

Annual Financial Report

National Ataxia Foundation

St. Louis Park, Minnesota

For the years ended December 31, 2023 and 2022



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<u>Page No.</u>

Independent Auditor's Report	3
Financial Statements	
Statements of Financial Position	6
Statements of Activities	7
Statements of Functional Expenses	9
Statements of Cash Flows	11
Notes to the Financial Statements	12



INDEPENDENT AUDITOR'S REPORT

Board of Directors National Ataxia Foundation St. Louis Park, Minnesota

Opinion

We have audited the accompanying financial statements of National Ataxia Foundation (the Foundation), which comprise the statements of financial position as of December 31, 2023 and 2022, and the related statements of activities, functional expenses and cash flows for the years then ended, and the related notes to the financial statements.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of the Foundation 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. Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of the Foundation and to meet our other ethical responsibilities in accordance with the relevant ethical requirements relating to our audit. 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 the 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 the Foundation's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

Auditor's 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 auditor's 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 generally accepted auditing standards 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, including omissions, 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 generally accepted auditing standards, 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 Foundation'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 Foundation'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.

Abdo Minneapolis, Minnesota April 24, 2024



FINANCIAL STATEMENTS

National Ataxia Foundation Statements of Financial Position

December 31, 2023 and 2022

	2023	2022
Assets		
Current Assets	A A A A A A A A A A	A A A C A A A A A A A A A A
Cash and cash equivalents	\$ 1,008,716	\$ 1,969,164
Accounts receivable	6,438	55,331
Prepaid expenses Total Current Assets	<u>255,729</u> 1,270,883	<u> </u>
Total Current Assets	1,270,003	2,211,303
Noncurrent Assets		
Right-of-use asset	57,320	89,034
Investments	2,788,623	2,707,996
Total Noncurrent Assets	2,845,943	2,797,030
Total Assets	\$ 4,116,826	<u>\$ 5,008,595</u>
Liabilities and Net Assets		
Current Liabilities	A A A A A A A A A A	<u>.</u>
Accounts payable	\$ 298,827	\$ 440,809
Accrued payroll and related expenses	35,140	29,226
Deferred revenue Operating lease liability, current portion	109,810	22,291
Total Current Liabilities	<u>32,750</u> 476,527	<u> </u>
	470,527	525,674
Long-term Operating Lease Liability, Less Current Portion	25,353	58,104
Total Liabilities	501,880	581,978
Total Liabilities	501,000	501,970
Net Assets		
Without donor restriction		
Board designated - operating reserve	396,499	420,985
Undesignated	537,880	1,963,826
Total Net Assets Without Donor Restriction	934,379	2,384,811
With donor restriction	2,680,567	2,041,806
Total Net Assets	3,614,946	4,426,617
Total Liabilities and Net Assets	\$ 4,116,826	<u>\$ 5,008,595</u>

National Ataxia Foundation Statements of Activities For the Years Ended December 31, 2023 and 2022

	2023			
	Without Donor Restriction	With Donor Restriction	Total	
Support and Revenue				
Support Contributions, memorials and honorariums	\$ 1,468,504	\$ 1,614,715	\$ 3,083,219	
In-kind contributions	121,917	- · · · · ·	121,917	
Total Support	1,590,421	1,614,715	3,205,136	
Revenue				
Conference income	264,816	-	264,816	
Earned income	570,833	-	570,833	
Investment income	144,002	-	144,002	
Total Revenue	979,651		979,651	
Net Assets Released from Restrictions	975,954	(975,954)	<u> </u>	
Total Support and Revenue	3,546,026	638,761	4,184,787	
Expenses				
Program services				
Research	1,574,354	-	1,574,354	
Education and service	1,146,980	-	1,146,980	
Drug Development Collaborative	1,188,427		1,188,427	
Total Program Services	3,909,761		3,909,761	
Supporting services				
Management and general	538,079	-	538,079	
Fundraising	548,618		548,618	
Total Supporting Services	1,086,697		1,086,697	
Total Expenses	4,996,458		4,996,458	
Change in Net Assets	(1,450,432)	638,761	(811,671)	
Beginning Net Assets	2,384,811	2,041,806	4,426,617	
Ending Net Assets	<u>\$ 934,379</u>	\$ 2,680,567	<u>\$ 3,614,946</u>	

See Independent Auditor's Report and Notes to the Financial Statements.

