

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

FINANCIAL STATEMENTS

Years Ended December 31, 2018 and 2017



Certified Public Accountants and Business Consultants

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

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YEARS ENDED DECEMBER 31, 2018 AND 2017

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Independent Auditors' Report

To the Board of Directors
Friedreich's Ataxia Research Alliance
Downingtown, Pennsylvania

We have audited the accompanying financial statements of Friedreich's Ataxia Research Alliance (a nonprofit organization), which comprise the statements of financial position as of December 31, 2018 and 2017, and the related statements of activities, functional expenses and cash flows for the years then ended and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditors' Responsibility

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditors' judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Friedreich's Ataxia Research Alliance as of December 31, 2018 and 2017, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

To the Board of Directors
Friedreich's Ataxia Research Alliance
Downingtown, Pennsylvania

Emphasis of Matter

As disclosed in Note B, Friedreich's Ataxia Research Alliance adopted new accounting guidance, implementing the FASB's ASU 2016-14, *Not-For-Profit Entities (Topic 958): Presentation of Financial Statements of Not-For-Profit Entities* for the years ended December 31, 2018 and 2017. Our opinion is not modified with respect to this matter.

Maille LLP

West Chester, Pennsylvania
May 9, 2019

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENTS OF FINANCIAL POSITION

DECEMBER 31, 2018 AND 2017

	<u>2018</u>	<u>2017</u>
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	\$ 2,162,521	\$ 1,459,689
Contributions receivable	195,821	358,567
Prepaid expenses	37,323	8,402
Investment in securities	1,620,731	1,933,814
TOTAL CURRENT ASSETS	<u>4,016,396</u>	<u>3,760,472</u>
COMPUTER EQUIPMENT, net of accumulated depreciation of \$6,629 (2018) and \$6,129 (2017)	506	1,006
OTHER ASSETS		
Investment in common stock	<u>1,091,500</u>	<u>1,091,500</u>
TOTAL ASSETS	<u>\$ 5,108,402</u>	<u>\$ 4,852,978</u>
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	<u>\$ 130,166</u>	<u>\$ 323,194</u>
NET ASSETS		
Without donor restrictions	4,914,855	4,208,302
With donor restrictions	<u>63,381</u>	<u>321,482</u>
TOTAL NET ASSETS	<u>4,978,236</u>	<u>4,529,784</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$ 5,108,402</u>	<u>\$ 4,852,978</u>

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENTS OF ACTIVITIES

YEARS ENDED DECEMBER 31, 2018 AND 2017

	<u>2018</u>	<u>2017</u>
NET ASSETS WITHOUT DONOR RESTRICTIONS		
Revenue and support		
Contributions	\$ 1,019,316	\$ 1,448,463
Grants	-	15,000
Special events	5,133,236	4,540,268
Investment return	(71,107)	222,780
Net assets released from restrictions	<u>2,536,365</u>	<u>2,005,679</u>
TOTAL REVENUE AND SUPPORT	<u>8,617,810</u>	<u>8,232,190</u>
Expenses		
Program services		
Education, awareness and outreach	231,494	244,313
Patient registry and CCRN	801,222	715,107
Research and grant program	5,625,749	5,363,415
Research conferences	150,510	280,759
TOTAL PROGRAM SERVICES	<u>6,808,975</u>	<u>6,603,594</u>
Fund-raising services		
Special events	876,200	822,484
Other fund-raising	109,905	101,685
TOTAL FUND-RAISING SERVICES	<u>986,105</u>	<u>924,169</u>
Supporting services		
General and administrative	116,177	93,217
TOTAL EXPENSES	<u>7,911,257</u>	<u>7,620,980</u>
CHANGE IN UNRESTRICTED NET ASSETS	<u>706,553</u>	<u>611,210</u>
NET ASSETS WITH DONOR RESTRICTIONS		
Contributions	2,278,264	2,299,186
Net assets released from restrictions	<u>(2,536,365)</u>	<u>(2,005,679)</u>
CHANGE IN TEMPORARILY RESTRICTED NET ASSETS	<u>(258,101)</u>	<u>293,507</u>
CHANGE IN NET ASSETS	448,452	904,717
NET ASSETS AT BEGINNING OF YEAR	<u>4,529,784</u>	<u>3,625,067</u>
NET ASSETS AT END OF YEAR	<u>\$ 4,978,236</u>	<u>\$ 4,529,784</u>

