FAMILIES OF SPINAL MUSCULAR ATROPHY
D/B/A CURE SMA

FINANCIAL STATEMENTS

JUNE 30, 2024

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INDEPENDENT AUDITORS' REPORT

Board of Directors
Families of Spinal Muscular Atrophy d/b/a Cure SMA
Elk Grove Village, Illinois

Opinion

We have audited the accompanying financial statements of FAMILIES OF SPINAL MUSCULAR ATROPHY D/B/A CURE SMA (an Illinois nonprofit organization), which comprise the statements of financial position as of June 30, 2024 and 2023, 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 FAMILIES OF SPINAL MUSCULAR ATROPHY D/B/A CURE SMA as of June 30, 2024 and 2023, 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 Auditors' Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of FAMILIES OF SPINAL MUSCULAR ATROPHY D/B/A CURE SMA 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.

Change in Accounting Principle

As more fully described in Note 1 to the financial statements, as of July 1, 2023, management adopted a new accounting principle that prescribes the recognition, measurement, presentation, and disclosure requirements related to the allowance for credit losses. Our opinion is not modified with respect to this matter.

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 FAMILIES OF SPINAL MUSCULAR ATROPHY D/B/A CURE SMA's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

Auditors' Responsibilities for the Audits 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 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 FAMILIES OF SPINAL MUSCULAR ATROPHY D/B/A CURE SMA'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 FAMILIES OF SPINAL MUSCULAR ATROPHY D/B/A CURE SMA'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.

Warady & Davis LLP

November 12, 2024

STATEMENTS OF FINANCIAL POSITION

As of June 30	2024	2023
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	**$ 3,808,783**	$ 4,602,807
Grants Receivable, net of Allowance for Doubtful Accounts of $22,000 and $25,000	**2,286,361**	1,826,782
Pledges Receivable, net of Allowance for Doubtful Accounts of $19,000 and $20,000	**355,728**	853,144
Accounts Receivable, net of Allowance for Credit Losses of $8,000 and $7,000	**513,662**	526,391
Deferred Expenses	**223,881**	1,702,133
Total Current Assets	**7,188,415**	9,511,257
PROPERTY AND EQUIPMENT, NET	**161,593**	253,762
NONCURRENT ASSETS		
Pledges Receivable, net of Discount	**844,693**	726,879
Operating Lease Right-of-Use Asset, net of Accumulated Amortization of $123,972 and $69,865	**177,967**	232,074
Security Deposits and Other Assets	**6,344**	6,344
Intangibles, net of Accumulated Amortization of $964,734 and $1,020,686	**33,647**	131,096
Investments	**2,291,309**	1,851,892
	3,353,960	2,948,285
	$ 10,703,968	$ 12,713,304
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts Payable	**$ 2,662,120**	$ 515,659
Grants Payable	**1,245,367**	1,542,929
Accrued Expenses	**660**	1,488,384
Accrued Payroll and Related Expenses	**103,453**	288,729
Accrued Vacation	**196,196**	181,292
Operating Lease Liability	**60,816**	57,207
Deferred Revenue	**—**	1,465,456
Total Current Liabilities	**4,268,612**	5,539,656
LONG-TERM LIABILITIES		
Grants Payable, net	**175,854**	181,928
Operating Lease Liability, net	**138,173**	198,989
Total Long-Term Liabilities	**314,027**	380,917
Total Liabilities	**4,582,639**	5,920,573
NET ASSETS		
Without Donor Restrictions	**1,424,129**	1,566,462
With Donor Restrictions - Time and Purpose	**2,558,327**	3,301,558
With Donor Restrictions - Endowment	**2,138,873**	1,924,711
Total Net Assets	**6,121,329**	6,792,731
	$ 10,703,968	$ 12,713,304

See accompanying notes.

STATEMENTS OF ACTIVITIES

For the Years Ended June 30	**2024**				2023			
		With Donor Restrictions				With Donor Restrictions		
	Without Donor Restrictions	**Time and Purpose**	**Endowment In Perpetuity**	**Total**	Without Donor Restrictions	Time and Purpose	Endowment In Perpetuity	Total
SUPPORT AND REVENUE								
Contributions								
Contributions and Grants	**$ 420,104**	**$ 4,191,126**	**$ 214,162**	**$ 4,825,392**	$ 606,915	$ 5,238,584	$ 315,342	$ 6,160,841
In-Kind Contributions	**113,890**			**113,890**	217,731			217,731
	533,994	**4,191,126**	**214,162**	**4,939,282**	824,646	5,238,584	315,342	6,378,572
Chapter Events								
Special Events Revenue	**3,172,043**			**3,172,043**	3,572,220			3,572,220
Donated Special Event Auction Items	**59,005**			**59,005**	84,870			84,870
Less: Event Expenses	**(428,448)**			**(428,448)**	(390,606)			(390,606)
	2,802,600			**2,802,600**	3,266,484			3,266,484
Program Revenues								
Summit of Strength Symposiums	**682,501**			**682,501**	677,500			677,500
Industry Sponsored Research	**1,581,564**			**1,581,564**	1,138,250			1,138,250
Annual Conference	**4,694,448**			**4,694,448**	2,166,179			2,166,179
	6,958,513			**6,958,513**	3,981,929			3,981,929
Other Revenues								
Grant Forfeitures	**10,547**			**10,547**	48,777			48,777
Employee Retention Credit Interest	**60,454**			**60,454**	48,224			48,224
Investment Income (Loss), net	**(781)**	**222,977**		**222,196**	(2,658)	125,476		122,818
Other Income	**55,168**			**55,168**	38,795			38,795
Total Other Revenues	**125,388**	**222,977**		**348,365**	133,138	125,476		258,614
Net Assets Released from Restrictions	**5,157,334**	**(5,157,334)**		**—**	4,389,841	(4,389,841)		—
Total Support and Revenues	**15,577,829**	**(743,231)**	**214,162**	**15,048,760**	12,596,038	974,219	315,342	13,885,599
Expenses								
Program Services	**12,493,257**			**12,493,257**	11,523,757			11,523,757
Management and General	**1,352,444**			**1,352,444**	1,272,690			1,272,690
Fundraising	**1,874,461**			**1,874,461**	1,527,141			1,527,141
Total Expenses	**15,720,162**			**15,720,162**	14,323,588			14,323,588
CHANGE IN NET ASSETS	**(142,333)**	**(743,231)**	**214,162**	**(671,402)**	(1,727,550)	974,219	315,342	(437,989)
Net Assets, Beginning of Year	**1,566,462**	**3,301,558**	**1,924,711**	**6,792,731**	3,294,012	2,327,339	1,609,369	7,230,720
NET ASSETS, ENDING	**$ 1,424,129**	**$ 2,558,327**	**$ 2,138,873**	**$ 6,121,329**	$ 1,566,462	$ 3,301,558	$ 1,924,711	$ 6,792,731