National Ataxia Foundation Statements of Activities (Continued) For the Years Ended December 31, 2023 and 2022

		2022	
	Without Donor Restriction	With Donor Restriction	Total
Support and Revenue			
Support Contributions, memorials and honorariums	\$ 1,638,224	\$ 1,767,801	\$ 3,406,025
In-kind contributions	9,870		9,870
Total Support	1,648,094	1,767,801	3,415,895
Revenue			
Conference income	309,574	-	309,574
Earned income	800,000	-	800,000
Investment loss	(127,884)		(127,884)
Total Revenue	981,690		981,690
Net Assets Released from Restrictions	1,278,770	(1,278,770)	
Total Support and Revenue	3,908,554	489,031	4,397,585
Expenses			
Program services			
Research	1,837,520	-	1,837,520
Education and service	579,104	-	579,104
Drug Development Collaborative	943,904		943,904
Total Program Services	3,360,528		3,360,528
Supporting services			
Management and general	377,042	-	377,042
Fundraising	393,619		393,619
Total Supporting Services	770,661		770,661
Total Expenses	4,131,189		4,131,189
Change in Net Assets	(222,635)	489,031	266,396
Beginning Net Assets	2,607,446	1,552,775	4,160,221
Ending Net Assets	<u>\$ 2,384,811</u>	<u>\$ 2,041,806</u>	<u>\$ 4,426,617</u>

See Independent Auditor's Report and Notes to the Financial Statements.

National Ataxia Foundation Statements of Functional Expenses For the Years Ended December 31, 2023 and 2022

				2023			
		Program	Services		Supporting	g Services	
			Drug				
		Education	Development	Total Program	Management		
	Research	and Service	Collaborative	Services	and General	Fundraising	Total
Salaries and Related Expenses							
Salaries and wages	\$ 494,104	\$ 362,830	\$ 162,033	\$ 1,018,967	\$ 138,082	\$ 293,427	\$ 1,450,476
Payroll taxes	38,208	27,159	12,319	77,686	9,732	21,710	109,128
Fringe benefits	45,455	52,132	13,763	111,350	21,428	39,024	171,802
Total Salaries and Related Expenses	577,767	442,121	188,115	1,208,003	169,242	354,161	1,731,406
Bank and credit card fees	1,332	3,592	-	4,924	43,689	-	48,613
Development	975	43	-	1,018	2,859	500	4,377
Dues and subscriptions	5,833	2,273	-	8,106	22,422	49,882	80,410
Insurance	-	-	-	-	12,931	-	12,931
Meeting expense	168,589	521,241	969	690,799	44,865	79,814	815,478
Miscellaneous	140	3,500	-	3,640	143	1,228	5,011
Occupancy	-	-	-	-	63,895	-	63,895
Office expense	2,286	1,690	4,913	8,889	31,985	10,276	51,150
Printing, marketing and multimedia	15,155	118,687	-	133,842	45,852	29,898	209,592
Professional services	61,747	27,313	12,140	101,200	100,196	22,859	224,255
Research grants	740,530	-	982,290	1,722,820	-	-	1,722,820
Support grants	-	26,520		26,520		-	26,520
Total Expenses	\$ 1,574,354	\$ 1,146,980	\$ 1,188,427	\$ 3,909,761	\$ 538,079	\$ 548,618	\$ 4,996,458

National Ataxia Foundation Statements of Functional Expenses (Continued) For the Years Ended December 31, 2023 and 2022

