

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

FINANCIAL STATEMENTS

Years Ended December 31, 2016 and 2015



Certified Public Accountants and Business Consultants

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

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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, 2016 and 2015, 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, 2016 and 2015, 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.



West Chester, Pennsylvania
June 13, 2017

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENTS OF FINANCIAL POSITION

DECEMBER 31, 2016 AND 2015

	<u>2016</u>	<u>2015</u>
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	\$ 844,839	\$ 1,014,552
Contributions receivable	269,394	138,397
Prepaid expenses	34,261	9,411
Investment in securities	<u>1,868,199</u>	<u>1,800,132</u>
TOTAL CURRENT ASSETS	3,016,693	2,962,492
COMPUTER EQUIPMENT, net of accumulated depreciation of \$5,295 (2016) and \$3,997 (2015)	1,840	3,138
OTHER ASSETS		
Investment in preferred stock	<u>1,091,500</u>	<u>1,091,500</u>
TOTAL ASSETS	<u>\$ 4,110,033</u>	<u>\$ 4,057,130</u>
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	<u>\$ 484,966</u>	<u>\$ 289,961</u>
NET ASSETS		
Unrestricted	3,597,092	3,604,380
Temporarily restricted	<u>27,975</u>	<u>162,789</u>
TOTAL NET ASSETS	<u>3,625,067</u>	<u>3,767,169</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$ 4,110,033</u>	<u>\$ 4,057,130</u>

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENTS OF ACTIVITIES

YEARS ENDED DECEMBER 31, 2016 AND 2015

	<u>2016</u>	<u>2015</u>
UNRESTRICTED NET ASSETS		
Revenue and support		
Contributions	\$ 898,712	\$ 1,149,411
Special events	3,910,167	3,547,233
Investment income	65,588	(31,047)
Net assets released from restrictions	1,428,764	1,804,668
TOTAL REVENUE AND SUPPORT	<u>6,303,231</u>	<u>6,470,265</u>
Expenses		
Program services		
Education, awareness and outreach	197,035	194,464
Patient registry and CCRN	431,781	702,437
Research and grant program	4,629,368	4,361,454
Research conferences	100,504	176,964
TOTAL PROGRAM SERVICES	<u>5,358,688</u>	<u>5,435,319</u>
Fund-raising services		
Special events	768,912	637,366
Other fund-raising	99,383	98,208
TOTAL FUND-RAISING SERVICES	<u>868,295</u>	<u>735,574</u>
Supporting services		
General and administrative	83,536	88,269
TOTAL EXPENSES	<u>6,310,519</u>	<u>6,259,162</u>
CHANGE IN UNRESTRICTED NET ASSETS	<u>(7,288)</u>	<u>211,103</u>
TEMPORARILY RESTRICTED NET ASSETS		
Contributions	1,293,950	1,639,440
Net assets released from restrictions	<u>(1,428,764)</u>	<u>(1,804,668)</u>
CHANGE IN TEMPORARILY RESTRICTED NET ASSETS	<u>(134,814)</u>	<u>(165,228)</u>
CHANGE IN NET ASSETS	(142,102)	45,875
NET ASSETS AT BEGINNING OF YEAR	<u>3,767,169</u>	<u>3,721,294</u>
NET ASSETS AT END OF YEAR	<u>\$ 3,625,067</u>	<u>\$ 3,767,169</u>

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED DECEMBER 31, 2016

	Program Services					Totals	Fund-Raising Services	Supporting Services	
	Education, Awareness and Outreach	Patient Registry and CCRN	Research and Grant Program	Research Conferences	Totals			General and Administrative	Totals
FUNCTIONAL EXPENSES									
Advertising	\$ -	\$ -	\$ -	\$ -	\$ -	210	\$ -	\$ -	210
Auction items	-	-	-	-	-	6,287	-	-	6,287
Awards and grants	-	382,000	4,455,203	15,700	4,852,903	-	-	-	4,852,903
Registration fees	200	-	-	200	400	6,113	50	50	6,563
Contracted services	-	-	-	-	-	66,695	14,829	14,829	81,524
Credit card and bank fees	-	20	230	60	310	73,367	100	100	73,777
Facilities and equipment	4,876	-	-	-	4,876	162,417	-	-	167,293
Rent	4,122	2,060	8,244	2,061	16,487	20,610	4,122	4,122	41,219
Books and subscriptions	5,157	335	335	-	5,827	5,963	481	481	12,271
Hospitality	450	208	133	-	791	12,510	67	67	13,368
Postage	419	-	-	-	419	4,830	1,811	1,811	7,060
Printing and copying	5,394	-	-	-	5,394	7,517	2,014	2,014	14,925
Supplies	289	-	-	66	355	89,210	3,375	3,375	92,940
Utilities	1,491	-	2,236	372	4,099	1,491	1,863	1,863	7,453
Event entertainment	-	-	-	-	-	30,890	-	-	30,890
Insurance	-	-	-	-	-	7,245	2,816	2,816	10,061
Miscellaneous	-	-	-	-	-	120	41	41	161
Membership dues	2,100	-	-	-	2,100	-	-	-	2,100
Staff development	-	-	-	-	-	-	-	-	-
Payroll, taxes and benefits	134,600	39,647	139,979	53,949	368,175	272,553	31,459	31,459	672,187
Conferences, meetings and travel	37,937	7,511	23,008	28,096	96,552	100,267	19,210	19,210	216,029
Depreciation	-	-	-	-	-	-	1,298	1,298	1,298
TOTAL FUNCTIONAL EXPENSES	\$ 197,035	\$ 431,781	\$ 4,629,368	\$ 100,504	\$ 5,358,688	\$ 868,295	\$ 83,536	\$ 83,536	\$ 6,310,519