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES

For the Year Ended June 30, 2024

	Research	Patient Services	Community Support	Awareness	Total Program Services	Management and General	Fundraising	Event Expenses	Total
Salaries	$ 798,560	$ 943,351	$ 831,935	$ 431,428	$ 3,005,274	$ 702,851	$ 1,200,049	$ —	$ 4,908,174
Payroll Taxes	57,165	67,530	59,554	30,884	215,133	50,313	85,905	—	351,351
Employee Benefits	81,047	95,742	84,435	43,786	305,010	71,333	121,795	—	498,138
Advertising	9,113	4,556	6,076	4,556	24,301	4,502	4,556	—	33,359
Bank Charges, Credit Card and Other Fees	—	—	—	—	—	91,321	44,029	—	135,350
Conferences and Meetings	45,552	140,024	4,783,927	436	4,969,939	144,781	59,467	128,013	5,302,200
Depreciation and Amortization	5,520	206,843	127,195	2,982	342,540	4,858	8,295	—	355,693
Dues and Subscriptions/Publications	—	—	—	—	—	19,710	5,500	—	25,210
Equipment Grants and Care Packages	—	—	101,596	—	101,596	—	—	—	101,596
Equipment Rental	—	—	8,790	—	8,790	15,336	—	—	24,126
Insurance Expense	7,907	9,341	8,238	4,272	29,758	20,209	11,883	—	61,850
Miscellaneous	—	—	—	—	—	1,513	—	—	1,513
Occupancy	19,946	23,562	20,779	10,776	75,063	17,555	29,974	46,227	168,819
Office Expenses	7,277	2,339	5,198	3,378	18,192	1,819	5,977	43,076	69,064
Prizes and Promotional Items	18,500	—	3,813	—	22,313	5,541	—	193,061	220,915
Professional Services	169,113	96,559	12,631	8,210	286,513	87,013	14,525	—	388,051
Research Grants	1,465,102	495,608	—	—	1,960,710	—	—	—	1,960,710
Shipping Expense	27,445	68,614	123,504	13,723	233,286	13,723	27,445	—	274,454
Staff Development/Training	3,696	4,366	3,851	1,997	13,910	3,253	5,554	—	22,717
Stationery and Printing	38,663	57,994	67,660	19,330	183,647	—	9,666	—	193,313
Technology	157,617	50,663	112,584	73,178	394,042	39,404	129,471	—	562,917
Telephone and Internet	10,148	11,988	10,573	5,483	38,192	8,933	15,250	—	62,375
Travel	48,956	57,833	51,003	26,449	184,241	43,089	73,570	18,071	318,971
Website	5,387	5,387	37,710	32,323	80,807	5,387	21,550	—	107,744
	2,976,714	2,342,300	6,461,052	713,191	12,493,257	1,352,444	1,874,461	428,448	16,148,610
Less: Event Expenses on Statements of Activities	—	—	—	—	—	—	—	(428,448)	(428,448)
TOTALS	$ 2,976,714	$ 2,342,300	$ 6,461,052	$ 713,191	$ 12,493,257	$ 1,352,444	$ 1,874,461	$ —	$ 15,720,162

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES (Continued)

For the Year Ended June 30, 2023

	Research	Patient Services	Community Support	Awareness	Total Program Services	Management and General	Fundraising	Event Expenses	Total
Salaries	$ 757,847	$ 927,986	$ 800,382	$ 397,446	$ 2,883,661	$ 720,801	$ 969,148	$ —	$ 4,573,610
Payroll Taxes	52,958	64,847	55,930	27,773	201,508	50,369	67,723	—	319,600
Employee Benefits	74,677	91,443	78,869	39,164	284,153	71,027	95,499	—	450,679
Advertising	57,150	28,575	38,100	28,576	152,401	15,157	28,575	—	196,133
Bad Debt Expense	—	—	—	—	—	2,000	—	—	2,000
Bank Charges, Credit Card and Other Fees	—	—	—	—	—	76,092	38,328	—	114,420
Conferences and Meetings	31,527	50,282	2,907,995	288	2,990,092	106,413	36,677	119,417	3,252,599
Depreciation and Amortization	7,549	39,736	175,659	2,868	225,812	6,989	5,198	—	237,999
Dues and Subscriptions/Publications	—	—	—	—	—	18,750	5,598	—	24,348
Equipment Grants and Care Packages	—	—	76,027	—	76,027	—	—	—	76,027
Equipment Rental	—	—	—	—	—	12,926	—	—	12,926
Insurance Expense	7,642	9,357	8,071	4,007	29,077	17,796	9,772	—	56,645
Miscellaneous	—	—	—	—	—	648	—	389	1,037
Occupancy	14,870	18,208	15,704	7,797	56,579	14,143	19,016	42,874	132,612
Office Expenses	6,821	2,192	4,872	3,166	17,051	1,705	5,603	27,800	52,159
Prizes and Promotional Items	60,379	—	2,017	—	62,396	196	586	187,682	250,860
Professional Services	302,096	182,178	10,063	6,541	500,878	57,544	11,572	—	569,994
Research Grants	2,091,809	953,682	—	—	3,045,491	—	—	—	3,045,491
Shipping Expense	23,992	59,979	107,962	11,996	203,929	11,996	23,992	—	239,917
Staff Development/Training	5,802	7,104	6,127	3,042	22,075	5,518	7,419	—	35,012
Stationery and Printing	36,763	55,145	64,336	18,381	174,625	—	9,191	—	183,816
Technology	142,738	45,880	101,956	66,271	356,845	35,685	117,249	—	509,779
Telephone and Internet	11,207	13,723	11,836	5,878	42,644	10,659	14,332	—	67,635
Travel	33,038	40,456	34,893	17,327	125,714	31,423	42,250	12,444	211,831
Website	4,853	4,853	33,973	29,120	72,799	4,853	19,413	—	97,065
	3,723,718	2,595,626	4,534,772	669,641	11,523,757	1,272,690	1,527,141	390,606	14,714,194
Less: Event Expenses on Statements of Activities	—	—	—	—	—	—	—	(390,606)	(390,606)
TOTALS	$ 3,723,718	$ 2,595,626	$ 4,534,772	$ 669,641	$ 11,523,757	$ 1,272,690	$ 1,527,141	$ —	$ 14,323,588