				2022			
		Program	Services		Supportin	g Services	
			Drug				
		Education	Development	Total Program	Management		
	Research	and Service	Collaborative	Services	and General	Fundraising	Total
Salaries and Related Expenses							
Salaries and wages	\$ 421,058	\$ 301,183	\$ 151,075	\$ 873,316	\$ 97,636	\$ 225,018	\$ 1,195,970
Payroll taxes	30,284	22,016	10,822	63,122	6,467	16,431	86,020
Fringe benefits	37,371	45,622	11,982	94,975	20,484	30,393	145,852
Total Salaries and Related Expenses	488,713	368,821	173,879	1,031,413	124,587	271,842	1,427,842
Bank and credit card fees	-	956	-	956	44,459	-	45,415
Development	150	6	-	156	982	-	1,138
Dues and subscriptions	6,114	4,149	-	10,263	16,917	46,295	73,475
Insurance	-	-	-	-	11,737	-	11,737
Meeting expense	266,247	174,878	200	441,325	22,921	39,905	504,151
Miscellaneous	220	-	-	220	4,834	915	5,969
Occupancy	-	-	-	-	61,739	-	61,739
Office expense	3,585	281	-	3,866	28,405	5,315	37,586
Printing, marketing and multimedia	504	524	-	1,028	6,831	13,154	21,013
Professional services	60,657	26,418	17,564	104,639	52,072	16,193	172,904
Research grants	1,011,330	,	752,261	1,763,591	1,558	-	1,765,149
Support grants		3,071		3,071			3,071
Total Expenses	<u>\$ 1,837,520</u>	<u>\$ 579,104 </u>	<u>\$ 943,904</u>	\$ 3,360,528	\$ 377,042	\$ 393,619	<u>\$ 4,131,189</u>

National Ataxia Foundation Statements of Cash Flows For the Years Ended December 31, 2023 and 2022

	 2023		2022
Cash Flows from Operating Activities	 		
Change in net assets	\$ (811,671)	\$	266,396
Adjustment to reconcile change in net assets			
to net cash provided by operating activities:			
Realized and unrealized loss (gain) on investments	(75,701)		194,093
Amortization of right of use asset	31,714		30,992
Changes in assets:			
Accounts receivable	48,893		(23,917)
Prepaid expenses	(68,659)		(121,375)
Changes in liabilities:			
Accounts payable	(141,982)		388,029
Accrued payroll and related expenses	5,914		8,434
Deferred revenue	87,519		(150,209)
Operating lease liability	 (31,549)		(30,374)
Net Cash Provided (Used) by Operating Activities	 (955,522)		562,069
Cash Flows from Investing Activities			
Purchase of investments	(1,283,625)		(1,221,776)
Proceeds from sale of investments	1,278,699		1,080,423
Net Cash Used by Investing Activities	 (4,926)		(141,353)
Change in Cash and Cash Equivalents	(960,448)		420,716
Beginning Cash and Cash Equivalents	 1,969,164		1,548,448
Ending Cash and Cash Equivalents	\$ 1,008,716	\$	1,969,164

Note 1: Summary of Significant Accounting Policies

A. Nature of Activities

National Ataxia Foundation (the Foundation) was incorporated as a Minnesota nonprofit corporation in 1957. The Foundation's mission is to accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia.

To further the mission, the Foundation provides services in the following program areas:

Education and Service

Increased awareness about hereditary and sporadic ataxia disorders is promoted through a variety of education programs and materials for ataxia families, researchers, physicians, allied health professionals, government agencies, legislative officials and the general public. The Foundation publishes Generations, an annual newsletter and a monthly e-newsletter devoted to ataxia related articles including the latest research and other information beneficial to individuals with ataxia. The Foundation also offers several webinars throughout the year on current topics relevant to the ataxia community. Other educational materials, such as books, videos and fact sheets are provided to persons with ataxia, family members and health care professionals on a "direct request" basis through the NAF office. The Foundation's advocacy activities, such as Hill Days, serve to raise awareness about ataxia and policy issues impacting the ataxia community. The annual ataxia conference, and sponsorship and/or participation in national and international meetings, symposiums and seminars also serve to increase ataxia awareness.

The National Ataxia Foundation attempts to locate people and families with hereditary and sporadic ataxia in order to provide them with information about ataxia. This is accomplished by providing updated information about ataxia to the general public by maintaining a website, social media channels, newsletters, and webinars. The Foundation assists individuals and families by identifying clinical resources and making appropriate referrals for neurological care, genetic counseling and gene testing. The Foundation also assists people with locating resources within their own communities, including support groups. The Foundation's network of support groups throughout the country provides families with access to in-person and virtual meeting opportunities.

