
| **7** **Total annual distributions.** Add lines 1 through 6 | |
| **8** Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI) See instructions | |
| **9** Distributable amount for 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--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 (if amount greater than zero, see instructions) | | | |
| **6** Remaining underdistributions for 2016 Subtract lines 3h and 4b from line 1 (if amount greater than zero, 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. . . . . | | | |

**Part VI** **Supplemental Information.**

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

| Facts And Circumstances Test |
| --- |
| |

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

Department of the Treasury
Internal Revenue Service

# Political Campaign and Lobbying Activities

**For Organizations Exempt From Income Tax Under section 501(c) and section 527**
▶**Complete if the organization is described below.** ▶**Attach to Form 990 or Form 990-EZ.**
▶**Information about Schedule C (Form 990 or 990-EZ) and its instructions is at** ***www.irs.gov/form990*****.**

OMB No 1545-0047

**2016**

**Open to Public Inspection**

**If the organization answered "Yes" on Form 990, Part IV, Line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then**
- Section 501(c)(3) organizations Complete Parts I-A and B Do not complete Part I-C
- Section 501(c) (other than section 501(c)(3)) organizations Complete Parts I-A and C below Do not complete Part I-B
- Section 527 organizations Complete Part I-A only

**If the organization answered "Yes" on Form 990, Part IV, Line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then**
- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)) Complete Part II-A Do not complete Part II-B
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)) Complete Part II-B Do not complete Part II-A

**If the organization answered "Yes" on Form 990, Part IV, Line 5 (Proxy Tax) (see separate instructions) or Form 990-EZ, Part V, line 35c (Proxy Tax) (see separate instructions), then**
- Section 501(c)(4), (5), or (6) organizations Complete Part III

| Name of the organization | **Employer identification number** |
|---|---|
| FRIEDREICH'S ATAXIA RESEARCH ALLIANCE | 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 expenditures ▶ $
3 Volunteer hours

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

1 Enter the amount of any excise tax incurred by the organization under section 4955 ▶ $ 0
2 Enter the amount of any excise tax incurred by organization managers under section 4955 ▶ $ 0
3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? ☐ Yes ☐ No
4a Was a correction made? ☐ Yes ☐ No
b If "Yes," describe in Part IV

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

1 Enter the amount directly expended by the filing organization for section 527 exempt function activities ▶ $
2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities ▶ $
3 Total exempt function expenditures Add lines 1 and 2 Enter here and on Form 1120-POL, line 17b ▶ $
4 Did the filing organization file**Form 1120-POL** for this year? ☐ Yes ☐ No
5 Enter the names, addresses and employer identification number (EIN) of all section 527 political organizations to which the filing organization made payments For each organization listed, enter the amount paid from the filing organization's funds Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC) If additional space is needed, provide information in Part IV

| **(a)** Name | **(b)** Address | **(c)** EIN | **(d)** Amount paid from filing organization's funds If none, enter -0- | **(e)** Amount of political contributions received and promptly and directly delivered to a separate political organization If none, enter -0- |
|---|---|---|---|---|
| | | | | |
| 2 | | | | |
| 3 | | | | |
| 4 | | | | |
| 5 | | | | |
| 6 | | | | |

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

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

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

| Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.) | (a) Filing organization's totals | (b) Affiliated group totals |
|---|---|---|
| **1a** Total lobbying expenditures to influence public opinion (grass roots lobbying) | 3,700 | |
| **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 | |
| **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 | |

| 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 |

**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 |
|---|---|---|---|---|---|---|
| **2a** | 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 |

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

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

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

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

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

## Part IV Supplemental Information

Provide the descriptions required for Part I-A, line 1, Part I-B, line 4, Part I-C, line 5, Part II-A (affiliated group list), Part II-A, lines 1 and 2 (see instructions), and Part II-B, line 1 Also, complete this part for any additional information

| Return Reference | Explanation | |
|---|---|---|

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# SCHEDULE D (Form 990)

Department of the Treasury
Internal Revenue Service

## Supplemental Financial Statements

▶ Complete if the organization answered "Yes," on Form 990, Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.
▶ Attach to Form 990.
Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990.