STATEMENTS OF CASH FLOWS

For the Years Ended June 30	2024	2023
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in Net Assets	**$ (671,402)**	$ (437,989)
Adjustments to Reconcile Change in Net Assets to Net Cash Used by Operating Activities		
Depreciation	**136,644**	184,666
Amortization	**219,049**	53,333
Amortization of Operating Lease Right-of-Use Asset	**54,107**	69,865
Stock Donations	**(154,608)**	(132,407)
Proceeds from Sale of Stock Donations	**152,040**	132,407
Net Realized Loss on Sales of Donated Stocks	**2,568**	—
Net Unrealized and Realized Gain on Investments	**(179,661)**	(95,246)
Donor-Restricted Endowment Contributions	**(214,162)**	(315,342)
Change in Allowances for Uncollectible Amounts	**(3,000)**	2,000
Changes in Assets and Liabilities:		
Grants Receivable	**(456,579)**	1,456,295
Pledges Receivable	**380,602**	(1,546,022)
Accounts Receivable	**11,729**	—
Other Receivables	—	122,677
Deferred Expenses	**1,478,252**	(1,608,914)
Operating Lease Right-of-Use Asset	—	(301,939)
Accounts Payable	**2,080,961**	2,729
Grants Payable	**(303,636)**	(320,615)
Accrued Expenses	**(1,487,724)**	272,836
Accrued Payroll and Related Expenses	**(185,276)**	207,069
Accrued Vacation	**14,904**	(9,590)
Operating Lease Liability	**(57,207)**	256,196
Deferred Revenue	**(1,465,456)**	1,465,456
Deferred Rent	—	(20,247)
Total Adjustments	**23,547**	(124,793)
Net Cash Used by Operating Activities	**(647,855)**	(562,782)
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of Property and Equipment	**(45,518)**	(164,288)
Capitalization of Intangibles	**(55,057)**	(84,670)
Purchases of Investments	**(749,035)**	(647,050)
Proceeds from Sales of Investments	**489,279**	301,478
Net Cash Used by Investing Activities	**(360,331)**	(594,530)
CASH FLOWS FROM FINANCING ACTIVITIES		
Donor-Restricted Endowment Contributions	**214,162**	315,342
NET DECREASE IN CASH AND CASH EQUIVALENTS	**(794,024)**	(841,970)
Cash and Cash Equivalents, Beginning	**4,602,807**	5,444,777
CASH AND CASH EQUIVALENTS, ENDING	**$ 3,808,783**	$ 4,602,807
SUPPLEMENTAL DISCLOSURES OF NONCASH OPERATING, INVESTING AND FINANCING ACTIVITIES		
Donated Services	**$ 22,700**	$ 131,571
Donated Goods and Supplies	—	85,460
Rent-Free use of Signage, Furniture and Accessories	**91,190**	—
Equipment Purchases in Payables	**5,900**	—
Intangibles Acquired Included in Payables	**59,600**	—
Donated Medical Devices Granted to Program Recipients	—	700
Donated Special Event Auction Items	**59,005**	84,870
	$ 238,395	$ 302,601
Construction in Progress from the Prior Year Reclassified to Intangibles	**$ 12,400**	$ 14,140

See accompanying notes.

NOTES TO FINANCIAL STATEMENTS

NATURE OF ORGANIZATION

Families of Spinal Muscular Atrophy d/b/a Cure SMA (the Organization) is an Illinois not-for-profit organization. The Organization’s efforts include advancing research, to provide patient and family support, and to promote public awareness with regard to the disease Spinal Muscular Atrophy (SMA). The Organization’s major sources of revenues are contributions, grants and program service fees from its annual conference and summit of strength symposiums. There were no concentrations of revenue or receivables from individual donors as of and for the year ended June 30, 2024. For the year ended June 30, 2023 two corporations and one foundation accounted for 55% of total receivables.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

This summary of significant accounting policies is presented to assist in understanding the Organization’s financial statements which have been prepared on the accrual basis of accounting. The financial statements and notes are representations of management who is responsible for their integrity and objectivity. These accounting policies conform to accounting principles generally accepted in the United States of America as applicable to nonprofit organizations and have been consistently applied in the preparation of the financial statements.

BASIS OF PRESENTATION

Financial statement preparation follows the requirements of the Financial Accounting Standards Board (FASB) Codification for “Financial Statements of Not-for-Profit Organizations”. Under the standards, the Organization is required to report information regarding its financial position and activities into two classes of net assets: net assets without donor restrictions and net assets with donor restrictions.

Net assets without donor restrictions - Net assets that are not subject to donor-imposed stipulations plus those resources for which donor-imposed stipulations have been satisfied. Net assets without donor restrictions may otherwise be designated for specific purposes by action of the Board of Directors.

Net assets with donor restrictions – Net assets subject to donor-imposed stipulations that may or will be met either by actions of the Organization (purpose restrictions) and/or the passage of time (time restrictions). As the restrictions are satisfied, net assets with donor restrictions are reclassified to net assets without donor restrictions and are reported in the accompanying statements of activities as net assets released from restrictions.

Additionally, net assets with donor restrictions may be stipulated by donors to be maintained in perpetuity. Investment income, including realized and unrealized gains and losses, are classified as time restricted net assets until those amounts are appropriated for expenditure by the Organization in a manner consistent with the standard of prudence prescribed by the Uniform Prudent Management of Institutional Funds Act (UPMIFA), unless a donor's contribution stipulates otherwise.

Revenues are reported as increases in net assets without donor restrictions unless use of the related asset is limited by donor-imposed restrictions. Expenses are reported as net assets without donor restrictions.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

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 the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenue and expenses during the reporting period. Actual results may differ from those estimates.

REVENUE RECOGNITION, GRANTS, PLEDGES AND OTHER RECEIVABLES

Contributions, including organization grants, and corporate and individual donations, are available for general use unless specifically restricted by the donor. Unconditional promises to give due in the next year are reflected as current pledges receivable and are recorded at their net realizable value. Unconditional promises to give due in future years are reflected as long-term pledges and are recorded at their net present value, using interest discount rates applicable to the years in which the promises are received. Conditional promises to give are not recorded as a receivable or recognized as revenue until the conditions are met.

