

**FRIEDREICH'S ATAXIA  
RESEARCH ALLIANCE AND  
STICHTING FRIEDREICH'S ATAXIA  
RESEARCH ALLIANCE EUROPE**

**CONSOLIDATED FINANCIAL STATEMENTS**

**DECEMBER 31, 2023 and 2022  
(with supplementary information)**

# FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

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## **INDEPENDENT AUDITORS' REPORT**

To the Board of Directors of  
Friedreich's Ataxia Research Alliance

### **Report on the Audit of the Financial Statements**

#### ***Opinion***

We have audited the financial statements of Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe (nonprofit organizations), which comprise the consolidated statements of financial position as of December 31, 2023 and 2022, and the related consolidated statements of activities and changes in net assets, functional expenses, and cash flows for the years then ended, and the related notes to the financial statements.

In our opinion, the accompanying financial statements present fairly, in all material respects, the consolidated financial position of Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe as of December 31, 2023 and 2022, 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.

#### ***Basis for Opinion***

We conducted our audits in accordance with auditing standards generally accepted in the United States of America ("GAAS"). Our responsibilities under those standards are further described in the Auditors' Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of the Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe and to meet our other ethical responsibilities, in accordance with the relevant ethical requirements relating to our audits. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

#### ***Responsibilities of Management 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, and for 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.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe's ability to continue as a going concern for one year after the date that the financial statements are available to be issued.

## ***Auditors' Responsibilities for the Audit of the Financial Statements***

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and, therefore, is not a guarantee that an audit conducted in accordance with GAAS will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with GAAS, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit 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 Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe 's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about the Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control-related matters that we identified during the audit.



## Report on Supplementary Information

Our audits were conducted for the purpose of forming an opinion on the financial statements as a whole. The supplementary information contained in the consolidating schedule of financial position as of December 31, 2023 and the consolidating schedule of activities for the year ended December 31, 2023 is presented for purposes of additional analysis and is not a required part of the financial statements. Such information is the responsibility of management and was derived from and relates directly to the underlying accounting and other records used to prepare the financial statements. The information has been subjected to the auditing procedures applied in the audit of the financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the financial statements or to the financial statements themselves, and other additional procedures in accordance with auditing standards generally accepted in the United States of America. In our opinion, the information is fairly stated in all material respects in relation to the financial statements as a whole.

*EisnerAmper LLP*

EISNERAMPER LLP  
Philadelphia, Pennsylvania  
June 18, 2024

EISNERAMPER  
LLP



**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND  
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Consolidated Statements of Financial Position**

	<b>December 31,</b>	
	<b>2023</b>	<b>2022</b>
<b>ASSETS</b>		
Cash and cash equivalents	\$ 3,993,332	\$ 3,279,967
Restricted cash	963,779	1,684,153
Contributions receivable, net	747,478	369,612
Prepaid expenses	49,155	52,398
Investments	<b>1,870,166</b>	1,728,750
	<b>7,623,910</b>	7,114,880
Total current assets	<b>7,623,910</b>	7,114,880
Right-of-use assets	<b>103,796</b>	140,436
Other assets	<b>5,458</b>	5,458
	<b>109,254</b>	145,894
Total other assets	<b>109,254</b>	145,894
Total assets	<b>\$ 7,733,164</b>	<b>\$ 7,260,774</b>
<b>LIABILITIES AND NET ASSETS</b>		
Liabilities:		
Accounts payable	\$ 1,164,034	\$ 276,962
Deferred revenues	4,567	11,490
Current portion of lease liabilities	<b>68,826</b>	57,082
	<b>1,237,427</b>	345,534
Total current liabilities	<b>1,237,427</b>	345,534
Long-term lease liabilities	<b>43,221</b>	84,815
Total liabilities	<b>1,280,648</b>	430,349
Net assets:		
Without donor restrictions	<b>5,488,737</b>	5,146,272
With donor restrictions	<b>963,779</b>	1,684,153
Total net assets	<b>6,452,516</b>	6,830,425
Total liabilities and net assets	<b>\$ 7,733,164</b>	<b>\$ 7,260,774</b>

See notes to consolidated financial statements.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND  
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Consolidated Statements of Activities and Changes in Net Assets**