OMB No 1545-0047

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.

| | | (a) Donor advised funds | (b) Funds and other accounts |
|---|---|---|---|
| 1 | Total number at end of year | | |
| 2 | Aggregate value of contributions to (during year) | | |
| 3 | Aggregate value of grants from (during year) | | |
| 4 | Aggregate value at end of year | | |

5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? ☐ Yes ☐ No

6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? ☐ Yes ☐ No

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

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

☐ Preservation of land for public use (e g , recreation or education) ☐ Preservation of an historically important land area
☐ Protection of natural habitat ☐ Preservation of a certified historic structure
☐ Preservation of open space

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

| | | Held at the End of the Year |
|---|---|---|
| a | Total number of conservation easements | 2a |
| b | Total acreage restricted by conservation easements | 2b |
| c | Number of conservation easements on a certified historic structure included in (a) | 2c |
| d | Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register | 2d |

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

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

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? ☐ Yes ☐ No

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

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

8 Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? ☐ Yes ☐ No

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

**Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.** Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items

b If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items

(i) Revenue included on Form 990, Part VIII, line 1 ▶ $ _____

(ii) Assets included in Form 990, Part X ▶ $ _____

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items

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

b Assets included in Form 990, Part X ▶ $ _____

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

3 Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply)

- a ☐ Public exhibition
- b ☐ Scholarly research
- c ☐ Preservation for future generations
- d ☐ Loan or exchange programs
- e ☐ Other

4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII

5 During the year, did the organization solicit or receive donations of art, historical treasures or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? ☐ Yes ☐ No

## Part IV Escrow and Custodial Arrangements.

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

1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? ☐ Yes ☐ No

b If "Yes," explain the arrangement in Part XIII and complete the following table

| | Amount |
|---|---|
| c Beginning balance | 1c |
| d Additions during the year | 1d |
| e Distributions during the year | 1e |
| f Ending balance | 1f |

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

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

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

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

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

- a Board designated or quasi-endowment ▶
- b Permanent endowment ▶
- c Temporarily restricted endowment ▶

The percentages on lines 2a, 2b, and 2c should equal 100%

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by

| | Yes | No |
|---|---|---|
| (i) unrelated organizations . . . . . 3a(i) | | |
| (ii) related organizations . . . . . 3a(ii) | | |
| b If "Yes" on 3a(ii), are the related organizations listed as required on Schedule R? . . . . . 3b | | |

4 Describe in Part XIII the intended uses of the organization's endowment funds

## Part VI Land, Buildings, and Equipment.

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

| Description of property | (a) Cost or other basis (investment) | (b)Cost or other basis (other) | (c)Accumulated depreciation | (d)Book value |
|---|---|---|---|---|
| 1a Land | | | | |
| b Buildings | | | | |
| c Leasehold improvements | | | | |
| d Equipment | | | | |
| e Other | | 7,135 | 5,295 | 1,840 |
| **Total.** Add lines 1a through 1e *(Column (d) must equal Form 990, Part X, column (B), line 10(c) )* ▶ | | | | 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.** *(Column (b) must equal Form 990, Part X, col (B) line 12 )* ▶ | | |

**Part VIII** **Investments—Program Related.** Complete if the organization answered 'Yes' on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

| (a) Description of investment | (b) Book value | (c) Method of valuation Cost or end-of-year market value |
|---|---|---|
| (1) INVESTMENT IN EDISON PHARMACEUTICALS, INC | 1,091,500 | C |
| (1) | | |
| (2) | | |
| (3) | | |
| (4) | | |
| (5) | | |
| (6) | | |
| (7) | | |
| (8) | | |
| (9) | | |
| **Total.** *(Column (b) must equal Form 990, Part X, col (B) line 13 )* ▶ | 1,091,500 | |

**Part IX** **Other Assets.** Complete if the organization answered 'Yes' on Form 990, Part IV, line 11d See Form 990, Part X, line 15

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

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

| 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.** (This must equal Form 990, Part I, line 12 ) | | | 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.** (This must equal Form 990, Part I, line 18 ) | | | 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

| Return Reference | Explanation |
|---|---|
| See Additional Data Table | |
| | |
| | |
| | |
| | |
| | |
| | |

**Part XIII Supplemental Information *(continued)***

| Return Reference | Explanation |
|---|---|
| | |
| | |
| | |
| | |
| | |
| | |
| | |

# Additional Data

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

**Supplemental Information**

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

**Supplemental Information**

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

**Supplemental Information**

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

**Supplemental Information**

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

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SCHEDULE F (Form 990)

Department of the Treasury
Internal Revenue Service

# Statement of Activities Outside the United States

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

► Attach to Form 990. ► See separate instructions.