Grants and contributions of cash and other assets are reported as restricted support if they are received with donor stipulations that limit the use of the donated assets. When a grantor or donor restriction expires, that is, when a stipulated time restriction ends or purpose restriction is satisfied, net assets with donor restriction are reclassified to net assets without donor restriction and reported in the statements of activities as net assets released from restrictions.

An allowance for uncollectible receivables is provided based upon management’s judgment, including such factors as prior collection history, type of revenue, composition of the individual receivables, and current economic conditions. For the allowance on its accounts receivable from program revenues, management also factors in supportable and reasonable future forecasts.

When all attempts to collect a receivable have failed, the receivable is written off against the allowance or bad debt expense.

The Employee Retention Credit (ERC) was enacted in 2020 under the CARES Act and was significantly expanded and extended for all of 2021 by the American Rescue Plan Act. The purpose of this refundable credit is to help businesses keep employees on payroll by offsetting some of the associated costs. ERC is conditional on the Organization meeting certain employer eligibility criteria, as well as incurring qualifying expenses with specific per-employee caps. As such, the Organization is accounting for the ERC as a conditional government grant under Accounting Standards Codification (ASC) 958-605. The remaining ERC receivable as of June 30, 2024 and 2023 totals $294,268, and is included in grants receivable on the statements of financial position. In addition, the Organization accrued $60,335 of interest receivable as of June 30, 2024, pursuant to an Internal Revenue Service (IRS) notice awarding that much of interest in addition to approving the entire outstanding ERC receivable claimed. The $354,603 total of ERC receivable and interest were collected in August 2024.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

REVENUE RECOGNITION, GRANTS, PLEDGES AND OTHER RECEIVABLES (Continued)

The Organization's program service fees are comprised of exhibit space sales, tickets and sponsorships payments for the Organization's annual conference event and summit of strength symposiums. In exchange, the Organization provides exhibit space, access to the events' symposiums and meetings, educational live and recorded webinars and social events, numerous recorded virtual programs, presentations on the latest SMA research, care and support developments, opportunities to host meetings and connect with the SMA families, and opportunities to conduct surveys, polling and Q&A sessions, among others. As all of these benefits are transferred during the days that the events take place, the revenues are recorded over the length of the related events, which are typically between one and five days. During 2023, the Organization's annual conference was held over five days between June 28 and July 2. The Organization prorated the revenues and expenses associated with its 2023 annual conference based on the number of days in each fiscal year. The prorated revenue of 40% for the two days of the conference that fell in the June 30, 2024 fiscal year are not reported as revenue for the fiscal year ending June 30, 2023. That amount of $1,465,456 is reported as deferred revenue at June 30, 2023 on the statements of financial position and recognized in annual conference revenue for the year ended June 30, 2024. Program service fees recognized over time are $5,376,949 and $2,843,679 for the years ended June 30, 2024 and June 30, 2023, respectively.

Balances are due prior to the commencement of each event. Amounts, if any, received prior to the end of the fiscal year for the next year's annual conference, or summit of strength symposiums are reported as deferred revenue on the statements of financial position at year-end. All such programs and activities occur typically within the same fiscal year as the payments are received. There are no contracts which contain variable consideration and there are very few, if any, contract modifications.

The Organization also has contracts with pharmaceutical companies for delivery of certain data in six-month intervals, where both the expected data to be transferred and the customer payments for each subsequent data tranche after the second increase proportionately. The Organization recognizes the revenue allocated to each performance obligation at the point in time when it completes such performance obligation by delivering the specified data to the customer. The total of such revenue recognized at a point in time and reported as industry sponsored research on the statements of activities amounted to $1,581,564 and $1,138,250 for the years ended June 30, 2024 and June 30, 2023, respectively.

Special events revenue, which includes registration fees, sponsorships, and purchases of auction items, is recorded as revenue when the event occurs, equal to the amounts received. If the amount is received in advance, the portion considered a direct benefit is deferred until the event occurs and is presented in deferred revenue on the statements of financial position, while the contribution portion, which is the excess amount paid over the direct benefit, is recorded when received unless considered conditional on the event taking place, in which case it is deferred.

IN-KIND CONTRIBUTIONS AND VOLUNTEER SUPPORT

Contributions of donated services that create or enhance non-financial assets or that require specialized skills, are provided by individuals possessing those skills, and would typically need to be purchased if not provided by donation, are recorded at their fair values in the period received. The valuation is based on prevailing hourly rates in the Chicagoland area for the same kind of donated professional services.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

IN-KIND CONTRIBUTIONS AND VOLUNTEER SUPPORT (Continued)

Gifts of goods and supplies, medical equipment and medical devices to be distributed to program participants are recorded at estimated fair value on the date of the gift using either the principal or the most advantageous market. The Organization values the items utilizing publicly available website pricing for selling identical or similar products and factoring the condition of the donated items. The Organization received donated in-kind contributions of $113,890, comprised of $22,700 of donated professional accounting services, included in professional services, and $91,190 of rent-free use of signage, furniture and accessories, included in conferences and meetings on the statements of functional expenses for the year ended June 30, 2024. The Organization received donated in-kind contributions of $217,731, comprised of donated goods and supplies of $85,460, of which $7,990 included in prizes and promotional items and $77,470 included in conferences and meetings, medical devices received and granted to program recipients of $700 included in equipment grants and care packages, and $131,571 of donated professional services, of which $120,000 of donated advertising is included in advertising expense, $10,250 of donated accounting services, included in professional services and $1,321 of donated printing, included in stationery and printing on the statements of functional expenses for the year ended June 30, 2023. All of the above in-kind contributions were utilized in the Organization’s program and supporting services.

Donated special event auction items are valued at the gross selling price received and totaled $59,005 and $84,870 for the years ended June 30, 2024 and 2023, respectively. All donated auction items were monetized.

There were no donor-imposed restrictions associated with the in-kind contributions received during the years ended June 30, 2024 and 2023.

A number of unpaid volunteers and members of the Board of Directors donate their time to ensure success of the Organization's activities. The value of these services is not reflected in these financial statements since they do not meet the criteria for recognition under the FASB Codification topic related to accounting for contributions received and made.

CASH EQUIVALENTS

The Organization considers all highly-liquid investments with an original maturity of three months or less when purchased to be cash equivalents.