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED DECEMBER 31, 2018

	Program Services				Totals	Fund-Raising Services	Supporting Services	Totals
	Education, Awareness and Outreach	Patient Registry and CCRN	Research and Grant Program	Research Conferences			General and Administrative	
FUNCTIONAL EXPENSES								
Advertising	\$ 1,406	\$ -	\$ -	\$ -	\$ 1,406	\$ 370	\$ -	\$ 1,776
Auction items	-	-	-	-	-	40,222	-	40,222
Awards and grants	-	699,241	5,373,695	5,000	6,077,936	-	-	6,077,936
Registration fees	-	-	-	-	-	9,560	517	10,077
Contracted services	3,750	25,000	5,000	-	33,750	79,369	16,736	129,855
Credit card and bank fees	-	155	550	243	948	76,774	211	77,933
Facilities and equipment	-	-	311	5,174	5,485	209,610	846	215,941
Rent	4,004	2,002	8,007	2,002	16,015	20,017	4,003	40,035
Books and subscriptions	2,810	-	6,266	49	9,125	11,740	1,707	22,572
Hospitality	1,482	-	-	-	1,482	9,219	1,406	12,107
Postage	198	-	20	239	457	7,080	952	8,489
Printing and copying	-	-	-	40	40	8,977	1,196	10,213
Supplies	53	128	-	199	380	104,571	2,593	107,544
Utilities	1,384	-	2,076	346	3,806	1,384	1,730	6,920
Event entertainment	-	-	-	-	-	9,200	-	9,200
Insurance	-	-	-	-	-	7,887	2,816	10,703
Miscellaneous	240	-	285	-	525	408	212	1,145
Membership dues	2,600	-	-	440	3,040	-	220	3,260
Payroll, taxes and benefits	188,384	68,011	199,705	73,484	529,584	297,861	62,174	889,619
Conferences, meetings and travel	25,183	6,685	29,834	63,294	124,996	91,856	18,358	235,210
Depreciation	-	-	-	-	-	-	500	500
TOTAL FUNCTIONAL EXPENSES	\$ 231,494	\$ 801,222	\$ 5,625,749	\$ 150,510	\$ 6,808,975	\$ 986,105	\$ 116,177	\$ 7,911,257

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED DECEMBER 31, 2017

	Program Services				Totals	Fund-Raising Services	Supporting	Totals
	Education, Awareness and Outreach	Patient Registry and CCRN	Research and Grant Program	Research Conferences			General and Administrative	
FUNCTIONAL EXPENSES								
Advertising	\$ 1,000	\$ 15,000	\$ -	\$ -	\$ 16,000	\$ 286	\$ -	\$ 16,286
Auction items	-	-	-	-	-	45,941	-	45,941
Awards and grants	-	626,257	5,171,280	26,512	5,824,049	-	-	5,824,049
Registration fees	900	-	-	-	900	9,224	544	10,668
Contracted services	15,000	-	-	49,753	64,753	70,926	15,025	150,704
Credit card and bank fees	-	85	372	104	561	86,534	272	87,367
Facilities and equipment	4,180	-	-	-	4,180	187,770	2,340	194,290
Rent	4,541	2,271	9,081	2,270	18,163	22,704	4,541	45,408
Books and subscriptions	2,740	-	-	1,000	3,740	6,823	1,891	12,454
Hospitality	27	-	-	167	194	10,651	208	11,053
Postage	2,647	-	4	255	2,906	6,474	1,515	10,895
Printing and copying	4,071	-	-	1,079	5,150	8,347	1,056	14,553
Supplies	1,164	-	-	683	1,847	83,996	3,671	89,514
Utilities	1,329	-	1,993	332	3,654	1,329	1,661	6,644
Event entertainment	-	-	-	-	-	10,077	-	10,077
Insurance	-	-	-	1,250	1,250	7,083	3,197	11,530
Miscellaneous	1,484	-	-	-	1,484	100	140	1,724
Membership dues	1,500	-	-	220	1,720	-	-	1,720
Payroll, taxes and benefits	168,463	68,690	170,628	94,691	502,472	277,516	38,789	818,777
Conferences, meetings and travel	35,267	2,804	10,057	102,443	150,571	88,388	17,533	256,492
Depreciation	-	-	-	-	-	-	834	834
TOTAL FUNCTIONAL EXPENSES	\$ 244,313	\$ 715,107	\$ 5,363,415	\$ 280,759	\$ 6,603,594	\$ 924,169	\$ 93,217	\$ 7,620,980