► 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" to Form 990, Part IV, line 14b.

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

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

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

| (a) Region | (b) Number of offices in the region | (c) Number of employees, agents, and independent contractors in region | (d) Activities conducted in region (by type) (e g , fundraising, program services, investments, grants to recipients located in the region) | (e) If activity listed in (d) is a program service, describe specific type of service(s) in region | (f) Total expenditures for and investments in region |
|---|---|---|---|---|---|
| (1) EUROPE | 0 | 0 | GRANTS TO RECIPIENTS LOCATED IN REGION | RESEARCH AND GRANT PROGRAM | 608,810 |
| (2) EAST ASIA AND THE PACIFIC | 0 | 0 | GRANTS TO RECIPIENTS LOCATED IN REGION | RESEARCH AND GRANT PROGRAM | 381,814 |
| (3) | | | | | |
| (4) | | | | | |
| (5) | | | | | |
| 3a 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" to Form 990, Part IV, line 15, for any recipient who received more than $5,000. Part II can be duplicated if additional space is needed.

| 1 | (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of non-cash assistance | (h) Description of non-cash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
|---|---|---|---|---|---|---|---|---|---|
| (1) | See Add'l Data | | | | | | | | |
| (2) | | | | | | | | | |
| (3) | | | | | | | | | |
| (4) | | | | | | | | | |
| (5) | | | | | | | | | |
| (6) | | | | | | | | | |
| (7) | | | | | | | | | |
| (8) | | | | | | | | | |
| (9) | | | | | | | | | |
| (10) | | | | | | | | | |
| (11) | | | | | | | | | |
| (12) | | | | | | | | | |
| (13) | | | | | | | | | |
| (14) | | | | | | | | | |
| (15) | | | | | | | | | |
| (16) | | | | | | | | | |

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 III** **Grants and Other Assistance to Individuals Outside the United States.** Complete if the organization answered "Yes" to Form 990, Part IV, line 16. Part III can be duplicated if additional space is needed.

| (a) Type of grant or assistance | (b) Region | (c) Number of recipients | (d) Amount of cash grant | (e) Manner of cash disbursement | (f) Amount of non-cash assistance | (g) Description of non-cash assistance | (h) Method of valuation (book, FMV, appraisal, other) |
|---|---|---|---|---|---|---|---|
| (1) | | | | | | | |
| (2) | | | | | | | |
| (3) | | | | | | | |
| (4) | | | | | | | |
| (5) | | | | | | | |
| (6) | | | | | | | |
| (7) | | | | | | | |
| (8) | | | | | | | |
| (9) | | | | | | | |
| (10) | | | | | | | |
| (11) | | | | | | | |
| (12) | | | | | | | |
| (13) | | | | | | | |
| (14) | | | | | | | |
| (15) | | | | | | | |
| (16) | | | | | | | |
| (17) | | | | | | | |
| (18) | | | | | | | |

## 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)* | ☐ 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)* | ☐ 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).

**990 Schedule F, Supplemental Information**

| Return Reference | Explanation |
|---|---|
| PART I, LINE 2 | GRANTS ARE REVIEWED BY INDEPENDENT SCIENTIFIC ADVISORS AND APPROVED BY BOARD |

## Additional Data

**Software ID:**

**Software Version:**

**EIN:** 52-2122720

**Name:** FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

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

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

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

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

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

| (a) Name of organization | (b) IRS code section and EIN(if applicable) | (c) Region | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of non-cash assistance | (h) Description of non-cash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
|---|---|---|---|---|---|---|---|---|
| | | EUROPE | RESEARCH CONFERENCE | 10,700 | WIRE | | | |
| | | EUROPE | MEDICAL RESEARCH | 87,500 | WIRE | | | |
| | | EUROPE | MEDICAL RESEARCH | 149,995 | WIRE | | | |

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SCHEDULE G (Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