Research

NAF is committed to funding cutting-edge basic and translational research into hereditary and sporadic ataxia. The goals of NAF's research program are to further elucidate the disease mechanisms of ataxias, bring early-career clinicians and scientists into ataxia research, and help drive the field towards developing treatments and a cure for ataxia. Annual grants are selected through a competitive review process that includes NAF's Medical and Research Advisory Board members and over 80 leading ataxia scientists and clinicians, both domestic and international.

Each year NAF awards grants to researchers from domestic and international non-profit and for-profit institutions that directly support basic and translational ataxia research through the following funding mechanisms:

- Pioneer SCA3 Translational Research Awards: Annually granted to outstanding research proposals that aim to make significant advancements in the development of treatments and/or improvements to patient care for Spinocerebellar Ataxia Type 3 (SCA3). Proposals may incorporate other forms of ataxia but must have a predominant focus on SCA3 translational or clinical research.
- 2. Seed Money Research Grant: Granted primarily as "seed monies" to assist investigators in the early or pilot phase of their studies and as additional support for ongoing investigations on demonstration of need. It is hoped that these studies will be further developed to attract future funding from other sources.
- 3. Early Career Investigator Award: The Early Career Investigator Award was created to encourage early career clinical and scientific investigators to pursue a career in the field of ataxia research.

Note 1: Summary of Significant Accounting Policies (Continued)

- 4. Post-doctoral Fellowship Award: Post-doctoral fellowship awards are to serve as a bridge from post-doctoral positions to junior faculty positions. Applicants should have completed at least one year of post-doctoral training, but not more than two at the time of application and should have shown a commitment to research in the field of ataxia. The award will permit individuals to spend an additional third year in a post-doctoral position and increase chances to establish an independent ataxia research program.
- 5. Pre-doctoral Fellowship to Promote Diversity in Ataxia Research: Merit-based award intended to enhance research and/or clinical training of promising graduate students from historically underrepresented backgrounds who are matriculated in pre-doctoral or clinical health professional degree training programs and who intend careers as scientists or other clinician-scientists within the field of ataxia.
- 6. National Ataxia Foundation Graduate Research Fellowship: The National Ataxia Foundation Graduate Research Fellowship is a competitive, non-renewable, merit-based award intended to encourage pre-doctoral students to pursue research and a career in the field of ataxia.
- 7. NAF Special Grants: Based on the emergent needs of the patient and research community, priority areas of ataxia research may be identified as eligible for specialized grant funding by NAF and may be awarded outside of the annual grant programs.

In addition to NAF annual grants, NAF sponsors several clinical research programs that aim to drive advancements in the ataxia research field and prepare the ataxia community for future clinical trials. One of these programs is the Ataxia Tissue and Brain Donation Program. NAF and the University of Florida's Center for NeuroGenetics (CNG) work together to maintain a repository of brain and spinal cord tissue from ataxia donors. This tissue is available to SCA researchers to help advance our understanding of these diseases and to develop new therapies. NAF sponsors both the costs of tissue donation and maintenance costs of the brain and tissue bank.

Drug Development Collaborative

Funding for several of NAF's other key clinical research programs are provided through the NAF Drug Development Collaborative (DDC). The DDC is a pre-competitive pharmaceutical industry consortium with a principal goal of accelerating the development of treatments for ataxia. The Collaborative provides a centralized source for access to resources needed to support research and development of Ataxia therapies. Specific objectives of the Collaborative include natural history and bio sample data collection, development of biomarkers, validation of rating scales, clinical trial design, patient-reported outcomes, and other data necessary for the development and approval of safe and effective therapies. Two significant programs that are largely sponsored by the DDC include:

- No-cost Genetic Counseling and Testing Initiative: This program provides virtual genetic counseling and testing for individuals at-risk for three of the most common dominant ataxias to members at no-cost to participants. The aim of this program is to help individuals overcome barriers that have historically inhibited wide-spread genetic testing as well as support drug development through expanding the patient population eligible for future clinical trials.
- 2. Clinical Research Consortium for the Study of Cerebellar Ataxia (CRC-SCA) Natural History Study: The CRC-SCA is one of the longest running and largest natural history studies of spinocerebellar ataxias (SCAs). A natural history study collects data that shows how a specific disease progresses in individuals over time. Natural history studies are essential for developing clinical trial designs that will facilitate drug development. There are over 300 patients enrolled at 16 CRC-SCA sites in the US and Canada. During annual visits, site investigators collect critical clinical data to aid in understanding disease progression and help guide future clinical trial design. Biofluids, such as plasma, serum, and cerebrospinal fluid, are also collected from patients and stored at the NINDS SCA-BRAC biorepository. Both de-identified clinical data and biofluids are available for request from non-participating investigators for approved research projects.