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENTS OF CASH FLOWS

YEARS ENDED DECEMBER 31, 2018 AND 2017

	<u>2018</u>	<u>2017</u>
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$ 448,452	\$ 904,717
Adjustments to reconcile change in net assets to net cash provided by operating activities		
(Gain) loss on sale of securities	1,762	(15,821)
Net unrealized (gain) loss on securities	97,573	(182,994)
Depreciation	500	834
(Increase) decrease in		
Contributions receivable	162,746	(89,173)
Prepaid expenses	(28,921)	25,859
Decrease in accounts payable	(193,028)	(161,772)
NET CASH PROVIDED BY OPERATING ACTIVITIES	<u>489,084</u>	<u>481,650</u>
CASH FLOWS FROM INVESTING ACTIVITIES		
Proceeds from sale of securities	342,637	306,229
Purchase of securities	(128,889)	(173,029)
NET CASH PROVIDED BY FINANCING ACTIVITIES	<u>213,748</u>	<u>133,200</u>
NET INCREASE IN CASH AND CASH EQUIVALENTS	702,832	614,850
CASH AND CASH EQUIVALENTS AT BEGINNING OF YEAR	<u>1,459,689</u>	<u>844,839</u>
CASH AND CASH EQUIVALENTS AT END OF YEAR	<u>\$ 2,162,521</u>	<u>\$ 1,459,689</u>

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND 2017

NOTE A - ORGANIZATION

Friedreich's Ataxia Research Alliance (FARA) was incorporated under the laws of the District of Columbia as a nonprofit corporation. The stated purposes of FARA are to marshal and focus the resources and relationships needed to treat and cure Friedreich's Ataxia by raising funds for research, promoting public awareness and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations dedicated to treating and curing Friedreich's Ataxia.

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Basis of Accounting

The financial statements have been prepared on the accrual basis of accounting.

Change in Accounting Principle

In August 2016, the FASB issued Accounting Standards Update No. 2016-14 ("ASU 2016-14"), *Not-for-Profit Entities (Topic 958); Presentation of Financial Statements for Not-for-Profit Entities*. The Organization has implemented ASU 2016-14 for these financial statements dated December 31, 2018 and 2017 and for the years then ended.

Financial Statement Presentation

Under Financial Accounting Standards Board Accounting Standards Codification (FASB ASC) 958-10-65-1, the Organization is required to report information regarding its financial position and activities according to two mutually exclusive classes according to the existence or absence of donor-imposed restrictions. See Net Assets with Donor Restrictions and Net Assets without Donor Restrictions.

Net Assets with Donor Restrictions

The part of net assets of the Organization that is subject to donor-imposed restrictions (donors include other types of contributors, including makers of certain grants). Some donors impose restrictions that are temporary in nature, for example, stipulating that resources be used after a specified date, for particular programs or services, or to acquire buildings or equipment. Other donors impose restrictions that are perpetual in nature, for example, stipulating that resources be maintained in perpetuity. Laws may extend those limits to investment returns from those resources and to other enhancements (diminishments) of those resources. Thus, those laws extend donor-imposed restrictions. When a restriction expires, net assets with donor restrictions are reclassified to net assets without donor restrictions.