	Year Ended December 31,					
	2023			2022		
	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total	Net Assets Without Donor Restrictions	Net Assets With Donor Restrictions	Total
<b>Support and revenue:</b>						
Contributions and conferences	\$ 4,037,159	\$ 3,573,926	\$ 7,611,085	\$ 2,696,949	\$ 4,343,977	\$ 7,040,926
Grants	-	-	-	75,000	38,747	113,747
Special events (net of direct benefits to donors of \$145,569 and \$191,456 for 2023 and 2022, respectively)	4,076,066	-	4,076,066	4,080,492	-	4,080,492
In-kind contributions	728,704	-	728,704	770,062	-	770,062
Investment return (loss), net	266,862	-	266,862	(270,929)	-	(270,929)
Net assets released from restrictions	4,294,300	(4,294,300)	-	5,285,834	(5,285,834)	-
<b>Total support and revenue</b>	<b>13,403,091</b>	<b>(720,374)</b>	<b>12,682,717</b>	<b>12,637,408</b>	<b>(903,110)</b>	<b>11,734,298</b>
<b>Expenses:</b>						
Program services:						
Education, awareness and outreach	357,618	-	357,618	395,929	-	395,929
Patient registry and CCRN	1,617,991	-	1,617,991	1,038,076	-	1,038,076
Research and grant program	9,088,465	-	9,088,465	9,073,049	-	9,073,049
Research conferences	302,502	-	302,502	233,493	-	233,493
<b>Total program services</b>	<b>11,366,576</b>	<b>-</b>	<b>11,366,576</b>	<b>10,740,547</b>	<b>-</b>	<b>10,740,547</b>
Supporting services:						
Fundraising services:						
Special events	1,052,479	-	1,052,479	879,864	-	879,864
Other	249,359	-	249,359	184,754	-	184,754
<b>Total fundraising services</b>	<b>1,301,838</b>	<b>-</b>	<b>1,301,838</b>	<b>1,064,618</b>	<b>-</b>	<b>1,064,618</b>
General and administrative	392,212	-	392,212	293,984	-	293,984
<b>Total supporting services</b>	<b>1,694,050</b>	<b>-</b>	<b>1,694,050</b>	<b>1,358,602</b>	<b>-</b>	<b>1,358,602</b>
<b>Total expenses</b>	<b>13,060,626</b>	<b>-</b>	<b>13,060,626</b>	<b>12,099,149</b>	<b>-</b>	<b>12,099,149</b>
<b>Change in net assets</b>	<b>342,465</b>	<b>(720,374)</b>	<b>(377,909)</b>	<b>538,259</b>	<b>(903,110)</b>	<b>(364,851)</b>
Net assets at beginning of year	5,146,272	1,684,153	6,830,425	4,608,013	2,587,263	7,195,276
<b>Net assets at end of year</b>	<b>\$ 5,488,737</b>	<b>\$ 963,779</b>	<b>\$ 6,452,516</b>	<b>\$ 5,146,272</b>	<b>\$ 1,684,153</b>	<b>\$ 6,830,425</b>

See notes to consolidated financial statements.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND  
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Consolidated Statement of Functional Expenses  
Year Ended December 31, 2023**

	Program Services					Supporting Services			
	Education Awareness and Outreach	Patient Registry and FA GCC	Research and Grant Program	Research Conferences	Totals	Fundraising Services			Totals
						Special Events	Other	General and Administrative	
<b>Expenses:</b>									
Auction items	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 79,474	\$ -	\$ -	\$ 79,474
Awards and grants	-	626,173	8,355,904	-	8,982,077	-	-	-	8,982,077
Registration fees	-	-	-	-	-	3,055	5,216	793	9,064
Contracted services	71,016	556,509	138,994	33,383	799,902	262,774	25,610	90,371	1,178,657
Credit card and bank fees	-	-	210	-	210	70,639	13,177	-	84,026
Facilities and equipment	-	-	-	-	-	218,313	-	4,771	223,084
Rent and utilities	13,703	4,061	12,182	4,061	34,007	30,964	7,361	8,882	81,214
Subscriptions and licensing fees	4,153	271,931	11,104	3,641	290,829	24,733	16,583	12,809	344,954
Hospitality	19	-	416	-	435	5,717	-	175	6,327
Postage	179	-	1,783	659	2,621	10,714	6,028	1,807	21,170
Printing and copying	1,861	-	-	4,134	5,995	14,870	6,968	534	28,367
Supplies	3	-	1,547	1,240	2,790	86,022	15,078	4,399	108,289
Telecommunications	1,346	-	-	-	1,346	1,055	-	74	2,475
Event entertainment	-	-	-	-	-	18,045	-	-	18,045
Insurance	-	-	-	-	-	5,186	11,256	2,737	19,179
Miscellaneous	-	-	45	-	45	351	-	2,946	3,342
Membership dues	2,600	-	1,152	440	4,192	642	-	-	4,834
Payroll, taxes and benefits	245,052	157,501	538,706	139,765	1,081,024	260,724	142,001	214,438	1,698,187
Sales taxes paid	-	-	-	-	-	8,936	-	-	8,936
Conferences, meetings and travel	17,686	1,816	26,422	115,179	161,103	95,834	81	47,476	304,494
<b>Total expenses</b>	<b>357,618</b>	<b>1,617,991</b>	<b>9,088,465</b>	<b>302,502</b>	<b>11,366,576</b>	<b>1,198,048</b>	<b>249,359</b>	<b>392,212</b>	<b>13,206,195</b>
Less: direct benefits to donors	-	-	-	-	-	(145,569)	-	-	(145,569)
<b>Total expenses per statements of activities</b>	<b>\$ 357,618</b>	<b>\$ 1,617,991</b>	<b>\$ 9,088,465</b>	<b>\$ 302,502</b>	<b>\$ 11,366,576</b>	<b>\$ 1,052,479</b>	<b>\$ 249,359</b>	<b>\$ 392,212</b>	<b>\$ 13,060,626</b>

See notes to consolidated financial statements.