INVESTMENTS

The Organization follows the provisions of the FASB Codification for accounting for investments held by not-for-profit organizations. This standard requires that investments in marketable securities be accounted for at fair value. Fair value is based on quoted market prices. Realized gains and losses are the differences between the proceeds received and the cost of investments sold. Unrealized gains and losses are the differences between the fair value and the cost of investments and are included in net investment income. Due to the long-term nature of many of the donor-restricted and board-designated endowment net assets that are included in the investment portfolio, investments are classified as noncurrent.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

PROPERTY AND EQUIPMENT

Property and equipment purchases of $1,000 or more are recorded at cost. Donated assets are recorded at their fair market value on the date of donation. Depreciation is calculated on the straight-line method over the estimated useful lives of the assets ranging from 3 to 5 years. Major renewals and betterments, which extend the useful life of an asset, are capitalized while routine maintenance and repairs are expensed as incurred.

INTANGIBLE ASSETS

The Organization capitalizes intellectual property, and other intangible costs of $1,000 or more with useful lives of greater than a year. Intangible assets are comprised of software, website and a data registry platform which has been capitalized as intellectual property. These costs are amortized over their estimated useful lives (typically three years) using the straight-line method. Amortization expense was $219,049 for the year ended June 30, 2024 and $53,333 for the year ended June 30, 2023.

Amortization expense for the next two years is:

Year Ending June 30	
2025	$ 32,059
2026	1,588
	$ 33,647

FUNCTIONAL ALLOCATION OF EXPENSES

The costs of providing program and support services have been reported on a functional basis in the statements of activities. Expenses are charged directly to programs, management and general, or fundraising categories based upon specific identifications. Accordingly, certain costs have been allocated among the programs and supporting services benefited, based on direct charges or appropriate methods determined by management. The primary method used in the allocation of shared costs is allocating personnel, and any other related costs based on estimates of time and effort spent by employees on the different functional categories.

LEASES

The Organization determines if an arrangement is a lease or contains a lease at the inception of the contract. The Organization’s operating lease is presented under the captions operating lease right-of-use asset, current portion of operating lease liability, and long-term portion of operating lease liability.

Right-of-use (ROU) assets represent the Organization’s right to use an underlying asset for the lease term and lease liabilities represent its obligation to make lease payments arising from the lease. Operating lease ROU assets and liabilities are recognized at the commencement date and subsequent lease modification date based on the present value of lease payments over the lease term. As the Organization’s lease agreement did not provide an implicit rate, management used a risk-free rate of return in determining the present value of the lease payments, a practical expedient allowed under this standard. The operating lease ROU asset also includes any lease prepayments made and excludes lease incentives.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

LEASES (Continued)

The lease terms may include options to extend or terminate the lease when it is reasonably certain that the Organization will exercise that option. Lease expense for lease payments is recognized on a straight-line basis over the lease term and reported in occupancy on the statements of functional expenses. The difference between actual lease payments and the straight-line of lease expense, as well as any tenant allowances are reflected as a reduction to the ROU asset on the statements of financial position.

The lease agreements do not contain any material residual value guarantees or material restrictive covenants. The Organization has elected to utilize all of the available practicable expedients allowed under U.S. Generally Accepted Accounting Principles (GAAP).

RECENTLY ADOPTED ACCOUNTING GUIDANCE – CREDIT LOSSES

In June 2016, the FASB issued guidance (ASC 326) which significantly changed how entities will measure credit losses (bad debts) 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 Organization that are subject to the guidance in ASC 326 are the Organization's accounts receivable resulting from exchange transactions. The Organization's allowances for uncollectible receivables from non-exchange transactions, which are the Organization's grants and pledges receivable are specifically excluded from the scope of this new standard.

Management adopted the standard effective July 1, 2023 utilizing the modified retrospective transition method. The Organization has historically experienced insignificant credit losses and was already recording an allowance for doubtful accounts on all accounts receivable, based on historical data, factoring the changes in current conditions, and the current composition of its receivables. Therefore, the adoption of this standard did not have a material impact on the Organization's financial statements and only marginally changed its methodology for determining the allowance for credit losses to also consider supportable and reasonable future forecasts.

NOTE 2—LIQUIDITY AND AVAILABILITY OF RESOURCES

Financial assets available for general expenditure, that is, without donor or other restrictions limiting their use, within one year of the statements of financial position date, are comprised of the following at June 30:

	2024	2023
Cash and Cash Equivalents	$ **3,808,783**	$ 4,602,807
Grants Receivable, net	**2,286,361**	1,826,782
Pledges Receivable, net	**1,200,421**	1,580,023
Accounts Receivable, net	**513,662**	526,391
Investments	**2,291,309**	1,851,892
Less: Net Assets with Donor Restrictions – Time and Purpose	**(2,558,327)**	(3,301,558)
Less: Net Assets with Donor Restrictions – Endowment	**(2,138,873)**	(1,924,711)
	$ **5,403,336**	$ 5,161,626

NOTE 2—LIQUIDITY AND AVAILABILITY OF RESOURCES (Continued)

As part of its liquidity management plan, the Organization attempts to maintain sufficient cash to meet current operating needs. As indicated in the above chart, assuming revenue is consistent in subsequent years, the Organization has sufficient liquid assets to meet at least one year of expenses.

NOTE 3—CONCENTRATIONS OF CREDIT RISK

The Organization maintains cash and cash equivalents with financial institutions, which at times, may exceed federally insured limits. The Organization has not experienced any losses in such accounts. Thus, management believes the Organization is not exposed to any significant credit risk on cash and cash equivalents.

Credit risk associated with grants, pledges and accounts receivables is considered to be limited due to high historical collection rates and because substantial portions of the outstanding amounts are due from pharmaceutical and other large corporations supportive of the Organization's mission and the employee retention credit, part of grants receivable, is due from the IRS.

The Organization's investments are exposed to various risks such as interest rate, credit and overall market volatility. Due to these risk factors, it is reasonably possible that changes in the fair value of investments will occur in the near term and materially affect the amounts reported in the financial statements.

NOTE 4—PLEDGES RECEIVABLE

Pledges receivable represent unconditional promises to give and consist of amounts receivable at June 30:

	2024	2023
Less than One Year	**$ 374,728**	$ 873,144
One to Five Years	**600,000**	500,000
More than Five Years	**400,000**	400,000
	1,374,728	1,773,144
Less: Discount to Net Present Value	**155,307**	173,121
Less: Allowance for Doubtful Accounts	**19,000**	20,000
	174,307	193,121
Net Pledges Receivable	**1,200,421**	1,580,023
Less: Current Portion, net of Allowance for Doubtful Accounts	**355,728**	853,144
Long-Term Portion	**$ 844,693**	$ 726,879

The discount rate used in determining the net present value of long-term pledges receivable was 5.3% and 4.5% for the years ended June 30, 2024 and 2023, respectively.