Net Assets without Donor Restrictions

The part of net assets of the Organization that is not subject to donor-imposed restrictions.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND 2017

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Cash and Cash Equivalents

Cash and cash equivalents include checking and money market accounts. FARA normally deposits its cash with three financial institutions.

Receivables

Receivables consist primarily of funds due for fund-raising events on FARA's behalf that were not remitted to FARA until the following year. No receivables are expected to remain outstanding for more than one year. Receivables are stated at the amount management expects to collect from outstanding balances. Management provides for probable uncollectible amounts through a provision for bad debt expense and an adjustment to a valuation allowance based on its assessment of the current status of individual receivables. Balances that are still outstanding after management has used reasonable collection efforts are written off through a charge to the valuation allowance and credit to the account receivable. FARA recorded no allowance for doubtful accounts as of December 31, 2018 and 2017.

Investments

FARA carries investments in marketable securities with readily determinable fair market values and all investments in debt securities at their fair values in the statements of financial position. FARA carries investments in common stock of a nonpublic entity at cost. Unrealized gains and losses are included in the change in net assets in the accompanying statements of activities.

Computer Equipment

Computer equipment is stated at cost. Depreciation of computer equipment is provided utilizing the straight-line method over five years. Depreciation expense was \$500 and \$834 for the years ended December 31, 2018 and 2017, respectively.

Contributions

In accordance with FASB ASC 958-605, unconditional contributions are recognized immediately and classified as either net assets with donor restrictions or net assets without donor restrictions. Conditional contributions received are accounted for as a liability or are unrecognized initially, that is, until the barriers to entitlement are overcome, at which point the transactions is recognized as unconditional and classified as either net assets with restrictions or net assets without restrictions.

Concentrations of Credit Risk

Cash deposits that potentially subject FARA to concentrations of credit risk consist of cash accounts not covered by FDIC insurance. At December 31, 2018, \$1,362,490 of FARA's bank balances of \$2,362,490 was exposed to credit risk. At December 31, 2017, \$1,458,888 of FARA's bank balances of \$2,209,880 was exposed to credit risk.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND 2017

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Donated Services

FARA recognizes contributed professional services if the service received (1) create or enhance nonfinancial assets or (2) require specialized skills, are provided by individuals possessing those skills and would typically need to be purchased if not provided by donation. A substantial number of volunteers have donated significant amounts of their time to FARA and its programs. For the years ended December 31, 2018 and 2017, there were no donated services that met the criteria for recognition as contributed services.

Income Tax Status

FARA has been granted tax-exempt status as a nonprofit organization under Section 501(c)(3) of the Internal Revenue Code and, accordingly, files federal tax Form 990 (Return of Organization Exempt From Income Tax) annually.

Use of Estimates

The preparation of financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Accordingly, actual results could differ from those estimates.

Functional Expenses

The costs of providing the Organization's program and other supporting services have been summarized on a functional basis in the statements of functional expenses. Accordingly, the expenses directly related to the program are combined with allocations of certain common costs of the Organization which have been allocated based on estimates made by management. Common costs allocated are payroll, taxes and benefits, as well as rent and utilities. Payroll, taxes and benefits are allocated based on estimates of time and effort. Rent and utilities are allocated on a square-footage basis.