# Supplemental Information Regarding Fundraising or Gaming Activities

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

▶ **Attach to Form 990 or Form 990-EZ.**

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

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

**1** Indicate whether the organization raised funds through any of the following activities Check all that apply

**a** ☐ Mail solicitations
**b** ☐ Internet and email solicitations
**c** ☐ Phone solicitations
**d** ☐ In-person solicitations
**e** ☐ Solicitation of non-government grants
**f** ☐ Solicitation of government grants
**g** ☐ Special fundraising events

**2a** Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? ☐ **Yes** ☐ **No**

**b** If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least $5,000 by the organization

| | **(i)** Name and address of individual or entity (fundraiser) | **(ii)** Activity | **(iii)** Did fundraiser have custody or control of contributions? **Yes** | **No** | **(iv)** Gross receipts from activity | **(v)** Amount paid to (or retained by) fundraiser listed in col **(i)** | **(vi)** Amount paid to (or retained by) organization |
|---|---|---|---|---|---|---|---|
| 1 | | | | | | | |
| 2 | | | | | | | |
| 3 | | | | | | | |
| 4 | | | | | | | |
| 5 | | | | | | | |
| 6 | | | | | | | |
| 7 | | | | | | | |
| 8 | | | | | | | |
| 9 | | | | | | | |
| 10 | | | | | | | |
| **Total** | | | | ▶ | | | |

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

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

| Revenue | | (a) Event #1 FARA ENERGY BALL (event type) | (b) Event #2 RIDE ATAXIA PHILADELPHIA (event type) | (c) Other events 62 (total number) | (d) Total events (add col (a) through col (c)) |
|---|---|---|---|---|---|
| | 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.

| Revenue | | (a) Bingo | (b) Pull tabs/Instant bingo/progressive bingo | (c) Other gaming | (d) Total gaming (add col (a) through col (c)) |
|---|---|---|---|---|---|
| | 1 Gross revenue | | | | |
| Direct Expenses | 2 Cash prizes | | | | |
| | 3 Noncash prizes | | | | |
| | 4 Rent/facility costs | | | | |
| | 5 Other direct expenses | | | | |
| | 6 Volunteer labor | ☐ 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 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 complete this part to provide any additional information (see instructions).

| Return Reference | Explanation |
|---|---|

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**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

| (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 |
|---|---|---|---|---|---|---|---|
| See Additional Data Table | | | | | | | |
| (1) | | | | | | | |
| (2) | | | | | | | |
| (3) | | | | | | | |
| (4) | | | | | | | |
| (5) | | | | | | | |
| (6) | | | | | | | |
| (7) | | | | | | | |
| (8) | | | | | | | |
| (9) | | | | | | | |
| (10) | | | | | | | |
| (11) | | | | | | | |
| (12) | | | | | | | |

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

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

| (a) Type of grant or assistance | (b) Number of recipients | (c) Amount of cash grant | (d) Amount of non-cash assistance | (e) Method of valuation (book, FMV, appraisal, other) | (f) Description of non-cash assistance |
|---|---|---|---|---|---|
| (1) | | | | | |
| (2) | | | | | |
| (3) | | | | | |
| (4) | | | | | |
| (5) | | | | | |
| (6) | | | | | |
| (7) | | | | | |

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

| Return Reference | Explanation |
|---|---|
| PART I, LINE 2 | GRANTS ARE REVIEWED BY INDEPENDENT SCIENTIFIC ADVISORS AND APPROVED BY BOARD |

# Additional Data

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

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

| **(a)** Name and address of organization or government | **(b)** EIN | **(c)** IRC section if applicable | **(d)** Amount of cash grant | **(e)** Amount of non-cash assistance | **(f)** Method of valuation (book, FMV, appraisal, other) | **(g)** Description of non-cash assistance | **(h)** Purpose of grant or assistance |
|---|---|---|---|---|---|---|---|
| ARIZONA STATE UNIVERSITY<br>1711 S RURAL ROAD<br>TEMPE, AZ 85287 | 86-0196696 | 501(C)(3) | 150,000 | | | | MEDICAL RESEARCH |
| CALIFORNIA INSTITUTE OF TECHNOLOGY<br>1200 EAST CALIFORNIA BLVD<br>123-15<br>PASADENA, CA 91125 | 95-1643307 | 501(C)(3) | 150,000 | | | | MEDICAL RESEARCH |
| DUKE UNIVERSITY<br>2200 W MAIN ST SUITE 710<br>DURHAM, NC 277054677 | 56-0532129 | 501(C)(3) | 200,000 | | | | MEDICAL RESEARCH |