Note 1: Summary of Significant Accounting Policies (Continued)

B. Basis of Accounting and Presentation

The accompanying financial statements have been prepared using the accrual basis of accounting in accordance with accounting principles generally accepted in the United States of America.

Revenues are recorded when earned and expenses are recorded when a liability is incurred. Contributions received are recorded as an increase in non-donor-restricted or donor-restricted support depending on the existence or nature of any donor restrictions. Accordingly, net assets of the Foundation and changes therein are classified and reported as follows:

Net Assets Without Donor Restriction - Those resources over which the Foundation has discretionary control.

<u>Net Assets With Donor Restriction</u> - Those resources subject to donor imposed restrictions, which are satisfied by actions of the Foundation or passage of time, or are to be maintained permanently.

C. 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.

D. Cash and Cash Equivalents

For purposes of the statement of cash flows, the Foundation considers short-term, highly liquid investments and investments purchased with a maturity of three months or less to be cash equivalents. The Foundation's cash balances held in bank depositories may exceed federally insured limits at times.

E. Investments

Investments are measured at fair value in the statements of financial position. Investment income or loss (including realized and unrealized gains and losses on investments, interest/ dividends, and investment advisory fees) is included in non-donor-restricted revenue and support unless the income or loss is restricted by donor or law.

F. Accounts Receivable

Accounts receivable consist primarily of amounts billed for services, are unsecured, and 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 the assessment of the current status of individual accounts.

The allowance estimate is derived from a review of the Foundation's historical losses based on the aging of receivables. This estimate is adjusted for management's assessment of current conditions, reasonable and supportable forecasts regarding future events, and any other factors deemed relevant by the Foundation. The Foundation believes historical loss information is a reasonable starting point in which to calculate the expected allowance for credit losses. As a result, management has determined that its allowance for credit losses should not be adjusted across any of its aging categories. Management expects to collect all balances.

G. Prepaid Expenses

Certain payments to vendors reflect costs applicable to future account periods and are recorded as prepaid items.

Note 1: Summary of Significant Accounting Policies (Continued)

H. Leases

The Foundation determines if an arrangement is a lease at inception. If an arrangement contains a lease, the Foundation performs a lease classification test to determine if the lease is an operating lease or a finance lease. Right-of-use (ROU) assets represent the right to use an underlying asset for the lease term and lease liabilities represent the Foundation's obligation to make lease payments arising from the lease. Operating lease liabilities are recognized on the commencement date of the lease based on the present value of the future lease payments over the lease term and are included in long-term liabilities and current liabilities on the statement of financial position. ROU assets are valued at the initial measurement of the lease liability, plus any indirect costs or rent prepayments, and reduced by any lease incentives and any deferred lease payments. Operating ROU assets are recorded on the face of the statement of financial position and are amortized over the lease term. To determine the present value of lease payments on lease commencement, the Foundation uses the implicit rate when readily determinable. Lease terms include options to extend or terminate the lease when it is reasonably certain that the Foundation will exercise that option. Lease expense is recognized on a straight-line basis over the life of the lease and is included within operating expenses on the statement of activities. The Foundation has made the following elections related to leases:

- The Foundation has elected to use a risk-free rate as the discount rate on all classes of underlying assets when an implicit rate is not readily available.
- The Foundation has elected the practical expedient to account for the lease and non-lease components as a single lease component for classes of underlying assets.
- The Foundation has elected to apply the short-term lease exception to all leases with a term of one year or less. Short-term leases will not be capitalized.

