

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

FINANCIAL STATEMENTS

Years Ended December 31, 2020 and 2019

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

TABLE OF CONTENTS

YEARS ENDED DECEMBER 31, 2020 AND 2019

	Page
Independent Auditors' Report	1
Financial Statements	
Statements of Financial Position	2
Statements of Activities	3
Statement of Functional Expenses (2020)	4
Statement of Functional Expenses (2019)	5
Statements of Cash Flows	6
Notes to Financial Statements	7

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, 2020 and 2019 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, 2020 and 2019 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.

Maillie LLP

West Chester, Pennsylvania
April 27, 2021

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENTS OF FINANCIAL POSITION

DECEMBER 31, 2020 AND 2019

	<u>2020</u>	<u>2019</u>
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	\$ 2,463,348	\$ 1,697,091
Restricted cash (See Note I)	4,580,469	123,976
Contributions receivable	277,880	191,637
Prepaid expenses	42,086	35,477
Investment in securities	1,944,826	2,128,027
TOTAL CURRENT ASSETS	<u>9,308,609</u>	<u>4,176,208</u>
OTHER ASSETS	<u>5,458</u>	<u>11,035</u>
TOTAL ASSETS	<u>\$ 9,314,067</u>	<u>\$ 4,187,243</u>
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	\$ 508,696	\$ 385,252
Deferred revenue	100,000	9,074
TOTAL CURRENT LIABILITIES	<u>608,696</u>	<u>394,326</u>
NET ASSETS		
Without donor restrictions	4,124,902	3,668,941
With donor restrictions	4,580,469	123,976
TOTAL NET ASSETS	<u>8,705,371</u>	<u>3,792,917</u>
TOTAL LIABILITIES AND NET ASSETS	<u>\$ 9,314,067</u>	<u>\$ 4,187,243</u>

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENTS OF ACTIVITIES

YEARS ENDED DECEMBER 31, 2020 AND 2019

	<u>2020</u>	<u>2019</u>
NET ASSETS WITHOUT DONOR RESTRICTIONS		
Revenue and support		
Contributions and conferences	\$ 1,091,319	\$ 1,575,358
Grants	459,000	116,500
Special events	3,192,804	4,556,102
Investment return	205,273	339,096
Net assets released from restrictions	3,874,860	1,576,840
TOTAL REVENUE AND SUPPORT	<u>8,823,256</u>	<u>8,163,896</u>
Expenses		
Program services		
Education, awareness and outreach	287,759	277,770
Patient registry and CCRN	977,662	844,106
Research and grant program	6,045,174	5,518,193
Research conferences	136,132	528,576
TOTAL PROGRAM SERVICES	<u>7,446,727</u>	<u>7,168,645</u>
Fund-raising services		
Special events	557,833	862,338
Other fund-raising	158,293	128,511
TOTAL FUND-RAISING SERVICES	<u>716,126</u>	<u>990,849</u>
Supporting services		
General and administrative	198,984	169,731
TOTAL EXPENSES	<u>8,361,837</u>	<u>8,329,225</u>
Impairment on investment in common stock (see Note F)	<u>(5,458)</u>	<u>(1,080,585)</u>
CHANGE IN NET ASSETS WITHOUT DONOR RESTRICTIONS	<u>455,961</u>	<u>(1,245,914)</u>
NET ASSETS WITH DONOR RESTRICTIONS		
Contributions and grants	8,331,353	1,637,435
Net assets released from restrictions	<u>(3,874,860)</u>	<u>(1,576,840)</u>
CHANGE IN NET ASSETS WITH DONOR RESTRICTIONS	<u>4,456,493</u>	<u>60,595</u>
CHANGE IN NET ASSETS	4,912,454	(1,185,319)
NET ASSETS AT BEGINNING OF YEAR	<u>3,792,917</u>	<u>4,978,236</u>
NET ASSETS AT END OF YEAR	<u>\$ 8,705,371</u>	<u>\$ 3,792,917</u>