Date of Management's Review

Management has evaluated subsequent events through May 9, 2019, the date which the financial statements were available to be issued.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND 2017

NOTE C – LIQUIDITY

FARA's financial assets available for general expenditures and research program commitments within one year of the balance sheet date are as follows:

Cash and cash equivalents	\$	2,162,521
Contributions receivable		195,821
Other investments (marketable securities)		1,620,731
Assets with donor restrictions		<u>(63,381)</u>
Assets available for general expenditures and research program commitments		3,915,692
Current liabilities		(130,166)
2019 research program commitments if benchmarks or milestones are met		<u>(3,263,234)</u>
Assets available for general expenditures	\$	<u><u>522,292</u></u>

FARA structures its financial assets to be available as general expenditures and research program commitments come due. Research program commitments assume that certain benchmarks or other criteria are met. FARA invests excess cash in short term investments (money market funds) and maintains an unrestricted investment reserve (other investments) in highly liquid marketable securities. FARA has approved a budget for 2019 with revenue and support and expense projections that are consistent with 2017 and 2018 results. In addition to the 2019 research program commitments noted in the table above, the 2019 budget includes an additional \$4.2 million in general, research program and fundraising expenses to be funded from 2019 contributions and excess cash on hand.

NOTE D - INVESTMENT IN COMMON STOCK

FARA purchased 550,000 shares of Series A preferred stock of Edison Pharmaceuticals, Inc. for \$1,100,000 directly from the issuer in a private placement. Par value per share is valued at \$.0001. In August of 2018, all of the organization's preferred shares were converted to common stock. The investment is accounted for using the cost method. The value of the investment as of December 31, 2018 and 2017 was \$1,091,500. In 2017, there was a press release indicating Edison underwent a name change to BioElectron Technology Corporation.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND 2017

NOTE E - FAIR VALUE MEASUREMENTS

Financial accounting standards establish a framework for measuring fair value. That framework provides a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value into three broad levels.

Level 1 inputs are unadjusted quoted prices for identical assets or liabilities in active markets that FARA has the ability to access. *Level 2* inputs are other than quoted prices that are observable for the asset or liability, either directly or indirectly through market corroboration, for substantially the full term of the financial instrument. *Level 3* inputs are unobservable inputs based on FARA's assumptions used to measure assets and liabilities at fair value. The asset or liability's fair value measurement level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement.

There were no Level 2 or Level 3 assets at December 31, 2018 or 2017.

Mutual funds are valued at the net asset value of shares held by FARA at year-end.

The preceding methods described may produce a fair value calculation that may not be indicative of net realizable value or reflective of future fair values. Furthermore, although FARA believes its valuation methods are appropriate and consistent with other market participants, the use of different methodologies or assumptions to determine the fair value of certain financial instruments could result in a different fair value measurement at the reporting date.

Donations of marketable securities are recorded as contributions (\$391,575 in 2018 and \$360,452 in 2017) on the date of donation at their fair values, which are based on quoted market prices (Level 1 inputs).

At December 31, 2018, no single mutual fund represented greater than 10% of FARA's portfolio. At December 31, 2017, one mutual fund represented 12% of FARA's portfolio.

NOTE F - BOARD-DESIGNATED NET ASSETS

There were no board designations made for the year ended December 31, 2018 or 2017.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND 2017

NOTE G - NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions are available for the following purposes:

	<u>2018</u>	<u>2017</u>
2018 Center of Excellence Contributions	\$ -	\$ 286,494
2018 Energy Ball Sponsorship	-	25,000
Restricted to research grants	30,791	9,988
2019 Energy Ball Sponsorship	25,000	-
Ataxian Athlete Initiative	90	-
2019 International Ataxia Research Conference	<u>7,500</u>	<u>-</u>
	<u>\$ 63,381</u>	<u>\$ 321,482</u>

NOTE H - SPECIAL EVENTS

FARA holds many special events during the year in an effort to raise contributions. During the years ended December 31, 2018 and 2017, FARA hosted the Energy Ball in Tampa, Florida, which raised approximately 29% of FARA's total revenues for 2018 and 23% in 2017.

NOTE I - LEASE AGREEMENT

FARA leases office space in a corporate center under a three-year lease that automatically renews from year-to-year unless terminated by either party. The lease provides for monthly rent payments at the current rate being charged for like space, as determined by the landlord. The lease also calls for charges for common area office services used on a monthly basis. The rental rate at December 31, 2018, was \$3,168 per month. For the years ended December 31, 2018 and 2017, rent expense was \$40,035 and \$45,407, respectively.

