

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

FINANCIAL STATEMENTS

JUNE 30, 2025



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

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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, 2025 and 2024, 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, 2025 and 2024, 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.

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.

A handwritten signature in black ink that reads "Warady & Davis LLP". The signature is cursive and fluid, with a ampersand symbol between "Warady" and "Davis".

November 11, 2025

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

STATEMENTS OF FINANCIAL POSITION

As of June 30

2025

2024

ASSETS

CURRENT ASSETS

Cash and Cash Equivalents	\$ 4,762,767	\$ 3,808,783
Grants Receivable, net of Allowances for Doubtful Accounts of \$9,000 and \$22,000	1,078,196	2,286,361
Pledges Receivable, net of Allowances for Doubtful Accounts of \$20,000 and \$19,000	799,750	355,728
Accounts Receivable, net of Allowances for Credit Losses of \$8,000 and \$8,000	628,861	513,662
Deferred Expenses	226,893	223,881
Total Current Assets	<u>7,496,467</u>	<u>7,188,415</u>
PROPERTY AND EQUIPMENT, NET	<u>59,085</u>	<u>161,593</u>
NONCURRENT ASSETS		
Pledges Receivable, net of Discount	676,624	844,693
Operating Lease Right-of-Use Asset, net of Accumulated Amortization of \$301,939 and \$123,972	—	177,967
Security Deposits and Other Assets	19,994	6,344
Intangibles, net of Accumulated Amortization of \$77,593 and \$964,734	1,588	33,647
Investments	2,391,493	2,291,309
Total Noncurrent Assets	<u>3,089,699</u>	<u>3,353,960</u>
	\$ 10,645,251	\$ 10,703,968

LIABILITIES AND NET ASSETS

CURRENT LIABILITIES

Accounts Payable	\$ 1,347,594	\$ 2,662,120
Grants Payable	1,201,221	1,245,367
Accrued Expenses	78,754	660
Accrued Payroll and Related Expenses	216,771	103,453
Accrued Vacation	199,445	196,196
Operating Lease Liability	—	60,816
Total Current Liabilities	<u>3,043,785</u>	<u>4,268,612</u>

LONG-TERM LIABILITIES

Grants Payable, net	178,977	175,854
Operating Lease Liability, net	—	138,173
Total Long-Term Liabilities	<u>178,977</u>	<u>314,027</u>
Total Liabilities	<u>3,222,762</u>	<u>4,582,639</u>

NET ASSETS

Without Donor Restrictions	2,609,833	1,424,129
With Donor Restrictions - Time and Purpose	2,670,455	2,558,327
With Donor Restrictions - Endowment	2,142,201	2,138,873
Total Net Assets	<u>7,422,489</u>	<u>6,121,329</u>
	\$ 10,645,251	\$ 10,703,968

See accompanying notes.

STATEMENTS OF ACTIVITIES

FAMILIES OF SPINAL MUSCULAR ATROPHY DB/A CURE SMA

For the Years Ended June 30	2025			2024		
	Without Donor Restrictions	With Donor Restrictions		Without Donor Restrictions	With Donor Restrictions	
	Time and Purpose	Time	Endowment In Perpetuity	Total	Time and Purpose	Endowment In Perpetuity
SUPPORT AND REVENUE						
Contributions						
Contributions and Grants	\$ 692,644	\$ 4,225,546	\$ 3,328	\$ 4,921,518	\$ 420,104	\$ 214,162
In-Kind Contributions	105,740	798,384	4,225,546	5,027,258	113,890	4,825,392
Chapter Events					533,994	113,890
Special Events Revenue	3,217,926			3,217,926	4,191,126	214,162
Donated Special Event Auction Items	121,509			121,509	53,005	3,172,043
Less: Event Expenses	(483,069)			(483,069)	(428,448)	(428,448)
	<u>2,856,366</u>			<u>2,856,366</u>	<u>2,802,600</u>	<u>2,802,600</u>
Program Revenues						
Summit of Strength Symposiums	815,000			815,000	682,501	682,501
Industry Sponsored Research	1,533,049			1,533,049	1,581,864	1,581,864
Annual Conference	4,504,249			4,504,249	4,694,448	4,694,448
	<u>6,912,298</u>			<u>6,912,298</u>	<u>6,958,513</u>	<u>6,958,513</u>
Other Revenues						
Grant Forfeitures	1,019			1,019	10,547	10,547
Employee Retention Credit Interest	167			167	60,454	60,454
Investment Income (Loss), net	78,771	218,282		297,053	(781)	222,977
Hotel Commissions	159,514			159,514	—	222,196
Lease Cancellation Income	112,500			112,500	—	—
Other Income	41,374			41,374	55,168	55,168
Total Other Revenues	333,345	218,282		611,627	125,388	222,977
Net Assets Released from Restrictions	4,331,700	(4,331,700)		—	5,157,334	(5,157,334)
Total Support and Revenues	<u>15,292,093</u>	<u>112,128</u>	<u>3,328</u>	<u>15,407,549</u>	<u>15,577,829</u>	<u>15,048,760</u>
Expenses						
Program Services	10,922,659			10,922,659	12,493,257	12,493,257
Management and General	1,305,150			1,305,150	1,352,444	1,352,444
Fundraising	1,878,580			1,878,580	1,874,461	1,874,461
Total Expenses	<u>14,106,389</u>			<u>14,106,389</u>	<u>15,720,162</u>	<u>15,720,162</u>
CHANGE IN NET ASSETS	1,185,704	112,128	3,328	1,301,160	(142,333)	214,162
Net Assets, Beginning of Year	1,424,129	2,558,327	2,138,873	6,121,329	1,566,462	1,924,711
NET ASSETS, END OF YEAR	\$ 2,609,833	\$ 2,670,455	\$ 2,142,201	\$ 7,422,489	\$ 1,424,129	\$ 6,121,329