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED DECEMBER 31, 2020

	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	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 3,501	\$ -	\$ 3,501
Auction items	-	-	-	-	-	28,591	-	28,591
Awards and grants	-	783,942	5,564,901	-	6,348,843	-	-	6,348,843
Registration fees	-	-	-	-	-	7,034	501	7,535
Contracted services	19,265	32,983	101,991	19,250	173,489	63,895	37,703	275,087
Credit card and bank fees	-	-	20	-	20	62,602	45	62,667
Facilities and equipment	-	-	-	-	-	44,827	5,651	50,478
Rent and utilities	6,328	3,164	12,657	3,165	25,314	31,642	6,328	63,284
Subscriptions and licensing fees	6,650	70,263	6,407	3,612	86,932	23,434	5,118	115,484
Hospitality	515	-	604	-	1,119	3,044	477	4,640
Postage	319	70	3	108	500	14,956	643	16,099
Printing and copying	-	-	-	66	66	9,250	689	10,005
Supplies	390	1,258	-	89	1,737	53,107	3,838	58,682
Telecommunications and internet	1,327	-	1,991	332	3,650	1,327	1,659	6,636
Event entertainment	-	-	-	-	-	4,000	-	4,000
Insurance	-	-	-	-	-	4,403	5,013	9,416
Miscellaneous	-	-	-	-	-	98	252	350
Membership dues	2,600	-	220	-	2,820	-	-	2,820
Payroll, taxes and benefits	244,995	85,969	352,860	83,215	767,039	335,427	128,933	1,231,399
Sales taxes paid	-	-	-	-	-	3,423	-	3,423
Conferences, meetings and travel	5,370	13	3,520	26,295	35,198	21,565	2,014	58,777
Depreciation	-	-	-	-	-	-	120	120
TOTAL FUNCTIONAL EXPENSES	\$ 287,759	\$ 977,662	\$ 6,045,174	\$ 136,132	\$ 7,446,727	\$ 716,126	\$ 198,984	\$ 8,361,837

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENT OF FUNCTIONAL EXPENSES

YEAR ENDED DECEMBER 31, 2019

	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	\$ 5,000	\$ -	\$ -	\$ -	\$ 5,000	\$ 175	\$ 455	\$ 5,630
Auction items	-	-	-	-	-	31,415	-	31,415
Awards and grants	-	699,210	5,309,603	2,500	6,011,313	-	-	6,011,313
Registration fees	-	-	-	-	-	6,799	834	7,633
Contracted services	-	28,380	9,000	600	37,980	91,002	18,878	147,860
Credit card and bank fees	35	52	234	9,378	9,699	90,263	747	100,709
Facilities and equipment	248	1,149	-	94,043	95,440	180,705	2,984	279,129
Rent and utilities	4,777	2,389	9,554	2,389	19,109	23,886	4,777	47,772
Subscriptions and licensing fees	2,969	17,836	6,000	4,147	30,952	10,715	2,613	44,280
Hospitality	-	-	925	500	1,425	7,480	350	9,255
Postage	463	-	13	46	522	7,560	1,017	9,099
Printing and copying	839	-	-	3,320	4,159	9,581	1,293	15,033
Supplies	1,287	220	-	4,985	6,492	93,121	3,063	102,676
Telecommunications and internet	1,272	-	1,909	318	3,499	1,272	1,591	6,362
Event entertainment	-	-	-	-	-	15,900	-	15,900
Insurance	-	-	-	-	-	7,724	2,816	10,540
Miscellaneous	322	-	-	-	322	246	166	734
Membership dues	2,600	-	953	-	3,553	-	-	3,553
Payroll, taxes and benefits	227,139	88,659	149,566	87,265	552,629	317,311	91,915	961,855
Sales taxes paid	-	-	-	-	-	9,828	-	9,828
Conferences, meetings and travel	30,819	6,211	30,436	319,085	386,551	85,866	35,846	508,263
Depreciation	-	-	-	-	-	-	386	386
TOTAL FUNCTIONAL EXPENSES	\$ 277,770	\$ 844,106	\$ 5,518,193	\$ 528,576	\$ 7,168,645	\$ 990,849	\$ 169,731	\$ 8,329,225