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE
STATEMENT OF FUNCTIONAL EXPENSES
YEAR ENDED DECEMBER 31, 2015

	Program Services					Totals	Supporting Services		Totals
	Education, Awareness and Outreach	Patient Registry and CCRN	Research and Grant Program	Research Conferences	Fund-Raising Services		General and Administrative		
FUNCTIONAL EXPENSES									
Advertising	\$ 2,699	\$ -	\$ -	\$ -	\$ 3,049	\$ 2,699	\$ -	\$ -	\$ 5,748
Auction items	-	-	-	-	30,451	-	-	-	30,451
Awards and grants	-	651,114	4,094,552	5,000	-	4,750,666	-	-	4,750,666
Registration fees	50	-	-	-	4,581	50	480	-	5,111
Contracted services	8,868	-	82,933	-	52,700	91,801	16,044	-	160,545
Credit card and bank fees	10	10	110	10	67,317	140	1,723	-	69,180
Facilities and equipment	-	-	-	-	114,334	-	1,000	-	115,334
Rent	3,626	1,813	7,252	1,813	18,129	14,504	3,625	-	36,258
Books and subscriptions	1,347	2,020	2,020	-	-	5,387	1,347	-	6,734
Hospitality	-	-	-	-	5,229	-	843	-	6,072
Postage	2,144	-	10	96	3,772	2,250	2,209	-	8,231
Printing and copying	4,437	-	-	141	7,066	4,578	2,218	-	13,862
Supplies	1,274	-	-	2,216	79,635	3,490	4,631	-	87,756
Utilities	1,671	-	2,506	418	1,671	4,595	2,088	-	8,354
Event entertainment	-	-	-	-	3,678	-	-	-	3,678
Insurance	-	-	-	-	5,245	-	3,730	-	8,975
Membership dues	2,100	-	-	-	-	2,100	-	-	2,100
Staff development	-	-	-	-	-	-	200	-	200
Payroll, taxes and benefits	140,316	42,016	151,690	58,929	266,307	392,951	34,808	-	694,066
Conferences, meetings and travel	25,922	5,464	20,381	108,341	72,410	160,108	12,007	-	244,525
Depreciation	-	-	-	-	-	-	1,316	-	1,316
TOTAL FUNCTIONAL EXPENSES	\$ 194,464	\$ 702,437	\$ 4,361,454	\$ 176,964	\$ 735,574	\$ 5,435,319	\$ 88,269	\$ 6,259,162	

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENTS OF CASH FLOWS

YEARS ENDED DECEMBER 31, 2016 AND 2015

	<u>2016</u>	<u>2015</u>
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$ (142,102)	\$ 45,875
Adjustments to reconcile change in net assets to net cash provided (used) by operating activities		
(Gain) loss on sale of securities	(18,363)	328
Net unrealized (gain) loss on securities	(29,569)	50,474
Depreciation	1,298	1,316
Increase in		
Contributions receivable	(130,997)	(27,197)
Prepaid expenses	(24,850)	(6,151)
Increase (decrease) in accounts payable	195,005	(679)
NET CASH PROVIDED (USED) BY OPERATING ACTIVITIES	<u>(149,578)</u>	<u>63,966</u>
CASH FLOWS FROM INVESTING ACTIVITIES		
Proceeds from sale of securities	889,227	862,291
Purchase of fixed assets	-	(2,131)
Purchase of securities	<u>(909,362)</u>	<u>(880,388)</u>
NET CASH USED BY FINANCING ACTIVITIES	<u>(20,135)</u>	<u>(20,228)</u>
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS	(169,713)	43,738
CASH AND CASH EQUIVALENTS AT BEGINNING OF YEAR	<u>1,014,552</u>	<u>970,814</u>
CASH AND CASH EQUIVALENTS AT END OF YEAR	<u>\$ 844,839</u>	<u>\$ 1,014,552</u>

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016 AND 2015

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.

Basis of Presentation

FARA is required to report information regarding its financial position and activities according to three classes of net assets: unrestricted net assets, temporarily restricted net assets and permanently restricted net assets.

Cash and Cash Equivalents

Cash and cash equivalents include checking and money market accounts. FARA normally deposits its cash with two 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, 2016 and 2015.

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. Unrealized gains and losses are included in the change in net assets in the accompanying statements of activities.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016 AND 2015

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

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 \$1,298 and \$1,316 for the years ended December 31, 2016 and 2015, respectively.