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

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|---|---|---|---|---|---|---|---|
| CHILDREN'S HOSPITAL OF PHILADELPHIA<br>34TH ST CIVIC CENTER BLVD<br>PHILADELPHIA, PA 19104 | 23-1352166 | 501(C)(3) | 407,553 | | | | MEDICAL RESEARCH |
| EMORY UNIVERSITY<br>201 DOWMAN DR<br>ATLANTA, GA 30322 | 58-0566256 | 501(C)(3) | 24,200 | | | | MEDICAL RESEARCH |
| UNIVERSITY OF OKLAHOMA<br>865 RESEARCH PARKWAY STE 540<br>OKLAHOMA CITY, OK 73104 | 73-1377584 | 501(C)(3) | 66,015 | | | | MEDICAL RESEARCH |

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

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|---|---|---|---|---|---|---|---|
| OHIO STATE UNIVERSITY<br>333 W 10TH AVE<br>COLUMBUS, OH 43210 | 31-6025986 | 501(C)(3) | 6,700 | | | | MEDICAL RESEARCH |
| PFIZER INC<br>235 EAST 42ND STREET<br>NEW YORK, NY 10017 | 13-5315170 | | 150,000 | | | | MEDICAL RESEARCH |
| REGENTS OF THE UNIVERSITY OF MINNESOTA<br>200 SE OAK ST 600<br>MINNEAPOLIS, MN 55455 | 41-6007513 | 501(C)(3) | 36,870 | | | | MEDICAL RESEARCH |

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

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|---|---|---|---|---|---|---|---|
| SCRIPPS RESEARCH INSTITUTE<br>10550 NORTH TORREY PINES ROAD<br>OSP-TPC7<br>LA JOLLA, CA 92037 | 33-0435954 | 501(C)(3) | 67,455 | | | | MEDICAL RESEARCH |
| THE JACKSON LABORATORY<br>600 MAIN STREET<br>BAR HARBOR, ME 04609 | 01-0211513 | 501(C)(3) | 21,360 | | | | MEDICAL RESEARCH |
| THE REGENTS OF THE UNIVERSITY OF CALIFORNIA LOS ANGELES<br>10920 WILSHIRE BLVD 5TH FLOOR<br>LOS ANGELES, CA 90024 | 95-6006143 | 501(C)(3) | 41,800 | | | | MEDICAL RESEARCH |

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

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|---|---|---|---|---|---|---|---|
| THE TRUSTEES OF THE UNIVERSITY OF PENNSYLVANIA<br>3451 WALNUT STREET RM P 221<br>FRANKLIN BLDG<br>PHILADELPHIA, PA 19104 | 23-1352685 | 501(C)(3) | 1,083,618 | | | | MEDICAL RESEARCH |
| THE UNIVERSITY OF ALABAMA BIRMINGHAM<br>701 20TH STREET SOUTH<br>BIRMINGHAM, AL 35294 | 63-6005396 | 501(C)(3) | 140,000 | | | | MEDICAL RESEARCH |
| UNIVERSITY OF FLORIDA<br>DEPT OF NEUROLOGY L3-100 MCKNIGHT<br>BRAIN INSTITUTE NEWELL DRIVE<br>GAINESVILLE, FL 32611 | 59-6002052 | 501(C)(3) | 220,230 | | | | MEDICAL RESEARCH |

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

| **(a)** Name and address of organization or government | **(b)** EIN | **(c)** IRC section if applicable | **(d)** Amount of cash grant | **(e)** Amount of non-cash assistance | **(f)** Method of valuation (book, FMV, appraisal, other) | **(g)** Description of non-cash assistance | **(h)** Purpose of grant or assistance |
|---|---|---|---|---|---|---|---|
| UNIVERSITY OF IOWA DEPT OF PEDIATRICS<br>200 HAWKINS DRIVE<br>IOWA CITY, IA 52242 | 42-6004813 | 501(C)(3) | 17,400 | | | | MEDICAL RESEARCH |
| UNIVERSITY OF ROCHESTER<br>515 HYLAN BUILDING RC BOX 270140<br>ROCHESTER, NY 14627 | 16-0743209 | 501(C)(3) | 157,782 | | | | MEDICAL RESEARCH |
| UNIVERSITY OF SOUTH FLORIDA FOUNDATION<br>4202 EAST FOWLER AVENUE<br>TAMPA, FL 33620 | 59-0879015 | 501(C)(3) | 150,000 | | | | MEDICAL RESEARCH |