NOTE 5—PROPERTY AND EQUIPMENT

At June 30, property and equipment consist of the following:

	2024	2023
Office Equipment	$ 48,944	$ 41,716
Office Furniture	47,246	47,246
Medical Equipment	1,197,488	1,157,773
Construction in Process	5,458	12,400
	1,299,136	1,259,135
Less: Accumulated Depreciation	1,137,543	1,005,373
Total	$ 161,593	$ 253,762

Depreciation expense was $136,644 for the year ended June 30, 2024 and $184,666 for the year ended June 30, 2023.

NOTE 6—INVESTMENTS

Investments at June 30 consist of the following:

	2024	2023
Mutual Funds and Exchange Traded Funds (ETF)		
Equity Funds		
Mid Cap	$ 198,568	$ 139,124
Index	684,681	462,990
Large Cap	63,424	34,797
Small Cap	95,933	80,526
International Large Growth	138,539	100,393
International Large Value	54,737	49,402
Total Equity Funds	1,235,882	867,232
Alternative Investments – Mutual Funds	132,869	151,938
Money Market Fund	131,587	330,748
Fixed Income Funds – Intermediate Term Bond Fund	790,971	501,974
Total Investments	$ 2,291,309	$ 1,851,892

NOTE 6—INVESTMENTS (Continued)

Investment income is comprised of the following for the year ended June 30:

	2024	2023
Net Realized Gains (Losses)	$ 14,032	$ (1,218)
Net Unrealized Gains	165,228	96,464
Interest and Dividends	58,529	38,783
Investment Expenses	(15,593)	(11,211)
Total Investment Income, net	$ 222,196	$ 122,818

NOTE 7—FAIR VALUE MEASUREMENTS

Fair value is defined as the exchange price that would be received for an asset or paid to transfer a liability (an exit price) in the principal or most advantageous market for the asset or liability in an orderly transaction between market participants on the measurement date.

The FASB Codification provides a framework for measuring fair value using a three-level hierarchy that prioritizes the inputs to valuation techniques used to measure fair value based upon the transparency of inputs to the valuation of an asset or liability as of the measurement date. The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets or liabilities (Level 1 measurements) and the lowest priority to unobservable inputs (Level 3 measurements). The three levels of the fair value hierarchy are described below:

Level 1 Inputs to the valuation methodology are unadjusted quoted prices for identical assets or liabilities in active markets that the Organization has the ability to access.

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 are unobservable and significant to the fair value measurement.

The asset's or liability's fair value measurement level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. Valuation techniques used need to maximize the use of observable inputs and minimize the use of unobservable inputs.

NOTE 7—FAIR VALUE MEASUREMENTS (Continued)

Following is a description of the valuation methodologies used for assets measured on a recurring basis at fair value. There have been no changes in the methodologies used at June 30, 2024 and 2023.

Level 1 Fair Value Measurements

All investments of the Organization are measured at Level 1. Exchange-traded funds traded on a national exchange or on the national market system of NASDAQ are valued at their last reported sale price or, if there has been no sale on that date, at the closing "bid" price if long, or closing "ask" price if short.

Mutual funds are valued at their market values, which are determined daily and are quoted on a national exchange.

Level 2 Fair Value Measurements

The Organization has no Level 2 fair value measurements.

Level 3 Fair Value Measurements

The Organization has no Level 3 fair value measurements.

NOTE 8—GRANTS PAYABLE

The Organization makes grants to various medical and research centers for research in relation to Spinal Muscular Atrophy. Grant agreements are subject to periodic reporting and compliance requirements and can be rescinded by the Organization if it is determined that a research project is no longer academically, technically, or commercially feasible.

The Organization's grants supported clinical care data collection to better understand SMA care. The Cure SMA Care Center Network kicked off in 2018. The goal of the SMA Care Center Network is to gather and disseminate new knowledge to advance the SMA standard of care for children and adults. These grantee centers provided patient consented electronic medical record data and electronic case report forms to the CURE SMA clinical data registry. Due to increasing costs and inefficiencies in data collection through the electronic medical record, Cure SMA closed the clinical data registry and related grant program effective June 2024.

The Organization is responsible for all costs incurred or committed at the time of termination. Research grant expense for the year ended June 30, 2024 was $1,960,710 and $3,045,491 for the year ended June 30, 2023.

As of June 30, 2024, the Organization's unconditional grants payable obligations have terms expiring through January 2026. Long-term grants are discounted to net present value. As of June 30, 2024, grants payable obligations amounted to $1,421,221 with a discount on long-term grants payable of $4,396, netted in that total at June 30, 2024. The discount rate used in determining the net present value of long-term grants payable at June 30, 2024 was 2.5%. As of June 30, 2023, the Organization's unconditional grants payable obligations have terms expiring through February 2025. Long-term grants are discounted to net present value. As of June 30, 2023, grants payable obligations amounted to $1,724,857 with a discount on the long-term grants payable of $4,548, netted in that total. The discount rate used in determining the net present value of long-term grants payable at June 30, 2023 was 2.5%.

NOTE 9—NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions as of June 30 are restricted for the following:

	2024	2023
Research	**$ 1,044,693**	$ 1,232,715
Annual Chapter Meeting	**233,398**	225,000
Scholarships	**—**	140,000
Equipment Pool and Care Packages	**244,805**	60,029
Directions Newsletter	**45,000**	22,500
Industry Collaboration	**467,768**	325,309
Congressional Dinner	**—**	57,500
Walk-n-Roll Program	**—**	12,500
Continuing Medical Education	**—**	50,000
Real World Evidence Collaboration	**189,440**	1,081,824
Technology Program	**63,064**	40,000
Children's Programs	**—**	10,000
Fundraising Support Staff	**120,000**	—
Care Center Network	**—**	117,000
Accumulated Endowment Fund Earnings (Losses)	**150,159**	(72,819)
	$ 2,558,327	$ 3,301,558

Net assets released from restrictions for the years ended June 30, were as follows:

	2024	2023
Research	**$ 746,354**	$ 647,270
Annual Chapter Meeting	**291,602**	225,000
Scholarships	**215,000**	75,000
Equipment Pool and Care Packages	**92,653**	166,157
Directions Newsletter	**22,500**	45,000
Walk-n-Roll	**257,500**	170,000
Industry Collaboration	**1,357,540**	1,357,537
Congressional Dinner	**130,000**	102,500
Continuing Medical Education	**50,000**	—
Advocacy Activities	**70,000**	—
Children's Programs	**35,000**	—
Pediatric Neuromuscular Clinical Research Network	**—**	335,000
Real World Evidence Collaboration	**1,697,586**	986,142
Technology Program	**6,936**	10,262
Info Packets	**—**	31,973
Care Center Network	**117,000**	123,000
Virtual Resources	**—**	20,000
Other	**67,663**	95,000
Total	**$ 5,157,334**	$ 4,389,841

NOTE 10—ENDOWMENT FUNDS

The Organization maintains two endowment funds consisting of gifts restricted by donors to be held in perpetuity. The Organization follows the Illinois Uniform Prudent Management of Institutional Funds Act (IUPMIFA) and its own governing documents. IUPMIFA requires the Organization to prudently manage its endowment funds. A majority of the Organization’s endowment contributions are subject to a specific agreement with the Organization.