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

STATEMENTS OF CASH FLOWS

YEARS ENDED DECEMBER 31, 2020 AND 2019

	<u>2020</u>	<u>2019</u>
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in net assets	\$ 4,912,454	\$ (1,185,319)
Adjustments to reconcile change in net assets to net cash provided (used) by operating activities		
Net realized gain on sale of securities	(69,795)	(2,243)
Net unrealized gain on securities	(112,779)	(307,052)
Impairment loss on common stock (See Note F)	5,458	1,080,585
Depreciation	120	386
(Increase) decrease in		
Contributions receivable	(86,243)	4,184
Prepaid expenses	(6,609)	1,846
Increase in		
Accounts payable	123,444	255,086
Deferred revenue	90,926	9,074
NET CASH PROVIDED (USED) BY OPERATING ACTIVITIES	<u>4,856,976</u>	<u>(143,453)</u>
CASH FLOWS FROM INVESTING ACTIVITIES		
Proceeds from sale of securities	496,643	133,839
Purchase of securities	<u>(130,869)</u>	<u>(331,840)</u>
NET CASH PROVIDED (USED) BY INVESTING ACTIVITIES	<u>365,774</u>	<u>(198,001)</u>
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS	5,222,750	(341,454)
CASH AND CASH EQUIVALENTS AT BEGINNING OF YEAR	<u>1,821,067</u>	<u>2,162,521</u>
CASH AND CASH EQUIVALENTS AT END OF YEAR (See Note E)	<u>\$ 7,043,817</u>	<u>\$ 1,821,067</u>
SUPPLEMENTAL NON-CASH DISCLOSURES		
Donated Legal Services	\$ 96,000	\$ -

See accompanying notes.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE A - ORGANIZATION

Friedreich's Ataxia Research Alliance (FARA) was incorporated under the laws of the District of Columbia as a nonprofit corporation. In 2019, FARA obtained foreign entity status in Pennsylvania. FARA obtained foreign entity status in 2020 for Florida. 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.

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 fund specific research projects. 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.

Treatment of Paycheck Protection Program (PPP) Loan

FARA has elected to apply the FASB ASC 958-605 conditional contribution model to account for the Paycheck Protection Program loan. Under this model, 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 transaction is recognized as restricted contributions and grants (See Note R).

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

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, 2020 and 2019.

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 net realizable value. Unrealized gains and losses and impairment loss on investment in common stock are included in the change in net assets in the accompanying statements of activities.

Revenue Recognition

Registration fees from special events and conferences and sponsorship support are recognized as revenue at a point in time when the event takes place. Special event, conference and sponsorship revenue received in advance is recorded as deferred revenue.

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.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Recent Accounting Pronouncements

In November 2016, the FASB issued Accounting Standards Update No. 2016-18 ("ASU 2016-18") *Statement of Cash Flows (Topic 230); Restricted Cash*. FARA has implemented ASU 2016-18 for these financial statements dated December 31, 2020 and 2019.

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, 2020, \$6,492,472 of FARA's bank balances of \$7,492,472 was exposed to credit risk. At December 31, 2019, \$1,401,458 of FARA's bank balances of \$2,331,671 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, 2020, FARA recognized donated legal services of \$96,000. For the year ended December 31, 2019, the value of donated services did not meet the criteria for recognition as contributed services.

Income Taxes and Uncertain Tax Positions

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.

FARA takes the position that it has no net income derived from unrelated business activities and believes it has appropriate support for any tax positions taken and, as such, does not have any uncertain tax positions that are material to the financial statements.

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, 2020 AND 2019

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

Functional Expenses

The costs of providing FARA'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 FARA which have been allocated based on estimates made by management. Common costs allocated are payroll, taxes and benefits, as well as rent, utilities, and legal fees. Payroll, taxes and benefits and legal fees are allocated based on estimates of time and effort. Rent and utilities are allocated on a square-footage basis.