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

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|---|---|---|---|---|---|---|---|
| WEILL MEDICAL COLLEGE OF CORNELL UNIVERSITY<br>445 E 69TH ST<br>NEW YORK, NY 10021 | 13-1623978 | 501(C)(3) | 150,000 | | | | MEDICAL RESEARCH |
| ALBANY RESEARCH INSTITUTE<br>113 HOLLAND AVE<br>ALBANY, NY 12208 | 14-1716021 | 501(C)(3) | 35,200 | | | | MEDICAL RESEARCH |
| HARVARD MEDICAL SCHOOL<br>1033 MASSACHUSETTS AVENUE<br>CAMBRIDGE, MA 02138 | 04-2103580 | 501(C)(3) | 54,740 | | | | MEDICAL RESEARCH |

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

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of non-cash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|---|---|---|---|---|---|---|---|
| INDIANA UNIVERSITY<br>107 S INDIANA AVE<br>BLOOMINGTON, IN 47405 | 35-6001673 | 501(C)(3) | 75,000 | | | | MEDICAL RESEARCH |
| NATIONAL ATAXIA FOUNDATION<br>2600 FERNBROOK LANE<br>MINNEAPOLIS, MN 55447 | 41-0832903 | 501(C)(3) | 5,000 | | | | RESEARCH CONFERENCE |
| THE REGENTS OF THE UNIVERSITY OF CALIFORNIA DAVIS<br>1850 RESEARCH PARK DRIVE<br>DAVIS, CA 95618 | 94-6036494 | 501(C)(3) | 90,000 | | | | MEDICAL RESEARCH |

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

| **(a)** Name and address of organization or government | **(b)** EIN | **(c)** IRC section if applicable | **(d)** Amount of cash grant | **(e)** Amount of non-cash assistance | **(f)** Method of valuation (book, FMV, appraisal, other) | **(g)** Description of non-cash assistance | **(h)** Purpose of grant or assistance |
|---|---|---|---|---|---|---|---|
| THOMAS JEFFERSON UNIVERSITY<br>1020 WALNUT STREET<br>PHILADELPHIA, PA 19107 | 23-2829095 | 501(C)(3) | 150,000 | | | | MEDICAL RESEARCH |
| THE UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER<br>5323 HARRY HINES BLVD<br>DALLAS, TX 75390 | 75-6002868 | 501(C)(3) | 123,360 | | | | MEDICAL RESEARCH |
| UNIVERSITY OF SOUTH FLORIDA<br>4202 EAST FOWLER AVENUE<br>TAMPA, FL 33620 | 59-3102112 | 501(C)(3) | 87,997 | | | | MEDICAL RESEARCH |

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SCHEDULE M (Form 990)

Department of the Treasury
Internal Revenue Service

# Noncash Contributions

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

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 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 ▶ ( _____ ) | | | | |
| 26 | Other ▶ ( _____ ) | | | | |
| 27 | Other ▶ ( _____ ) | | | | |
| 28 | Other ▶ ( _____ ) | | | | |

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

| | | | Yes | No |
|---|---|---|---|---|
| 30a | During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least three years from the date of the initial contribution, and which is not required to be used for exempt purposes for the entire holding period? | 30a | | No |
| b | If "Yes," describe the arrangement in Part II | | | |
| 31 | Does the organization have a gift acceptance policy that requires the review of any non-standard contributions? | 31 | | No |
| 32a | Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions? | 32a | | No |
| b | If "Yes," describe in Part II | | | |
| 33 | If the organization did not report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II | | | |

**Part II** **Supplemental Information.**

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

| Return Reference | Explanation |
|---|---|

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**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