**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND  
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Consolidated Statement of Functional Expenses  
Year Ended December 31, 2022**

	Program Services					Supporting Services			
	Education Awareness and Outreach	Patient Registry and CCRN	Research and Grant Program	Research Conferences	Totals	Fundraising Services			Totals
						Special Events	Other	General and Administrative	
<b>Expenses:</b>									
Auction items	\$ -	\$ -	\$ -	\$ -	\$ -	\$ 15,447	\$ -	\$ -	\$ 15,447
Awards and grants	-	774,269	8,460,000	-	9,234,269	-	-	-	9,234,269
Bad debts	-	-	-	-	-	-	-	22,500	22,500
Registration fees	-	-	-	-	-	5,272	4,627	546	10,445
Contracted services	112,222	63,752	123,057	27,196	326,227	249,480	17,105	65,749	658,561
Credit card and bank fees	13	-	55	40	108	78,129	11,141	164	89,542
Facilities and equipment	-	1,778	-	1,000	2,778	244,305	286	5,933	253,302
Rent and utilities	7,311	3,389	14,621	3,389	28,710	24,722	5,981	8,373	67,786
Subscriptions and licensing fees	4,025	70,019	7,417	54	81,515	19,390	10,214	5,614	116,733
Hospitality	1,029	-	-	-	1,029	3,324	44	754	5,151
Postage	320	1,246	-	2,113	3,679	8,791	8,349	1,297	22,116
Printing and copying	464	-	-	1,550	2,014	13,406	6,528	563	22,511
Supplies	5,514	1,956	-	1,167	8,637	73,262	1,459	4,276	87,634
Telecommunications	1,616	-	-	-	1,616	1,366	69	-	3,051
Event entertainment	-	-	-	-	-	10,540	-	-	10,540
Insurance	-	-	-	-	-	1,580	7,644	9,278	18,502
Miscellaneous	-	-	-	-	-	-	-	641	641
Membership dues	3,600	-	440	147	4,187	-	-	-	4,187
Payroll, taxes and benefits	250,623	117,246	453,068	100,492	921,429	225,350	110,489	143,902	1,401,170
Sales taxes paid	-	-	-	-	-	8,180	-	-	8,180
Conferences, meetings and travel	9,192	4,421	14,391	96,345	124,349	88,776	818	24,394	238,337
<b>Total expenses</b>	<b>\$ 395,929</b>	<b>\$ 1,038,076</b>	<b>\$ 9,073,049</b>	<b>\$ 233,493</b>	<b>\$ 10,740,547</b>	<b>\$ 1,071,320</b>	<b>\$ 184,754</b>	<b>\$ 293,984</b>	<b>\$ 12,290,605</b>
Less: direct benefits to donors	-	-	-	-	-	(191,456)	-	-	(191,456)
<b>Total expenses per statements of activities</b>	<b>\$ 395,929</b>	<b>\$ 1,038,076</b>	<b>\$ 9,073,049</b>	<b>\$ 233,493</b>	<b>\$ 10,740,547</b>	<b>\$ 879,864</b>	<b>\$ 184,754</b>	<b>\$ 293,984</b>	<b>\$ 12,099,149</b>

See notes to consolidated financial statements.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND  
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Consolidated Statements of Cash Flows**

	Year Ended December 31,	
	2023	2022
<b>Cash flows from operating activities:</b>		
Change in net assets	\$ (377,909)	\$ (364,851)
Adjustments to reconcile change in net assets to net cash used in operating activities:		
Amortization of right-of use assets	57,914	43,925
Net realized loss (gains) on sale of securities	94,983	(12,976)
Net unrealized loss (gains) on securities	(231,231)	349,445
Donated securities	(284,652)	(176,540)
Proceeds from sale of donated securities	282,334	176,540
Bad debts	-	22,500
(Increase) decrease in:		
Contributions receivable	(377,866)	(132,293)
Prepaid expenses	3,243	41,644
Increase (decrease) in:		
Accounts payable	887,072	15,814
Deferred revenue	(6,923)	(10,870)
Lease liabilities	(51,124)	(42,464)
Net cash used in operating activities	<u>(4,159)</u>	<u>(90,126)</u>
<b>Cash flows from investing activities:</b>		
Proceeds from sale of securities	998,025	222,576
Purchase of securities	<u>(1,000,875)</u>	<u>(310,929)</u>
Net cash used in investing activities	<u>(2,850)</u>	<u>(88,353)</u>
<b>Net decrease in cash, cash equivalents and restricted cash</b>	<b>(7,009)</b>	<b>(178,479)</b>
Cash, cash equivalents and restricted cash at beginning of year	<u>4,964,120</u>	<u>5,142,599</u>
<b>Cash, cash equivalents and restricted cash at end of year</b>	<u><u>\$ 4,957,111</u></u>	<u><u>\$ 4,964,120</u></u>
<b>Supplemental non-cash disclosures:</b>		
Obtaining a right-of-use asset in exchange for a lease liability	<u>\$ 21,274</u>	<u>\$ 184,361</u>
Donated professional services	<u>\$ 176,250</u>	<u>\$ 153,000</u>
Donated auction items	<u><u>\$ 552,454</u></u>	<u><u>\$ 617,062</u></u>

See notes to consolidated financial statements.

# FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

## Notes to Consolidated Financial Statements December 31, 2023 and 2022

### NOTE A - ORGANIZATION

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

Stichting Friedreich's Ataxia Research Alliance Europe ("FARA Europe") was incorporated in the Netherlands in 2023. FARA Europe receives grants and donations from FARA and other entities and individuals and contracts with European clinical sites conducting natural history studies. The transactions between FARA Europe and FARA are recorded in U.S. dollars. FARA Europe's strategic priorities include unifying, consolidating, and supporting the Friedreich's Ataxia ("FA") clinical infrastructure across Europe. Through collaboration with FARA, FARA Europe aims to establish and support a global entity, the FA Global Clinical Consortium ("FA GCC"), with the goal of informing and accelerating the development of new treatments for FA.

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

#### [1] Principles of consolidation:

The accompanying financial statements of FARA and FARA Europe (collectively, the "Organization") have been prepared using the accrual basis of accounting and conform to accounting principles generally accepted in the United States of America ("U.S. GAAP") as applicable to not-for-profit organizations. The consolidated financial statements include the accounts of FARA and FARA Europe. FARA Europe is governed by the common board of directors of FARA. All significant intercompany accounts and transactions have been eliminated.

#### [2] Classification of net assets:

Resources in the financial statements are classified for accounting and reporting purposes in classes of net assets according to the existence or absence of donor-imposed restrictions. The accompanying financial statements may include the following classes of net assets:

(i) *Net assets without donor restrictions:*

Net assets without donor restrictions are used to account for funds which have not been restricted by donors and over which the Board of Directors has discretionary control.

(ii) *Net assets with donor restrictions:*

Net assets with donor restrictions are subject to donor-imposed or certain grantor-imposed restrictions. Some donor-imposed restrictions are temporary in nature, such as those that will be met by the passage of time or other events specified by the donor. Other donor-imposed restrictions are perpetual in nature, where the donor stipulates that resources be maintained in perpetuity. Donor-imposed restrictions are released when a restriction expires, that is, when the stipulated time has elapsed, when the stipulated purpose for which the resource was restricted has been fulfilled, or both.

# FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

## Notes to Consolidated Financial Statements December 31, 2023 and 2022

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

#### [3] Cash and cash equivalents:

The Organization considers all highly liquid investments with maturities of three months or less when purchased to be cash equivalents. Cash and cash equivalents include checking and money market accounts. The Organization normally deposits its cash with seven financial institutions.

#### [4] Contributions receivable:

Contributions receivable consists primarily of funds due for fund-raising events on the Organization's behalf that were not remitted to the Organization 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. The Organization recorded the allowance for doubtful accounts in the amount of \$0 and \$22,500 as of December 31, 2023 and 2022, respectively.

#### [5] Investments:

The Organization carries investments in marketable securities with readily determinable fair market values and all investments in debt securities at their fair values in the consolidated statements of financial position. Unrealized gains and losses and impairment loss on investment in common stock are included in the change in net assets in the accompanying consolidated statements of activities.

#### [6] Leases:

Operating leases are recorded as operating lease right-of-use ("ROU") assets and operating lease liabilities on the accompanying consolidated statement of financial position. Operating lease ROU assets and the related lease liabilities are recognized based on the present value of the future minimum lease payments over the lease term at commencement date. As the Organization's leases do not provide an implicit rate, an incremental borrowing rate based on the information available at the commencement date or the adoption date is used as a practical expedient in determining the present value of future payments. The operating lease ROU assets exclude lease incentives and initial direct costs incurred.

The Organization's policy with respect to short-term leases is to exempt such agreements from the requirements of the Financial Accounting Standards Board ("FASB") Accounting Standards Codification ("ASC") 842 and account for the associated lease cost within real estate maintenance and insurance on the consolidated schedule of functional expenses on a straight-line basis over the lease term. No right-of-use asset nor lease liability is established on FARA's consolidated statement of financial position with respect to short-term leases. Short-term leases are generally defined as with an original term of twelve months or less upon commencement.

Finance leases are recorded as finance lease ROU assets and finance lease liabilities on the accompanying consolidated statement of financial position. Finance lease ROU assets and the related lease liabilities are recognized based on the present value of the future minimum lease payments over the lease term at commencement date. If an implicit rate is not available, an incremental borrowing rate based on the information available at commencement date is used as a practical expedient in determining the present value of future payments.

# FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

## Notes to Consolidated Financial Statements December 31, 2023 and 2022

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

#### [7] Revenue recognition:

##### *Contributions and grants:*

Funding for the Organization's activities is achieved almost entirely through foundation, corporate and other support, contributions, and in-kind contributions, including unconditional promises to give. These donations provide funding to be used to support the Organization's mission. As the donors are not receiving a benefit as a result of these transactions, the donations are considered to be contributions to the Organization. Some contributions require that funds be expended for a specific purpose, and are considered to be net assets with donor restrictions. There were no conditional government grants as of December 31, 2023 that will be recognized in subsequent years as costs are incurred and service requirements are met.

The Organization recognizes unconditional contributions when cash, securities or other assets, or an unconditional promise to give is received, and are recorded after discounting to the present value of the expected future cash flows (if the unconditional contributions are scheduled to be paid over multiple years). Conditional promises to give, that is, those with a measurable performance or other barrier and a right of return, are not recognized until the conditions on which they depend have been met.

The CARES Act provides an employee retention credit ("CARES Employee Retention credit"), which is a refundable tax credit against certain employment taxes. From March 12, 2020 through December 31, 2020, the tax credit is equal to 50% of qualified wages up to \$10,000 or a maximum credit of up to \$5,000 per employee. From January 1, 2021 through September 30, 2021, the tax credit is equal to 70% of qualified wages up to \$10,000 during a quarter or a maximum credit of up to \$14,000 per employee (or \$7,000 per quarter).

During the fiscal year ended December 31, 2022, FARA recorded \$313,695 related to the CARES Employee Retention credit in contributions and grants revenue on the Organization's consolidated statements of activities and changes in net assets. The entire balance of the credit was collected in 2022.

##### *Special events:*

The Organization earns revenue from contracts with customers through special events.

Fee-for-service revenue related to special events is recognized when or as the performance obligations in each contract are satisfied for the amount of consideration the Organization expects to be entitled to receive for the related service.

The Organization records special events revenue equal to contribution revenue less the cost of direct benefits to donors which is included in special events revenue on the consolidated statements of activities and changes in net assets. The recognition of revenue is conditional on the event taking place, as this is the point in time when the performance obligation of hosting the event occurs, and attendees can no longer request a refund for their ticket purchases. The amounts are collected at the time of ticket purchase and are included in deferred revenue until recognized. As of December 31, 2023 and 2022, there were conditional contributions associated with special events of \$4,567 and \$11,490, respectively, which is included in deferred revenue on the consolidated statements of financial position. There were no other contract assets or contract liabilities at either December 31, 2023 or December 31, 2022.

# FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

## Notes to Consolidated Financial Statements December 31, 2023 and 2022

### NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

#### [7] Revenue recognition: (continued)

##### *In-kind:*

The Organization receives various forms of gifts-in-kind, which are contributions of nonfinancial assets including professional services or auction items. Donated services are recognized in the financial statements if they (i) create or enhance financial assets or require specialized skills, (ii) are provided by individuals possessing these skills, and (iii) would typically need to be acquired if not provided by donation. The donated services are valued at the estimated prevailing rate for like services in the principal marketplace for use at the time the services are provided and reported as an expense concurrently as utilized. During the years ended December 31, 2023 and 2022, the Organization recorded contributed legal and communication professional services of \$176,250 and \$153,000, respectively.

Contributed auction items are recorded at the proceeds for which they were sold, which amounted to \$552,454 and \$617,062 for the years ended December 31, 2023 and 2022, respectively.

Contributed materials and services are reflected as revenue in the accompanying consolidated statements of activities and changes in net assets. The related offsetting expense is recorded in the same amount on the consolidated statements of activities and changes in net assets. In addition to those included above, the Organization also receives donated services from unpaid volunteers. These services do not meet the criteria for recognition as contributed services and are therefore not included in the accompanying financial statements.

#### [8] Concentrations of credit risk:

Cash deposits that potentially subject the Organization to concentrations of credit risk consist of cash accounts not covered by FDIC insurance. At December 31, 2023, \$3,862,075 of FARA's bank balances of \$4,957,111 was exposed to credit risk. At December 31, 2022, \$4,213,895 of FARA's bank balances of \$4,964,120 was exposed to credit risk.

#### [9] Federal tax status:

The Internal Revenue Service has classified FARA as exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. FARA Europe was formed as a non-profit entity under the laws of the Netherlands and is exempt from income taxes.

Accounting for uncertainty in income taxes clarifies the accounting for uncertainty in income taxes recognized in an enterprise's financial statements. Management has analyzed the tax positions taken by the Organization, and has concluded that as of December 31, 2023, there are no uncertain tax positions taken or expected to be taken that would require recognition of a liability or disclosure in the financial statements. The Organization recognizes accrued interest and penalties associated with uncertain tax positions, if any. There were no income tax related interest or penalties recorded for the year ended December 31, 2023.