Reclassification

Certain amounts in the prior year have been reclassified to conform to the current year presentation.

Date of Management's Review

Management has evaluated subsequent events through April 27, 2021, the date which the financial statements were available to be issued.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE C - REVENUE RECOGNITION

Performance Obligations and Significant Judgements

For the years ended December 31, 2020 and 2019, FARA recognized \$17,830 and \$356,997, respectively, in revenue from special fundraising events and conferences. See Note S for the impact of the COVID-19 pandemic on performance obligations in 2020. FARA recognizes revenue from special fundraising events and conferences upon the completion of the event for which registration fees have been earned. The performance obligation consists of providing registrants access to events and is recognized at the point the event has occurred and attended by the registrants. The following table reflects the registration fees included in special events and contributions and conferences on the statement of activities:

	2020		
	Special Fundraising Events	Conferences	Total
Performance obligations satisfied at a point in time	\$ <u>17,830</u>	\$ <u>-</u>	\$ <u>17,830</u>
	2019		
	Special Fundraising Events	Conferences	Total
Performance obligations satisfied at a point in time	\$ <u>195,147</u>	\$ <u>161,850</u>	\$ <u>356,997</u>

Contract Assets and Liabilities

Contract assets arise when FARA recognizes revenue for amounts that cannot be billed under the terms of the contract with the customer. FARA does not have any material contract assets as of December 31, 2020 and 2019. Contract liabilities include advance payments for special events and sponsorships and are reported on the Statement of Financial Position as deferred revenue. Total contract liabilities totaled \$100,000 and \$9,074 as of December 31, 2020 and 2019, respectively.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE D - LIQUIDITY

The following table reflects FARA's financial assets available for general expenditures within one year as of December 31, 2020 and 2019 after accounting for assets with donor restrictions. Financial assets are considered unavailable when illiquid, not convertible to cash within one year, or subject to donor restrictions not expected to be released within one year.

	<u>As of December 31, 2020</u>		
	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>	<u>Total</u>
Liquidity resources			
Cash and cash equivalents	\$ 2,463,348	\$ 4,580,469	\$ 7,043,817
Contributions receivable	277,880	-	277,880
Other investments (marketable securities)	1,944,826	-	1,944,826
Assets not available for expenditures within one year	-	(1,537,380)	(1,537,380)
Total liquidity resources	<u>4,686,054</u>	<u>3,043,089</u>	<u>7,729,143</u>
Liquidity liabilities and commitments			
Current liabilities	(508,696)	-	(508,696)
2021 program commitments - patient engagement, Ataxian Athlete, ambassador training	-	(20,850)	(20,850)
2021 staffing commitments to support research and special projects	-	(522,023)	(522,023)
2021 research and grant program commitments			
Research commitments - Institutional research programs	-	(1,541,000)	(1,541,000)
Research commitments - Directed research projects	(213,834)	(959,216)	(1,173,050)
Research commitments - Grant program and patient registry & CCRN in FA	<u>(2,089,385)</u>	<u>-</u>	<u>(2,089,385)</u>
Total 2021 research and grant program commitments	<u>(2,303,219)</u>	<u>(2,500,216)</u>	<u>(4,803,435)</u>
Total liquidity liabilities and commitments	<u>(2,811,915)</u>	<u>(3,043,089)</u>	<u>(5,855,004)</u>
REMAINING ASSETS AVAILABLE FOR GENERAL EXPENDITURES WITHIN ONE YEAR	<u>\$ 1,874,139</u>	<u>\$ -</u>	<u>\$ 1,874,139</u>

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE D - LIQUIDITY (Continued)