I. Revenue Recognition

The Foundation follows the provisions of Accounting Standards Codification 606, *Contracts with Customers* on revenues derived from its Drug Development Collaborative and conference income. In the case of the Collaborative, revenue is recognized over the collaborative period, which is over a period of one year or less. Drug Development Collaborative agreements are signed annually. Earned income received in advance of the collaborative period is reported as deferred revenue. In the case of conference income, revenue is recognized at the time the event is held, which is at a point in time. Conference income received in advance of the event is deferred revenue.

• Performance Obligations

The performance obligation related to Drug Development Collaborative is satisfied over the collaborative period; therefore, the Foundation recognizes revenue over a period of time on a monthly basis. The performance obligation related to the conference income is satisfied once the event is held; therefore, the Foundation recognizes revenue at a point in time.

Contract Balances

Deferred revenue consists of payments received in advance that relate to the Collaborative and conferences. All deferred revenue will be recognized over the next year. Deferred conference revenue was \$9,810 and \$22,290 for the years ended December 31, 2023 and 2022, respectively. Deferred Drug Development Collaborative revenue was \$100,000 and \$0 for the years ended December 31, 2023 and 2022, respectively.

The Foundation's other revenues are explicitly excluded from the scope of ASC Topic 606 and are not recorded in accordance with that standard. All contributions are considered to be available for unrestricted use unless specifically restricted by the donor. The Board's general policy is to allocate up to thirty percent of all restricted contributions for unrestricted use unless the contribution was solicited by the Foundation for a specific purpose. The board has discretion to use this allocation or waive it.

Note 1: Summary of Significant Accounting Policies (Continued)

J. Property and Equipment

Property and equipment are capitalized at cost. Depreciation is provided for using the straight-line method over the estimated useful life of the asset. The Foundation considers items with a cost greater than \$2,500 and a useful life greater than one year to be property and equipment. Items below \$2,500 are expensed when purchased.

K. Functional Expenses

The costs of providing program and other activities have been summarized on a functional basis in the statements of activities. Accordingly, certain costs have been allocated among the programs and supporting services benefited. The costs are allocated based on time spent by employees or by management's estimates.

Expense	Method of Allocation
Salaries and Benefits	Based on time allocation
Occupancy	Unallocated
Printing, marketing and multimedia	Direct expense
Professional services	Direct expense
Program expense	Direct expense
Development	Direct expense
Insurance	Direct expense
Dues and subscriptions	Direct expense
Meeting expense	Direct expense
Office expense	Direct expense
Bank and credit card fees	Direct expense
Clinical trial readiness	Direct expense
Miscellaneous	Direct expense
Research grants	Direct expense

L. Income Taxes

The Foundation is exempt from income taxes under Section 501(c)(3) of the Internal Revenue Code and is exempt from Federal and State income taxes.

M. New Accounting Pronouncements

In June 2016, the Financial Accounting Standards Board ("FASB") issued Accounting Standards Update ("ASU") No. 2016-13, *Financial Instruments – Credit Losses (Topic 326): Measurement of Credit Losses on Financial Instruments ("ASC 2016-13" or ASC 326")*, which significantly changed how entities will measure credit losses for most financial assets and certain other instruments that aren't measured at fair value through net income. The most significant change in this standard is a shift from the incurred loss model to the expected loss model. Under the standard, disclosures are required to provide users of the financial statements with useful information in analyzing an entity's exposure to credit risk and the measurement of credit losses. Financial assets held by the Foundation that are subject to the guidance in FASB ASC 326 were trade accounts receivable. The Foundation adopted the standard effective January 1, 2023. The impact of the adoption had no impact to the financial statements and primarily resulted in new, enhanced disclosures only.

N. Advertising

The Foundation follows the policy of charging the costs of advertising to expense as incurred. Advertising expense paid to vendors was \$209,592 and \$21,013 for the years ended December 31, 2023 and 2022, respectively.

Note 1: Summary of Significant Accounting Policies (Continued)

O. Subsequent Events

Subsequent events have been evaluated through April 24, 2024, which is the date the financial statements were available to be issued.