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**NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)**

**[10] 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.

**[11] Functional expenses:**

The costs of providing the Organization's program and other supporting services have been summarized on a functional basis in the consolidated 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, utilities, legal, and other professional service fees. Payroll, taxes and benefits, legal, and other professional service fees are allocated based on estimates of time and effort. Rent and utilities are allocated on a square-footage basis.

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**Notes to Consolidated Financial Statements  
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**NOTE C - LIQUIDITY**

The following tables reflect the Organization's financial assets available for general expenditures within one year from December 31, 2023 and 2022, 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.

	<b>December 31, 2023</b>		
	<b>Without Donor Restrictions</b>	<b>With Donor Restrictions</b>	<b>Total</b>
Liquidity resources:			
Cash and cash equivalents	\$ 3,993,332	\$ 963,779	\$ 4,957,111
Contributions receivable	747,478	-	747,478
Investment	1,870,166	-	1,870,166
Contracted restricted resources to be received in 2024 for existing commitments as of December 31, 2023	-	2,896,406	2,896,406
Assets without commitments as of December 31, 2023	-	(426,753)	(426,753)
<b>Total liquidity resources</b>	<b>6,610,976</b>	<b>3,433,432</b>	<b>10,044,408</b>
Liquidity liabilities and commitments:			
Current liabilities including leases	(1,232,860)	-	(1,232,860)
2024 Fundraising commitments	(4,567)	(75,000)	(79,567)
2024 Program commitments - Ataxian Athlete	-	(2,279)	(2,279)
2024 Staffing commitments to support research and special projects	-	(391,842)	(391,842)
2024 Research and Grant program commitments:			
Institutional research programs	-	(2,445,086)	(2,445,086)
Directed research projects	(1,440,690)	(519,225)	(1,959,915)
Grant program and patient registry & CCRN in FA	(1,648,031)	-	(1,648,031)
<b>Total 2024 Research and Grant program commitments</b>	<b>(3,088,721)</b>	<b>(2,964,311)</b>	<b>(6,053,032)</b>
<b>Total liquidity liabilities and commitments</b>	<b>(4,326,148)</b>	<b>(3,433,432)</b>	<b>(7,759,580)</b>
Remaining assets available for general expenditures within one year	<b>\$ 2,284,828</b>	<b>\$ -</b>	<b>\$ 2,284,828</b>

The Organization 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. The Organization invests excess cash in short-term investments (money market funds) and maintains an unrestricted investment reserve (investments) in highly liquid marketable securities.



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**Notes to Consolidated Financial Statements  
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**NOTE C - LIQUIDITY (CONTINUED)**

	<b>December 31, 2022</b>		
	<b>Without Donor Restrictions</b>	<b>With Donor Restrictions</b>	<b>Total</b>
Liquidity resources:			
Cash and cash equivalents	\$ 3,279,967	\$ 1,684,153	\$ 4,964,120
Contributions receivable	369,612	-	369,612
Investment	1,728,750	-	1,728,750
Contracted restricted resources to be received in 2023 for existing commitments as of December 31, 2022	-	1,195,459	1,195,459
Assets without commitments as of December 31, 2022	-	(898,103)	(898,103)
<b>Total liquidity resources</b>	<b>5,378,329</b>	<b>1,981,509</b>	<b>7,359,838</b>
Liquidity liabilities and commitments:			
Current liabilities including leases	(334,044)	-	(334,044)
2023 Fundraising commitments	(11,490)	(130,000)	(141,490)
2023 Program commitments - Ataxian Athlete	-	(5,775)	(5,775)
2023 Staffing commitments to support research and special projects	-	(477,316)	(477,316)
2023 Research and Grant program commitments:			
Institutional research programs	-	(374,462)	(374,462)
Directed research projects	(638,878)	(993,956)	(1,632,834)
Grant program and patient registry & CCRN in FA	(2,052,847)	-	(2,052,847)
<b>Total 2023 Research and Grant program commitments</b>	<b>(2,691,725)</b>	<b>(1,368,418)</b>	<b>(4,060,143)</b>
<b>Total liquidity liabilities and commitments</b>	<b>(3,037,259)</b>	<b>(1,981,509)</b>	<b>(5,018,768)</b>
Remaining assets available for general expenditures within one year	<u>\$ 2,341,070</u>	<u>\$ -</u>	<u>\$ 2,341,070</u>

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND  
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**Notes to Consolidated Financial Statements  
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**NOTE D - CASH AND CASH EQUIVALENTS**

The following table provides a reconciliation of cash, cash equivalents and restricted cash reported within the consolidated statements of financial position that sums to the total of the same such amounts shown in the consolidated statements of cash flows as of December 31, 2023 and 2022:

	<u>2023</u>	<u>2022</u>
Cash and cash equivalents	<b>\$ 3,993,332</b>	\$ 3,279,967
Cash restricted for donor restricted purposes	<b>963,779</b>	1,684,153
	<b><u>\$ 4,957,111</u></b>	<b><u>\$ 4,964,120</u></b>

**NOTE E - INVESTMENTS AND FAIR VALUE MEASUREMENTS**

FASB ASC 820, *Fair Value Measurements and Disclosures*, provides the framework for measuring fair value. The framework provides a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value, and defines fair value as the price that would be received to sell an asset or paid to transfer a liability (i.e., the "exit price") in an orderly transaction between market participants.