Contributions

Contributions received are recorded as unrestricted, temporarily restricted, or permanently restricted support depending on the existence and/or nature of any donor restrictions. Temporarily restricted contributions are reported as temporarily restricted support and are reclassified upon expiration of the restriction. Conditional promises to give are recognized only when the conditions on which they depend are substantially met and the promises become unconditional.

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, 2016, \$697,399 of FARA's bank balances of \$1,337,132 was exposed to credit risk. At December 31, 2015, \$1,290,079 of FARA's bank balances of \$1,949,678 was exposed to credit risk.

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 year ended December 31, 2015, FARA received \$82,933 in pro bono legal fees. This amount was included as contribution revenue in the statement of activities along with a corresponding expense that represents the amount FARA would have paid for the services if purchased. For the year ended December 31, 2016, 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.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016 AND 2015

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Date of Management's Review

Management has evaluated subsequent events through June 13, 2017, the date which the financial statements were available to be issued.

NOTE C - INVESTMENT IN PREFERRED 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. The investment is accounted for using the cost method. During the year ended December 31, 2014, FARA sold 4,250 shares of preferred stock for a purchase price of \$249,815, leaving 545,750 shares remaining at a cost basis of \$1,091,500. In 2017, there was a press release indicating Edison underwent a name change to BioElectron Technology Corporation, but FARA has not been formally notified of the name change or any other change to corporate structure.

NOTE D - 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.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016 AND 2015

NOTE D - FAIR VALUE MEASUREMENTS (Continued)

The assets of FARA for which fair values are determined on a recurring basis are as follows:

	<u>2016</u>	<u>2015</u>
COMMON STOCK	\$ <u>1,076</u>	\$ <u>-</u>
MUTUAL FUNDS		
Bonds	376,754	473,740
Common stock	926,234	779,448
Fixed income	529,824	481,568
Other	<u>34,311</u>	<u>65,376</u>
	<u>1,867,123</u>	<u>1,800,132</u>
	<u>\$ 1,868,199</u>	<u>\$ 1,800,132</u>

There were no Level 2 or Level 3 assets at December 31, 2016 or 2015.

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

Common stock is valued at the market 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 (\$268,107 in 2016 and \$196,103 in 2015) on the date of donation at their fair values, which are based on quoted market prices (Level 1 inputs).

At December 31, 2016 and 2015, one mutual fund represented 20% and 26% of FARA's portfolio, respectively.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016 AND 2015

NOTE E - TEMPORARILY RESTRICTED NET ASSETS

Temporarily restricted net assets are available for the following purposes:

	<u>2016</u>	<u>2015</u>
Crisp Family Foundation, Gene Therapy		
Focused Research	\$ -	\$ 150,789
Education/Awareness	-	5,000
Patient/researcher travel	20,975	-
Restricted to research grants	<u>7,000</u>	<u>7,000</u>
	<u>\$ 27,975</u>	<u>\$ 162,789</u>

NOTE F - SPECIAL EVENTS

FARA holds many special events during the year in an effort to raise contributions. During the years ended December 31, 2016 and 2015, FARA hosted the Energy Ball in Tampa, Florida, which raised approximately 28% of FARA's total revenues for 2016 and 26% in 2015.

NOTE G - 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, 2016, was \$3,075 per month. For the years ended December 31, 2016 and 2015, rent expense was \$41,219 and \$36,258, respectively.

Future minimum lease payments are as follows:

<u>Year Ended</u> <u>December 31,</u>	
2017	\$ 37,830
2018	<u>9,504</u>
	<u>\$ 47,334</u>

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016 AND 2015

NOTE H - INVESTMENT INCOME

Investment income consists of the following:

	<u>2016</u>	<u>2015</u>
Interest and dividends	\$ 29,213	\$ 30,315
Investment gains (losses)	<u>47,932</u>	<u>(50,802)</u>
	77,145	(20,487)
Investment fees	<u>(11,557)</u>	<u>(10,560)</u>
	<u>\$ 65,588</u>	<u>\$ (31,047)</u>

NOTE I - 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 2,800 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

NOTE J - RELATED PARTIES

During the years ended December 31, 2016 and 2015, Board members provided \$770,179 and \$1,126,895 in contributions to FARA, respectively.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2016 AND 2015

NOTE K - COMMITMENTS

FARA has committed to funding several research grants in 2016, assuming that certain benchmarks or other criteria are met by the grant recipients by a certain point in time. As of December 31, 2016, FARA has committed a total of \$2,616,618 in grants for various research projects, including drug discovery, gene and stem cell therapy, mechanism or pathway of disease, CCRN and cardiac research.

NOTE L - CENTER OF EXCELLENCE

In February 2017, FARA, in partnership with the Hamilton and Finneran families, signed an agreement with the Children's Hospital of Pennsylvania to donate funds to 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, \$1,225,500 for the year ended December 31, 2018, and \$1,121,000 is due in the year ended December 31, 2019. In April 2016 the donors 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. These commitments have not been recorded on FARA's financial statements, as they are contingent upon the review of the Center's work and progress.