**990 Schedule O, Supplemental Information**

| Return Reference | Explanation |
|---|---|
| FORM 990, PART III, LINE 4A | 2016 KEITH MICHAEL ANDRUS MEMORIAL AWARDS (FOR CARDIAC RESEARCH) TITLE INVESTIGATION OF C ARDIAC PATHOPHYSIOLOGICAL MECHANISM AND RELEVANT BIOMARKER IN THE CONTEXT OF FXN DEFICIENC Y AND FXN OVEREXPRESSION INDUCED TOXICITY INVESTIGATOR DR HELENE PUCCIO (IGBMC, UNIVERS ITY OF STRASBOURG, FRANCE) DR PUCCIO AND DR BRAHIM BELBELLAA, A POSTDOCTORAL FELLOW IN H ER GROUP, ARE INVESTIGATING THE POTENTIAL ADVERSE EFFECTS OF OVEREXPRESSION OF CARDIAC FRA TAXIN, GENERATING A NEW CARDIAC-SPECIFIC CONDITIONAL KNOCKOUT MOUSE MODEL, AND IDENTIFYING POTENTIAL BIOMARKERS OF CARDIAC FRATAXIN DEFICIENCY THESE PRE-CLINICAL STUDIES ARE CRITI CAL 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 T RIAL CAN BEGIN TITLE IMPACT OF FRATAXIN DEFICIENCY ON CARDIAC SUBSTRATE METABOLISM INVES TIGATOR 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 WORS EN HEART FUNCTION PROTEINS THAT MEDIATE HEART METABOLISM ARE CURRENTLY BEING TARGETED FOR TREATING CARDIOMYOPATHY OF VARIOUS ORIGINS, WITH THE GOAL OF PREVENTING THE PROGRESSION T O 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 SKELET AL MUSCLE WOULD PROVIDE A RATIONALE FOR TESTING FOR ALTERED METABOLITE PROFILES IN THE PLA SMA THAT COULD SIGNAL THE WORSENING OF CARDIAC FUNCTION 2016 KYLE BRYANT TRANSLATIONAL RE SEARCH AWARD TITLE A HUMAN IPSC-BASED CARDIAC MODEL OF FRIEDREICH'S ATAXIA FOR DRUG DISCO VERY AND PATIENT STRATIFICATION USING ALL-OPTICAL ELECTROPHYSIOLOGY INVESTIGATORS DR JO NATHAN CHERRY (RANA THERAPEUTICS) AND DR GRAHAM DEMPSEY (Q-STATE BIOSCIENCES) A COLLABOR ATIVE STUDY BETWEEN RANA THERAPEUTICS AND Q-STATE BIOSCIENCES TO DEVELOP A NOVEL, HUMAN "D ISEASE-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 DIFF ERENTIATED INTO PATIENT-SPECIFIC CARDIAC CELLS OR CARDIOMYOCYTES (CMS) THE FUNCTIONAL PRO PERTIES OF THE DERIVED CMS CAN THEN BE STUDIED WITH Q-STATE'S PLATFORM TECHNOLOGY CALLED O PTOPATCH, WHERE SPECIFIC OPTOGENETIC PROTEINS CAN BE EXPRESSED IN CMS TO ALLOW FOR LIGHT-D RIVEN STIMULATION AND RECORDING OF ELECTRICAL ACTIVITY IN THOSE CELLS THESE TYPES OF LIGH T-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 SCI ENTISTS SUCCESSFUL COMPLETION |