The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets (Level 1 measurements), and the lowest priority to unobservable inputs (Level 3 measurements). The three levels of the fair value hierarchy are described as follows:

- Level 1: Inputs to the valuation methodology are unadjusted quoted prices for identical assets or liabilities in active markets.
- Level 2: Inputs to the valuation methodology include (a) quoted prices for similar assets or liabilities in active markets; (b) quoted prices for identical or similar assets or liabilities in inactive markets; (c) inputs other than quoted prices that are observable for the asset or liability; or (d) inputs that are derived principally from or corroborated by observable market data by correlation or other means.
- Level 3: Inputs to the valuation methodology are unobservable and significant to the fair value measurement. Assets utilizing Level 3 inputs are funds held in trust by others.

The financial instrument's level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. The valuation levels are not necessarily an indication of the risk or liquidity associated with the underlying assets.

As of December 31, 2023 and 2022, FARA's investments consist of the following:

	<u>2023</u>	<u>2022</u>
U.S. Government debts	<b>\$ 235,529</b>	\$ -
Mutual funds - fixed income	<b>417,532</b>	658,018
Mutual funds- equity	<b>1,217,105</b>	1,070,732
	<b><u>\$ 1,870,166</u></b>	<b><u>\$ 1,728,750</u></b>

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND  
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**Notes to Consolidated Financial Statements  
December 31, 2023 and 2022**

**NOTE E - INVESTMENTS AND FAIR VALUE MEASUREMENTS (CONTINUED)**

These investments are valued at the closing market price on the stock exchange where they are traded, and are considered to be Level 1 on the aforementioned fair value hierarchy. There were no Level 2 or Level 3 assets at December 31, 2023 or 2022.

**NOTE F - LEASES**

FARA has a lease agreement that has been recorded in accordance with ASC 842 as an operating lease.

The liabilities under the operating lease are recorded at the present value of the minimum lease payments. During the years ended December 31, 2023 and 2022, lease expenses of \$71,071 and \$57,152, respectively, relating to the operating lease, are included in management and general on the consolidated statements of activities and changes in net assets. There are no costs related to variable lease components.

The following maturity analysis of the annual undiscounted cash flows of the operating lease liabilities as of December 31, 2023 is approximately as follows:

<u>Year Ending December 31,</u>		
2024	\$	68,826
2025		51,620
Less: present value discount		<u>(8,399)</u>
Total	\$	<u>112,047</u>

**NOTE G - NET ASSETS WITH DONOR RESTRICTIONS**

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

	<u>2023</u>	<u>2022</u>
Multi-year staff growth for research and special projects	\$ 784,253	\$ 1,188,947
Research and grant programs	77,247	334,431
Future fundraising events	100,000	155,000
Ataxian Athlete Initiative	<u>2,279</u>	<u>5,775</u>
	<u>\$ 963,779</u>	<u>\$ 1,684,153</u>

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND  
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**Notes to Consolidated Financial Statements  
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**NOTE G - NET ASSETS WITH DONOR RESTRICTIONS (CONTINUED)**

Net assets were released from donor restriction by incurring expenses satisfying the restricted purpose specified by the donors as follows for the years ended December 31, 2023 and 2022:

	<u>2023</u>	<u>2022</u>
<b>Satisfaction of purpose restrictions:</b>		
Research, conferences, and grant programs	<b>\$ 3,719,959</b>	\$ 4,593,587
Ataxian Athlete Initiative	<b>14,647</b>	9,226
Patient engagement, advocacy and awareness	-	38,747
Ambassador training	-	3,000
Future fundraising events	<b>155,000</b>	200,590
<b>Satisfaction of purpose and time restrictions:</b>		
Multi-year staff growth for research and special projects	<b>404,694</b>	440,684
	<b><u>\$ 4,294,300</u></b>	<b><u>\$ 5,285,834</u></b>

**NOTE H - SPECIAL EVENTS**

FARA holds many special events during the year in an effort to raise contributions. During the years ended December 31, 2023 and 2022, FARA hosted the Energy Ball in Tampa, Florida, which raised approximately 15% of FARA's total revenues for 2023 and 16% in 2022.

**NOTE I - RELATED PARTIES**

During the years ended December 31, 2023, and 2022, Board members provided \$4,784,585 and \$3,839,961 in revenue and support to FARA, respectively. This excludes the value of donated services described in Note B. The increase in Board member contributions from 2022 to 2023 was due to contributions to support the Institutional Research Programs described in Note O, support for Directed Research Projects, and an overall increase in Board member giving.