	As of December 31, 2019		
	Without Donor Restrictions	With Donor Restrictions	Total
Liquidity resources			
Cash and cash equivalents	\$ 1,697,091	\$ 123,976	\$ 1,821,067
Contributions receivable	191,637	-	191,637
Other investments (marketable securities)	<u>2,128,027</u>	<u>-</u>	<u>2,128,027</u>
Total liquidity resources	4,016,755	123,976	4,140,731
Liquidity liabilities and commitments			
Current liabilities	(385,252)	-	(385,252)
2020 program commitments - patient engagement, Ataxian Athlete, ambassador training	-	(16,340)	(16,340)
2020 research and grant program commitments			
Research commitments - Grant program and patient registry & CCRN in FA	<u>(1,959,246)</u>	<u>(107,636)</u>	<u>(2,066,882)</u>
Total 2020 research and grant program commitments	<u>(1,959,246)</u>	<u>(107,636)</u>	<u>(2,066,882)</u>
Total liquidity liabilities and commitments	<u>(2,344,498)</u>	<u>(123,976)</u>	<u>(2,468,474)</u>
REMAINING ASSETS AVAILABLE FOR GENERAL EXPENDITURES WITHIN ONE YEAR	\$ <u>1,672,257</u>	\$ <u>-</u>	\$ <u>1,672,257</u>

FARA structures its financial assets to be available as general expenditures and research program commitments come due. Assets with donor restrictions are released when restrictions have been satisfied. 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.

NOTE E - CASH AND CASH EQUIVALENTS

The following table provides a reconciliation of cash, cash equivalents and restricted cash reported within the statement of financial position that sums to the total of the same such amounts shown in the statement of cash flows as of December 31, 2020 and 2019:

	<u>2020</u>	<u>2019</u>
Cash and cash equivalents	\$ 2,463,348	\$ 1,697,091
Cash restricted for donor restricted purposes	<u>4,580,469</u>	<u>123,976</u>
	<u>\$ 7,043,817</u>	<u>\$ 1,821,067</u>

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE F - INVESTMENT IN COMMON STOCK

In 2005, 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. In 2017, Edison underwent a name change to BioElectron Technology Corporation. In August of 2018, FARA converted its preferred shares to common stock. In 2019, BioElectron Technology Corporation ceased operations and all assets were acquired. The value of the stock had decreased to \$.02 per share based on management's determination of the probability they would receive future royalty revenues. In 2019, an impairment on investment in common stock was recorded for \$1,080,585. The value of the investment in common stock was \$10,915 in 2019. In 2020, based on management's estimate, the value of the stock has decreased to \$.01 per share. As a result, an impairment on investment in common stock was recorded in the current year for \$5,458 and the remaining value of the investment as of December 31, 2020 was \$5,458.

NOTE G - 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, 2020 or 2019.

Mutual funds are valued at the net asset value of shares held by FARA at year-end. Included in mutual funds as of December 31, 2020 are \$922,776 of bonds and \$1,022,050 of common stocks. Included in mutual funds as of December 31, 2019 are \$783,603 of bonds and \$1,344,424 of common stocks.

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 (\$249,979 in 2020 and \$351,436 in 2019) on the date of donation at their fair values, which are based on quoted market prices (Level 1 inputs).

At December 31, 2020, six investment funds represented 79% of FARA's portfolio. In 2019, five investment funds represented 64% of FARA's portfolio.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE H - BOARD-DESIGNATED NET ASSETS

There were no board designations made for the year ended December 31, 2020 or 2019.

NOTE I - NET ASSETS WITH DONOR RESTRICTIONS

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

	<u>2020</u>	<u>2019</u>
Restricted to Multi-year Staff Growth for Research and Special Projects	\$ 2,059,403	\$ -
Restricted to Research and Grant Programs	2,500,216	107,636
Patient Engagement, Advocacy & Awareness	13,650	-
Ambassador Training	5,000	5,000
Ataxian Athlete Initiative	2,200	1,200
Education Initiative: Clinical Trial Design	-	10,140
	<u>\$ 4,580,469</u>	<u>\$ 123,976</u>

NOTE J - SPECIAL EVENTS

FARA holds many special events during the year in an effort to raise contributions. During the years ended December 31, 2020 and 2019, FARA hosted the Energy Ball in Tampa, Florida, which raised approximately 9% of FARA's total revenues for 2020 and 21% in 2019. See Note S for the impact of the COVID-19 pandemic on special events. In addition, in 2020, the FARA Energy Ball raised a relatively lower % of total revenue due to higher total revenue with donor restrictions including multi-year support as detailed in Note I.