During 2012, the Organization entered into an agreement with a donor to establish an endowment fund for the purpose of providing scholarships to cover the fees to attend the Organization's annual conference for any families of patients newly diagnosed with Spinal Muscular Atrophy. During the fiscal year ending June 30, 2022, the agreement was modified, so that effective December 2021, the appropriations for expenditure from the fund must be used for the purpose of launching up to two new care centers per year. To the extent that the Organization has established all the care centers deemed appropriate by its Board of Directors, any excess appropriated annual funds shall then be allocated to fund a portion of the direct costs of operating all care centers. The agreement requires the following: (a) all earnings of the endowment fund are reinvested into the corpus of the endowment, (b) no withdrawals from the endowment fund are allowed if the fund balance is less than $1,000,000, (c) up to 2.5% of the fund may be withdrawn, if the fund balance is above $1,000,000 but less than $2,000,000, so long as such withdrawal does not reduce the fund balance below $1,000,000, (d) up to 5% of the fund may be withdrawn, if the fund balance is above $2,000,000.

In 2019, the Organization entered into an agreement with a donor to establish an endowment fund for the purpose of providing support to the Care Center Network. Income earned from investments, including net realized and unrealized gains and losses and interest and dividends, is recorded in the net asset class owning the assets, except for net assets with donor restrictions in perpetuity where the income is recorded as with donor restrictions – time and purpose and then reclassified to without donor restrictions upon appropriation for expenditure.

As a result of this interpretation, the Organization classifies as net assets with donor restrictions in perpetuity (1) the original value of gifts donated to the permanent endowment, (2) the original value of subsequent gifts to the permanent endowment and (3) accumulations to the permanent endowment made in accordance with the direction of the applicable donor gift instrument at the time the accumulation is added to the fund.

The Organization's investment guidelines and policies are overseen by members of the finance committee reporting to the Organization's Board of Directors. The overall investment objective of the Organization is to maximize the return on invested assets while minimizing risk and expenses. This is done through prudent investing and planning, as well as through the maintenance of a diversified portfolio. Investments shall be diversified with a view to minimizing risk. Investments in the equity securities of any one company shall not exceed 5% of the portfolio nor shall the total securities position (debt and equity) in any one company exceed 10% of the portfolio. No more than 25% of the entire portfolio may be invested in the securities of any one sector. The assets of the Organization have a long investment time horizon.

NOTE 10—ENDOWMENT FUNDS (Continued)

The primary investment objective of the portfolio is to grow the corpus in excess of inflation and to meet the current and future obligations as dictated by the Organization's spending objectives. This objective is to be achieved through the establishment of an optimal portfolio structure and through the retention of quality investment managers capable of meeting the specific performance goals of the Organization. The investment portfolio is expected to achieve the following over rolling five year periods: (a) provide an annualized rate of return that will support the spending policy net of inflation, (b) outperform the return of a hypothetical portfolio composed of indexes weighted according to the target allocation, (c) outperform the median manager in a universe of organizations and endowments, (d) the volatility of returns, as measured by the standard deviation of quarterly returns, should be comparable to that of the benchmark index.

Endowment net asset composition by type of fund as of June 30, 2024 is as follows:

		With Donor Restrictions		
	Without Donor Restrictions	Time and Purpose Restrictions	Endowment in Perpetuity	Total
Donor-Restricted Endowment Funds	$ —	$ 150,159	$ 2,138,873	$ 2,289,032

Changes in endowment net assets for the year ended June 30, 2024 are as follows:

		With Donor Restrictions		
	Without Donor Restrictions	Time and Purpose Restrictions	Endowment in Perpetuity	Total Endowment Net Assets
Endowment Net Assets (Deficit), Beginning of Year	$ —	$ (72,819)	$ 1,924,711	$ 1,851,892
Contributions and Grants	—	—	214,162	214,162
Investment Income, net of Fees	—	43,317	—	43,317
Net Realized and Unrealized Gain	—	179,661	—	179,661
Endowment Net Assets, End of Year	$ —	$ 150,159	$ 2,138,873	$ 2,289,032

From time-to-time, certain donor-restricted endowment funds may have fair values less than the amount required to be maintained by donors or by law (underwater endowments).

At June 30, 2023, one fund with an original gift value of $95,581 and fair value of $93,369 had such a deficiency of $2,212, which is reported in the net assets with time and purpose restriction. As of June 30, 2023, the second endowment fund had $1,829,130 of original gifts from donors and unappropriated prior year endowment earnings, which in accordance with the endowment agreement had to be transferred to the corpus of the permanently restricted endowment. The fund had a fair value of $1,758,523 as of June 30, 2022, and a deficiency of $70,607, which is also reported in the net assets with time and purpose restriction.

NOTE 10—ENDOWMENT FUNDS (Continued)

Although Organization management has interpreted UPMIFA to permit spending from underwater endowments in accordance with prudent measures required under law, the Organization elected not to appropriate any funds for spending from its underwater funds during the years ended June 30, 2024 and 2023.

At June 30, 2024, there were no underwater endowment funds.

Endowment net asset composition by type of fund as of June 30, 2023 is as follows:

	Without Donor Restrictions	With Donor Restrictions: Time and Purpose Restrictions	With Donor Restrictions: Endowment in Perpetuity	Total
Donor-Restricted Endowment Funds	$ —	$ (72,819)	$ 1,924,711	$ 1,851,892

Changes in endowment net assets for the year ended June 30, 2023 are as follows:

	Without Donor Restrictions	With Donor Restrictions: Time and Purpose Restrictions	With Donor Restrictions: Endowment in Perpetuity	Total Endowment Net Assets
Endowment Net Assets (Deficit), Beginning of Year	$ —	$ (198,295)	$ 1,609,369	$ 1,411,074
Contributions and Grants	—	—	315,342	315,342
Investment Income, net of Fees	—	27,571	—	27,571
Net Realized and Unrealized Gains	—	97,905	—	97,905
Endowment Net Assets (Deficit), End of Year	$ —	$ (72,819)	$ 1,924,711	$ 1,851,892

NOTE 11—RETIREMENT PLAN

The Organization sponsors a 401(k) retirement plan for all eligible employees immediately upon their date of hire. The plan provides for employer profit-sharing contributions for full-time and part-time employees that are immediately 100% vested. The Organization's contribution to the plan was $134,936 for 2024 and $133,899 for 2023.