Note 2: Investments

Investment income for the year ended December 31, 2023 and 2022 consisted of the following:

	 2023	 2022
Interest/Dividend Income Unrealized/Realized Gain (Loss) on Investments Investment Advisory Fees	\$ 73,728 75,701 (5,427)	\$ 70,303 (194,093) (4,094)
Total Investment Income	\$ 144,002	\$ (127,884)

Note 3: Fair Value Investments

The Foundation has adopted ASC Topic 820, Fair Value Measurements and Disclosures. ASC Topic 820 applies to reported balances that are required or permitted to be measured at fair value under an existing accounting pronouncement. It emphasizes that fair value is a market-based measurement, not an entity-specific measurement. Therefore, a fair value measurement should be determined based on the assumptions that the market participants would use in pricing the asset or liability and establishes a fair value hierarchy. The fair value hierarchy consists of three levels of inputs that may be used to measure fair value, as follows:

Level 1 - inputs to the valuation methodology are unadjusted quoted prices for identical assets or liabilities in active market that the Foundation has the ability to access, and where transactions occur within.

Level 2 - inputs to the valuation methodology include:

- Quoted prices for similar assets or liabilities in active markets;
- Quoted prices for identical or similar assets or liabilities in inactive markets;
- Inputs, other than quoted prices, that are observable for the asset or liability;
- Inputs that are derived principally from or corroborated by observable market data by correlation or other means.
- If the asset or liability has a specified (contractual) term, the Level 2 input must be observable for substantially the full term of the asset or liability.

Level 3 - inputs to the valuation methodology reflect management's assumptions about significant unobservable inputs that market participants would use in pricing the asset or liability.

The asset's and 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. Valuation techniques used need to maximize the use of observable inputs and minimize the use of unobservable inputs.

Note 3: Fair Value Investments (Continued)

The methods above may produce a fair value calculation that may not be indicative of net realizable value or reflective of future fair value. Furthermore, while the Foundation 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.

Following is a description of the valuation methodology used for each asset measured at fair value on a recurring basis:

• Cash: Measured at cash value.

Mutual funds and stocks

- Equity Funds and Fixed income: Valued at the closing price reported in the active market in which the individual securities are traded.
- Exchange Traded Funds: Valued at the closing price reported in the active market in which the individual securities are traded.
- Money Market Funds: Measured at cost which approximates fair value.
- *Mutual Funds*: Valued at the daily closing price as reported by the fund. Mutual funds held by the Foundation are open-end mutual funds that are registered with the Securities and Exchange Commission. These funds are required to publish their daily net asset value (NAV) and to transact at that price. The mutual funds held are deemed to be actively traded.

Information regarding assets measured at fair value on a recurring basis as of December 31, 2023 and 2022 were as follows:

		20)23	
	Fair Va	lue Measurement Level 2	s Using Level 3	Total Assets Measured at Fair Value
Cash Equity funds and fixed income Exchange traded funds Money market funds Mutual funds and stocks Total Assets at Fair Value	\$ 458,604 1,206,052 47,633 10,009 1,066,325 \$ 2,788,623	\$ - - - - - -	\$ - - - - - - -	\$ 458,604 1,206,052 47,633 10,009 1,066,325 \$ 2,788,623
		20)22	
	Fair Va Level 1	lue Measurement		Total Assets Measured at Fair Value
Cash Money market funds	\$ 76,823 1,642,051	\$ - -	\$ - -	\$ 76,823 1,642,051

Total Assets at Fair Value	\$ 2,707,996	\$-	\$-	\$ 2,707,996

989,122

989,122

The Foundation does not have any liabilities measured at fair value on a recurring basis nor any assets or liabilities measured at fair value on a nonrecurring basis.

Note 4: Retirement Plan

The Foundation maintains a 401k matching plan for US employees. For December 31, 2023 and 2022, the amount of 401k matching expense was \$58,358 and \$52,528, respectively. The Foundation also matches deferrals for a Canadian employee participating in a Registered Retirement Savings Plan (RRSP). For December 31, 2023 and 2022, the amount of RRSP matching expense was \$2,448 and \$0, respectively

Note 5: Leases

Effective July 1, 2017, the Foundation entered into a property lease agreement with Interchange Investors, LLC that calls for fixed monthly base payments starting at \$2,563 per month and incrementally increasing to \$2,864 per month until expiration in September 2025. The agreement also provides that the Foundation is responsible for a proportional share of the property's incurred ownership taxes and operating expenses. The Foundation has determined that this lease is an operating lease.