NOTE K - 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. During 2019, FARA negotiated a new lease with additional space that extends the lease through September 2022. The rental rate at December 31, 2020, was \$4,490 per month. For the years ended December 31, 2020 and 2019, rent expense was \$63,284 and \$47,772, respectively.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE K - LEASE AGREEMENT (Continued)

Future minimum lease payments are as follows:

Year Ending December 31,		
2021	\$	54,220
2022		<u>41,423</u>
	\$	<u><u>95,643</u></u>

NOTE L - INVESTMENT RETURN

Investment return consists of the following:

	<u>2020</u>	<u>2019</u>
Interest and dividends	\$ 38,997	\$ 45,344
Net investment gains (losses)	<u>182,574</u>	<u>309,295</u>
	221,571	354,639
Investment fees	<u>(16,298)</u>	<u>(15,543)</u>
	<u>\$ 205,273</u>	<u>\$ 339,096</u>

NOTE M - RELATED PARTIES

During the years ended December 31, 2020 and 2019, Board members provided \$891,307 and \$1,309,710 in revenue and support to FARA, respectively. The decrease in Board member contributions from 2019 to 2020 was due to a planned change in multi-year support for the Center of Excellence as part of Institutional Research Programs (See Note O) which is funded by a Board member multi-year contribution.

NOTE N - RESEARCH AND PROGRAM COMMITMENTS

FARA has committed to funding ongoing research and grant programs in 2021, assuming that certain benchmarks or other criteria are met by the grant recipients by a certain point in time. As of December 31, 2020, FARA has committed a total of \$3,262,435 for 2021. 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. This is an addition to commitments of \$1,541,000 for Institutional Research described in Note O. All commitments as of December 31, 2020 are classified as with or without donor restrictions in Note D.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE O - INSTITUTIONAL RESEARCH PROGRAMS

FARA has identified opportunities to fund research at institutions where there are multiple investigators with an expertise and commitment to FA research and/or opportunity to leverage technologies, innovation or new growth to the FA community. By establishing these institutional funding programs FARA is able to promote collaboration and synergy across basic, translational and clinical research, provide a longer-term commitment for research, attract new investigators, and leverage the institutions resources and engagement.

The FA Center of Excellence (COE) was established at the Children's Hospital of Philadelphia/University of Pennsylvania in 2014 with the Hamilton & Finneran families making a multi-year commitment to FARA and the COE. The 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. FARA has maintained this funding partnership with the CureFA Foundation (established by the Hamilton and Finneran families) to advance research through the COE. In 2020, FARA, in partnership with the CureFA Foundation, signed an agreement with the Children's Hospital of Philadelphia to contribute funds for COE research over the next three years. The agreement calls for a charitable gift in the amount of \$425,000 per year for 3 years (through 2022). As of December 31, 2020, the commitment by the CureFA Foundation and payment obligations for the COE for the first year have been met and recorded on FARA's financial statements. Of note, this a reduction from prior years due to the fact that COE is now also receiving funding and support from other private and public organizations to support their FA research.

The Friedreich's Ataxia Accelerator (FAA) at the Broad Institute of MIT and Harvard was established in 2020. The FAA is supporting the work of three research labs as they apply their expertise to the discovery of new approaches that could lead to novel treatments for FA. In June 2020, FARA, in partnership with the CureFA Foundation and EndFA, signed an agreement with the Broad Institute to contribute funds for FA research over the next three years. The agreement calls for a charitable gift in the amount of \$1,841,000 per year for 3 years (through 2022). As of December 31, 2020, FARA has received \$3,182,000 from co-funding partners towards the 2020 and 2021 commitment to the Broad Institute and FARA has met payment obligations of \$1,641,000, receipts and payments have been recorded on FARA's financial statements.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE P - PATIENT REGISTRY AND CCRN

The Friedreich's Ataxia Global Patient Registry (FAGPR) is the only worldwide registry of Friedreich's ataxia patients. The goals of the FAGPR are to collect information on all FA patients in one registry, to develop the registry into a powerful resource for research, and to engage the FA community in studies aimed at advancing our knowledge of FA and the treatments being developed. FARA partners with international patient advocacy organizations through a Governance Board to ensure multi-stakeholder engagement and oversight of the FAGPR. In 2020, about 1,000 individuals with FA provided updated informed consent and clinical data and the FAGPR was utilized to enroll several clinical trials and research studies.