**990 Schedule O, Supplemental Information**

| Return Reference | Explanation |
|---|---|
| FORM 990, PART III, LINE 4A | OF THESE STUDIES WILL ESTABLISH THE REQUISITE TECHNOLOGY TO (1) EVALUATE THE EFFECTS OF T HERAPEUTICS DEVELOPED BY RANA AND (2) STUDY THE PHENOTYPE ACROSS A BROAD COHORT OF FA PATI ENTS BROADLY, THIS WILL OPEN THE OPPORTUNITY FOR PATIENT STRATIFICATION FOR CLINICAL TRIA LS AND SCREENING OF THERAPEUTICS TO TREAT THIS DEVASTATING DISEASE 2016 GENERAL GRANT HIG HLIGHTS TITLE DEVELOPMENT OF OLIGONUCLEOTIDE ACTIVATORS OF FXN EXPRESSION INVESTIGATOR D R DAVID COREY (UT SOUTHWESTERN) IN EARLY 2016, DR COREY'S LABORATORY REPORTED THE DISCOV ERY 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 PAT IENT-DERIVED CELLS TO DETERMINE IF HIS FINDINGS CAN BE APPLIED WIDELY THROUGHOUT THE FRIED REICH'S ATAXIA PATIENT POPULATION HE WILL ALSO TEST MANY MORE COMPOUNDS TO IDENTIFY THE B EST 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 COM MUNITY 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 DEVE RMAN (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 FR ATAXIN TO THE NERVOUS SYSTEM AND OTHER SITES AFFECTED IN FRIEDREICH'S ATAXIA INCLUDING CAR DIAC MUSCLE AND THE PANCREAS RECENTLY, VOYAGER THERAPEUTICS ENTERED INTO A LICENSING AGRE EMENT 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/PGGRANT LIST ASPX AND COMPLETE LISTINGS OF GRANTS AWARDED BY YEAR CAN BE ACCESSED AT WWW CUREFA N ET/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 S ELECTED 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 SIGNIF ICANCE 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 D OI 10 1016/J JNS 2016 06 006 EPUB 2016 JUN 4 USING HUMAN PLURIPOTENT STEM CELLS TO STUD Y FRIEDREICH ATAXIA CARDIOMYOPATHY CROMBIE DE, PERA MF, DELATYCKI MB, P BAY A INT J CARD IOL 2016 JUN 1,212 37-43 DOI |

## 990 Schedule O, Supplemental Information

| Return Reference | Explanation |
| --- | --- |
| FORM 990, PART III, LINE 4A | 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 |

## 990 Schedule O, Supplemental Information

| Return Reference | Explanation |
| --- | --- |
| 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 |

## 990 Schedule O, Supplemental Information

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

## 990 Schedule O, Supplemental Information

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

## 990 Schedule O, Supplemental Information

| Return Reference | Explanation |
| --- | --- |
| FORM 990, PART VI, SECTION B, LINE 15 | EVALUATION AND COMPENSATION COMMITTEE PERFORMS EMPLOYEE EVALUATIONS AND DETERMINES SALARY INCREASES ON A YEARLY BASIS FOR ALL EMPLOYEES COMMITTEE EXAMINES BENCHMARK DATA IN DETERMINING SALARIES FOR PRESIDENT AND EXECUTIVE DIRECTOR |

**990 Schedule O, Supplemental Information**

| Return Reference | Explanation |
| --- | --- |
| FORM 990, PART VI, SECTION C, LINE 18 | FORM 990 IS AVAILABLE ON THE ORGANIZATION'S WEBSITE AS WELL AS GUIDESTAR ORG AND CHARITYNAVIGATOR ORG |

**990 Schedule O, Supplemental Information**

| Return Reference | Explanation |
| --- | --- |
| FORM 990, PART VI, SECTION C, LINE 19 | FINANCIAL STATEMENTS ARE AVAILABLE ON THE ORGANIZATION'S WEBSITE THE GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY AND FORM 1023 ARE AVAILABLE UPON REQUEST |

**990 Schedule O, Supplemental Information**

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

## 990 Schedule O, Supplemental Information

| Return Reference | Explanation |
|---|---|
| FORM 990, PART XII, LINE 2C | FARA'S AUDIT COMMITTEE CONSISTS OF THE FINANCE COMMITTEE, EXECUTIVE DIRECTOR AND ONE AT-LARGE BOARD MEMBER EACH YEAR THE AUDIT COMMITTEE SEEKS THE SERVICES OF AN OUTSIDE ACCOUNTING FIRM AND CONTRACTS FOR A FULL AUDIT, PREPARATION OF FINANCIAL STATEMENTS AND FILING OF THE 990 THE AUDIT COMMITTEE IS RESPONSIBLE FOR REVIEWING RECOMMENDATIONS FROM THE AUDIT AND PROPOSING NEW POLICIES AND PROCEDURES AS NECESSARY THE AUDIT COMMITTEE ALSO PARTICIPATES IN DETAILED REVIEW OF FINANCIAL STATEMENTS AND 990 PRIOR TO SHARING WITH THE FULL BOARD FOR A VOTE FARA'S BOARD OF DIRECTORS RECEIVES THE FINANCIAL STATEMENTS AND 990 FOR REVIEW AND VOTES TO APPROVE PRIOR TO PUBLIC FILING |