The Foundation adopted FASB ASC 842, effective January 1, 2022, using a modified retrospective approach. As a result, the Foundation was required to recognize a ROU asset and corresponding lease liability on the face of the statement of financial position for the year ended December 31, 2023 and 2022.

As noted above, the Foundation's lease agreement calls for variable payments that were not determinable at the lease commencement and are not included in the measurement of the lease asset and liabilities. Variable lease payments incurred will be recognized during the year they are incurred as an operating expense.

The ROU lease asset and corresponding lease liability were calculated utilizing a risk-free discount rate of 2.333%, according to the Foundation's elected policy. The Foundation's lease agreement does not contain any material residual value guarantees or material restrictive covenants.

Additional information about the Foundation's lease for the year ended December 31, 2023, is as follows:

Lease expense (included in operating expenses) Operating lease expense Variable lease expense	\$	33,406 27,997
Total Lease Expense:	\$	61,403
Other Information Cash paid for amounts included in the measurement of lease liabilities Operating cash flows from operating leases Weighted-average remaining lease term in years for operating leases Weighted-average discount rate for operating leases	\$	33,240 1.75 2.333%
Future minimum payments for leases are as follows:		
Year Ended December 31,	A	mount
2024 2025 Total undiscounted cash flows Less: present value discount	\$	33,693 25,552 59,245 (1,142)
Total Lease Liabilities	\$	58,103

Note 6: Net Assets with Donor Restrictions

Net assets with donor restrictions were available for the following purposes at December 31:

	 2023		2022	
SCA2 Fund MR Imaging Study Fund	\$ 880,250 612,044	\$	500,000	
General Research (Includes stock) CSO Funding SCA3 Clementz	394,144 360,800 291,120		385,387 450,588 340,604	
AAC Travel Grant SCA3	122,635 13,143		138,542 138,333	
MSA Friedreich's Fund	3,848		3,848 6,279	
SCA27B Fund CRC SCA I	379		44,415	
Million \$ Research Fund	 -		33,810	
Total	\$ 2,680,567	Ş	2,041,806	

Note 7: Board Designated Net Assets

Board designated net assets are designated for the purpose of an operating reserve. Board designated net assets are \$396,499 and \$420,985 as of December 31, 2023 and 2022, respectively.

Note 8: Concentrations

From time to time, the Foundation's cash balances at financial institutions exceed Federal Deposit Insurance Corporation ("FDIC") insurance limits of \$250,000. In the years ending December 31, 2023 and 2022, the Foundation exceeded that limit by \$721,725 and \$3,113,980, respectively. Management does not believe this presents a significant risk to the Foundation.

Note 9: In-kind Contributions

The Foundation's in-kind contributions consist of the following in 2023 and 2022:

	 20232022		Usage in 2022 Programs/Activities		Fair Value Techniques		
Google and Microsoft Advertising Grants	\$ 121,917	\$	-	Programs and Fundraising	Estimated wholesale price of identical or similar products		
Website Services	 -		9,870	Management and General	Estimated wholesale price of identical or similar products		
Total In-kind Contributions	\$ 121,917	\$	9,870				

The in-kind contributions as of December 31, 2023 and 2022 had no donor restrictions.

Note 10: Liquidity and Availability of Financial Assets

Financial assets available for general expenditure, that is, without donor or other restrictions limiting their use, within one year of the statement of financial position dates, comprise the following:

	2023	2022
Cash and cash equivalents	\$ 1,008,716	\$ 1,969,164
Investments	2,788,623	2,707,996
Accounts receivable	6,438	55,331
Total Financial Assets Available Within One Year	3,803,777	4,732,491
Less: Amounts unavailable for general expenditures within one year due to:		
Board designated	(396,499)	(420,985)
Restricted by donors	(2,680,567)	(2,041,806)
Financial assets available to meet general expenditures within one year	\$ 726,711	\$ 2,269,700

As part of our liquidity management, the Foundation structures its financial assets to be available as its general expenditures, liabilities, and other obligations become due. The Foundation invests cash in excess of monthly requirements in short-term investments such as money market funds, certificates of deposit, savings accounts, or other similar investments.