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

In 2020, there were 12 sites, 8 in the United States, 2 in Canada, 1 in Australia and 1 in New Zealand. More than 1,100 individuals with FA have been enrolled in a natural history and the data and learnings being shared broadly through more than 25 peer-reviewed publications and the Friedreich's Ataxia Integrated Clinical Database (FA-ICD). The FA-ICD represents a collaborative partnership between the FARA and Critical Path Institute (C-Path), with a goal of expanding the FA-ICD platform by engaging with other data contributors to secure additional datasets. FA-ICD is designed to catalyze and accelerate FA research and drug development by curating and standardizing FA clinical trial and natural history data into CDISC format, and making this data publicly available to qualified researchers. In 2019 and 2020, this dataset was shared with more than 8 research groups.

NOTE Q - 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. FARA made employer matching contributions of \$27,037 and \$21,362 during the years ended December 31, 2020 and 2019, respectively.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

NOTES TO FINANCIAL STATEMENTS

DECEMBER 31, 2020 AND 2019

NOTE R - PAYCHECK PROTECTION PROGRAM LOAN

In April 2020 FARA received funds of \$174,600 under the Small Business Administration's Paycheck Protection Program. The stated terms were to accrue interest at 1%, payments were to be deferred for the first six months and the loan was to mature in two years. Under this Program, the loan and accrued interest, or a portion thereof, may be forgiven after eight to twenty-four weeks as long as FARA used the loan proceeds for eligible purposes including payroll, benefits, rent, utilities, and maintains its payroll levels.

The funds have been accounted for under the FASB ASC 958-605 Conditional Contribution model. Although loan forgiveness had not been granted by the Small Business Administration as of December 31, 2020, management determined that the conditions for forgiveness under the loan have been substantially met and therefore recognized the entire amount as restricted contributions and grants in the accompanying Statement of Activities. FARA received official forgiveness of \$174,600 from the Small Business Administration in January 2021.

NOTE S - RISKS AND UNCERTAINTIES

The COVID-19 pandemic has had significant impact to FARA operations and programs in 2020 and this continues into 2021. Nearly all in-person fundraising events were cancelled beginning in March 2020 through June 2021. Some events were transitioned to virtual platforms to maintain community engagement and fundraising activities. In 2021, FARA is seeing some return to in-person, depending on type of event, geographic location and timing of the event. FARA anticipates that by the 3rd quarter of 2021, most events should return to in-person or hybrid formats. As related to Notes C and J, FARA had a significant reduction in registration revenue as five out of six rideAtaxia events were cancelled, FARA didn't host any conferences that required registration and the FARA Energy Ball event, held virtually, experienced reduced revenue.

FARA's research programs have also been impacted by the pandemic as nearly all academic and clinical research centers were shut down for several months and in some countries for most of 2020. This has meant delayed starts of newly awarded grants in 2020 and delays in progress for previously funded/ongoing research grants. This has resulted in FARA's 2021 research funding and grant commitments being larger than prior years and FARA has more restricted revenue in 2020 carrying forward into 2021.

NOTE T - SUBSEQUENT EVENTS

In February 2021, FARA applied for and received a second draw of loan proceeds in the amount of \$212,315 under the Small Business Administration's Paycheck Protection Program. The loan accrues interest at 1%, payments are deferred for the first six months and the loan will mature in two years. Under this Program, the loan and accrued interest, or a portion thereof, may be forgiven after eight to twenty-four weeks as long as FARA uses the loan proceeds for eligible purposes including payroll, benefits, rent, utilities, and maintains its payroll levels.