**NOTE J - RESEARCH AND PROGRAM COMMITMENTS**

Many of the research grants that FARA funds are for multiple years which means that FARA has commitments to funding ongoing research and grant programs, assuming that certain benchmarks or other criteria are met by the grant recipients by a certain point in time. As of December 31, 2023 and 2022, FARA had committed a total of \$3,607,946 and \$3,685,680, respectively, for the following year from the Grant Program and Directed Projects. 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 FA GCC natural history and clinical outcome measures study. These are in addition to commitments of \$2,445,086 and \$374,462 as of December 31, 2023 and 2022, respectively, for Institutional Research described in Note K. All commitments as of December 31, 2023 and 2022 are classified as with or without donor restrictions in Note C.

# **FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

## **Notes to Consolidated Financial Statements December 31, 2023 and 2022**

### **NOTE K - 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 called for a charitable gift in the amount of \$425,000 per year for 3 years (through 2022). As of December 31, 2022, the commitment by the CureFA Foundation and payment obligations for the COE for all three years had been met and recorded on FARA's financial statements. In 2023, FARA, also in partnership with the CureFA Foundation, signed a new agreement with the Children's Hospital of Philadelphia to contribute funds for COE research over the next three years. This agreement called for a charitable gift in the amount of \$500,000 per year for 3 years (through 2025). As of December 31, 2023, 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.

The Friedreich's Ataxia Accelerator ("FAA") at the Broad Institute of MIT and Harvard was established in 2020 with a multi-year commitment from End-FA, CureFA Foundation and FARA. The FAA comprises a portfolio of complementary projects that are creating a growing Boston-based community committed to FA research. This portfolio includes gene editing strategies, small molecule drug discovery, frataxin bypass therapeutic approaches, genetic modifier studies and cardiac research. In June 2020, FARA, in partnership with the CureFA Foundation and End-FA, signed an agreement with the Broad Institute to contribute funds for FA research over the next three years. The agreement called for a charitable gift in the amount of \$1,841,000 per year for 3 years (through 2022). As of December 31, 2022, FARA had received \$5,523,000 from co-funding partners towards the 2020, 2021, and 2022 commitments to the Broad Institute and FARA had met payment obligations of \$5,523,000. As of August 2023, FARA had received all co-funding and met payment obligations for all research activities under the original agreement, established in June 2020 along with the 2022 amendment/supplement which carried obligations into 2023. In October 2023, FARA, in partnership with the CureFA Foundation and EndFA, signed a new agreement with the Broad Institute to contribute funds for FA research for the next three years, beginning October 1, 2023. The agreement called for a charitable gift of \$1,945,086 per year for 3 years (through 2025). As of December 31, 2023, FARA has received \$1,945,086 from co-funding partners toward the October 1, 2023 first year pledge and FARA has met payment obligations of \$1,945,086.

### **NOTE L - FA GCC**

The FA GCC was launched in 2023 and is the harmonization of two clinical research consortiums and natural history studies; the Collaborative Clinical Research Network in Friedreich's Ataxia (FACOMS study) and the European Friedreich's Ataxia Consortium for Translational Studies. The mission of the FA GCC is to accelerate the development of treatments for Friedreich's Ataxia by empowering patients and researchers, understanding natural history, conducting research and developing infrastructure that facilitates clinical research across the globe. The consortium is comprised of a funding board (FARA and FARA Europe), scientific steering committee, operations and management team, working groups, patient advocacy/advisory team and the investigator members of each clinical site; participation includes investigators from 33 sites representing 18 countries.

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## **Notes to Consolidated Financial Statements December 31, 2023 and 2022**

### **NOTE L - FA GCC (CONTINUED)**

Each FA GCC clinical site is provided funding to participate in the UNIFIED Natural History Study (UNIFAI) 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.

The significant value and importance of having natural history data and a clinical research infrastructure was demonstrated in February 2023 when the first treatment for FA was approved. The approval of this treatment would not have been possible without the contribution of natural history data early in the development to inform clinical trial design and later in the process providing external control data to a study that supported regulatory approval of the drug. We believe that continued investment in clinical research infrastructure, globally, and continuation of natural history studies, are essential to accomplish our mission.

### **NOTE M - 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 \$36,390 and \$29,768 during the years ended December 31, 2023 and 2022, respectively.

### **NOTE N - RISKS AND UNCERTAINTIES**

FARA maintains its cash in bank accounts in amounts which, at times, may exceed federally insured limits. FARA has not experienced any losses in such accounts, and management believes that FARA is not exposed to any significant risk of loss on these accounts.

FARA invests in a professionally managed portfolio that contains short-term investments, U.S. Government issues, and mutual funds (equities and fixed income). Such investments are exposed to various risks, such as market and credit risks. Due to the level of risk associated with such investments, and the level of uncertainty related to changes in value of such investments, it is at least reasonably possible that changes in risk in the near term could materially affect investment balances and the amounts reported in the consolidated financial statements.

### **NOTE O - SUBSEQUENT EVENTS**

Management has evaluated subsequent events through June 18, 2024, which is the date the financial statements were available to be issued.