Future minimum lease payments are as follows:

Year Ending <u>December 31,</u>	
2019	<u>\$ 38,016</u>

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND 2017

NOTE J - INVESTMENT RETURN

Investment return consists of the following:

	<u>2018</u>	<u>2017</u>
Interest and dividends	\$ 42,297	\$ 37,283
Net investment gains (losses)	<u>(99,335)</u>	<u>198,815</u>
	(57,038)	236,098
Investment fees	<u>(14,069)</u>	<u>(13,318)</u>
	<u>\$ (71,107)</u>	<u>\$ 222,780</u>

NOTE K - RELATED PARTIES

During the years ended December 31, 2018 and 2017, Board members provided \$2,089,370 and \$1,623,656 in revenue and support to FARA, respectively.

NOTE L - COMMITMENTS

FARA has committed to funding several research grants in 2019 and 2020, assuming that certain benchmarks or other criteria are met by the grant recipients by a certain point in time. As of December 31, 2018, FARA has committed a total of \$3,263,234 for 2019 and \$510,000 for 2020. The grants will fund various research projects, including drug discovery, gene and stem cell therapy, mechanism or pathway of disease, biomarker discovery and validation, cardiac research and the Collaborative Clinical Research Network (CCRN) natural history and clinical outcome measures study.

In 2017, the CureFA Foundation agreed to co-fund four research grants with FARA. Three of the four grants had payment commitments met in 2018. One grant is still active with payment anticipated in 2019, therefore FARA anticipates co-funding from CureFA Foundation in the amount of \$62,500 in 2019.

NOTE M - CENTER OF EXCELLENCE

In April 2016 the donors, the Hamilton and Finneran families, signed an agreement to provide FARA with contributions of \$1,403,500, \$1,225,500 and \$1,121,000 in 2017, 2018 and 2019, respectively, towards the Center of Excellence. In February 2017, FARA, in partnership with the Hamilton and Finneran families, signed an agreement with the Children's Hospital of Philadelphia to donate funds for the Center of Excellence over the next three years. The agreement calls for a charitable gift in the amount of \$1,403,500 for the year ended December 31, 2017, \$1,225,000 for the year ended December 31, 2018, and \$1,121,000 is due in the year ended December 31, 2019. As of December 31, 2018, two of these commitments have been recorded on FARA's financial statements. The remaining 2019 commitment has not been recorded on FARA's financial statement, as they are contingent upon the review of the Center's work and progress.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2018 AND 2017

NOTE N - EMPLOYEE BENEFIT PLAN

On January 1, 2017 FARA adopted a 401(k) profit sharing plan and trust that covers all qualified employees. The plan provides for a discretionary profit sharing contribution, as well as a matching employer contribution. The Plan provides for matching contributions up to 3% on deferrals from eligible employees. The Company made employer matching contributions of \$15,310 and \$10,043 during the years ended December 31, 2018 and 2017, respectively.

NOTE O - PATIENT REGISTRY AND CCRN

The Friedreich's Ataxia Global Patient Registry is the only worldwide registry of Friedreich's Ataxia patients. This registry currently holds the demographic and clinical information on more than 3,500 Friedreich's ataxia patients from across the United States and internationally. This registry was created to serve the patient, physician, and research communities.

The Collaborative Clinical Research Network in Friedreich's Ataxia (CCRN in FA) is an international network of clinical research centers that work together to advance treatments and clinical care for individuals with Friedreich's Ataxia. Each network site is provided funding to participate in a longitudinal natural history study and to:

- Identify and validate clinical outcome measures and biomarkers in FA that are necessary for clinical trials
- Facilitate the implementation and delivery of clinical trials
- Share data and resources to advance treatments for FA
- Define best clinical practices for FA and provide the highest level of clinical care for patients