NOTE 12—CHAPTERS

The Organization has established chapters consisting of volunteers who promote local and regional fund-raising and outreach efforts for the Organization by hosting events in their respective states and regions. As of June 30, 2024 and 2023, there were 37 and 36 active chapters, respectively throughout the United States. Fund-raising and patient service support activities are coordinated by the staff of the Organization, and revenue and expenses related to all such activities are included in the accompanying statements of activities.

NOTE 13—INCOME TAXES

Families of Spinal Muscular Atrophy d/b/a CURE SMA is qualified as a charitable organization exempt from federal income taxes under provisions of the Internal Revenue Code as entities described in Section 501(c)(3) and is similarly classified by the State of Illinois.

The Organization follows the guidance in the FASB Codification topic related to uncertainty in income taxes which prescribes a comprehensive model for recognizing, measuring, presenting and disclosing in the financial statements uncertain tax positions that the Organization has taken or expects to take in its tax returns. Under the guidance, the Organization may recognize the tax benefit from an uncertain tax position only if it is "more likely than not" that it is sustainable, based on its technical merits. The tax benefits recognized in the financial statements from such a position should be measured based on the largest benefit that has a greater than 50% likelihood of being realized upon ultimate settlement with a taxing authority having full knowledge of all relevant information. Management believes that the Organization has appropriate support for the positions taken on its returns.

NOTE 14—OPERATING LEASES

In February 2022, the Organization entered into a lease agreement for office space in Elk Grove Village, Illinois, expiring July 2027 with rent abatement for the first five months, March through July 2022. Monthly base rental payments commence at $5,114 per month and increase on March 1 of every year by approximately 3% per annum, plus variable monthly charges for the Organization's share of operating expenses and real estate taxes. The Organization also leases warehouse storage on a month-to-month basis. The fixed and variable lease payments under the warehouse storage and office lease are included in occupancy on the statements of functional expenses.

In March 2021, the Organization entered into a noncancelable operating lease for a postage machine, with twenty-one quarterly base rent payments of $248, plus variable insurance and maintenance charges per quarter through June 2026. In May 2022, an operating lease was entered into for copier equipment, with sixty-three base rent payments of $865, plus variable monthly maintenance, insurance and overage charges through August 2028.

Lease expense consists of fixed base rents, plus a variable component, which includes operating expenses, utilities and real estate taxes for the office lease, and maintenance, insurance and overage charges for the equipment leases. The fixed and variable rental payments under the copier and postage machine leases are reported as equipment rental on the statements of functional expenses.

The components of lease expense included in operating expenses are comprised of the following for the years ended June 30:

	2024	2023
Fixed Lease Cost	**$ 78,079**	$ 57,990
Variable Operating Lease Expense	**54,952**	39,306
Total Operating Lease Cost (Rent)	**$ 133,031**	$ 97,296

In addition, the Organization rents furniture and equipment on a short-term basis for meetings and special events. The Organization has applied a practical expedient allowing it to exclude all such leases from the computation of its ROU asset, the lease liability balances and footnote disclosures. The related expense, although reported on the statements of functional expenses is excluded from the lease cost disclosed above.

NOTE 14—OPERATING LEASES (Continued)

The operating lease ROU asset and liability are calculated utilizing a risk-free rate of return, utilizing another practical expedient permitted under GAAP.

As of June 30, 2024 the operating lease ROU asset and the lease liability balances are as follows:

Operating Lease Right-of-Use Asset	$ 177,967
Operating Lease Liability	$ 198,989
Less: Current Portion	60,816
Long-Term Portion	$ 138,173
Weighted-Average Remaining Lease Term (Years)	3.1
Weighted Average Discount Rate	2.9%
Cash Paid for Amounts Included in Measuring Operating Lease Liability for the Year Ended June 30, 2024:	
Operating Cash Flows from Operating Lease	$ 63,840
Right-of-Use Asset Obtained in Exchange for Lease Obligation:	
Operating Lease	$ —

Future minimum lease payments of the above operating leases as of June 30, 2024 are as follows:

Year Ending June 30	
2025	$ 77,132
2026	79,104
2027	79,452
2028	7,486
	$ 243,174

As of June 30, 2023 the operating lease ROU asset and the lease liability balances are as follows:

Operating Lease Right-of-Use Asset	$ 232,074
Operating Lease Liability	$ 256,196
Less: Current Portion	57,207
Long-Term Portion	$ 198,989
Weighted-Average Remaining Lease Term (Years)	4.1
Weighted Average Discount Rate	2.9%
Cash Paid for Amounts Included in Measuring Operating Lease Liability for the Year Ended June 30, 2023:	
Operating Cash Flows from Operating Lease	$ 56,867
Right-of-Use Asset Obtained in Exchange for Lease Obligation:	
Operating Lease	$ 301,939

NOTE 15—RECLASSIFICATIONS

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

NOTE 16—SUBSEQUENT EVENTS

Management has evaluated subsequent events through November 12, 2024, the date on which the financial statements were available for issuance.

The Organization’s office lease was amended, with terms contingent on the landlord’s closing on the sale of the building before September 30, 2024. The building’s actual sale closing date was July 15, 2024, causing the amended terms of the lease to come into effect. A key change is that the lease’s new expiration date is December 31, 2025, or at an earlier date specified by the Organization at its discretion. The amendment also calls for a compensation fee of $225,000 payable to the Organization for the early termination, of which 50% is due upon closing on the sale and the remainder upon the early expiration date and surrender of the premises by the Organization. The early termination fee was not accrued as of June 30, 2024, as the amount was still contingent on the closing of the property. Similarly, the lease modification was not effective until July 15, 2024 and will result in remeasurement of the Organization’s operating lease ROU asset and lease liability during the fiscal year ending June 30, 2025. The Organization’s management is currently negotiating a lease agreement for a new office and management expects to surrender the old office space prior to December 31, 2024.

There were no other subsequent events which require disclosure.