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES

FAMILIES OF SPINAL MUSCULAR ATROPHY DB/A CURE SMA

For the Year Ended June 30, 2025

	Research	Community Support	Advocacy	Total	Program Services	Management and General	Fundraising	Event Expenses	Total
Salaries	\$ 1,589,129	\$ 821,347	\$ 415,017	\$ 2,825,493	\$ 724,832	\$ 1,275,453	\$ 92,231	\$ 4,825,778	
Payroll Taxes	11,491.4	59,394	30,011	204,319	52,414	—	—	348,964	
Employee Benefits	167,417	86,530	43,722	297,669	76,362	134,370	—	508,401	
Advertising	13,399	5,935	4,466	23,820	4,806	4,466	—	33,092	
Depreciation and Amortization	27,114	90,740	3,076	120,930	5,372	9,453	—	135,755	
Bank Charges, Credit Card, and Other Fees	—	—	—	—	87,298	40,333	—	127,631	
Conferences and Meetings	140,885	3,210,494	—	3,351,379	115,465	27,997	184,650	3,679,491	
Dues and Subscriptions/Publications	—	—	11,475	11,475	10,338	7,097	—	28,910	
Equipment Grants and Care Packages	—	196,619	—	196,619	—	—	—	196,619	
Equipment Rental	—	7,868	—	7,868	14,267	—	—	22,135	
Insurance Expense	10,760	5,561	2,809	19,130	16,163	8,636	—	43,929	
Miscellaneous	—	—	—	—	16,500	—	—	16,500	
Occupancy	40,510	20,938	10,580	72,028	18,476	32,514	48,703	171,721	
Office Expenses	4,359	2,356	1,532	8,247	825	2,710	16,967	28,749	
Prizes and Promotional Items	37,245	—	—	37,245	4,157	—	216,586	257,988	
Professional Services	501,969	15,348	9,976	527,293	69,096	17,650	—	614,039	
Research Grants	2,368,243	—	—	2,368,243	—	—	—	2,368,243	
Shipping Expense	72,893	93,719	10,413	177,025	10,414	20,826	—	208,265	
Staff Development/Training	7,231	3,737	1,889	12,857	3,298	5,804	—	21,959	
Stationery and Printing	58,945	41,261	11,789	111,995	—	5,894	—	117,889	
Technology	166,962	90,250	58,662	315,874	31,586	103,787	—	451,247	
Telephone and Internet	15,345	7,931	4,007	27,283	6,999	12,316	—	46,598	
Travel	67,417	34,845	17,607	119,869	30,749	54,110	16,163	220,891	
Website	11,466	40,133	34,399	85,998	5,733	22,933	—	114,664	
Less: Event Expenses on Statements of Activities	5,416,203	4,835,026	671,430	10,922,659	1,305,150	1,878,580	483,069	14,589,458	
	\$ 5,416,203	\$ 4,835,026	\$ 671,430	\$ 10,922,659	\$ 1,305,150	\$ 1,878,580	\$ —	\$ 14,106,389	
							(483,069)	(483,069)	

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES (Continued)

For the Year Ended June 30, 2024

FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA

	Research	Patient Services	Community Support	Awareness	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	56,313	55,905	—	351,351
Employee Benefits	81,047	95,712	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
Depreciation and Amortization	5,520	206,843	127,195	2,982	342,540	4,858	8,295	—	355,693
Conferences and Meetings	45,352	140,024	4,783,927	436	4,969,939	144,781	59,467	128,013	5,302,200
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
<i>Less: Event Expenses on Statements of Activities</i>	<i>2,976,714</i>	<i>2,342,300</i>	<i>6,461,052</i>	<i>713,191</i>	<i>12,493,257</i>	<i>1,352,444</i>	<i>1,874,461</i>	<i>428,448</i>	<i>16,148,610</i>
	\$ 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.

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

STATEMENTS OF CASH FLOWS

For the Years Ended June 30	2025	2024
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in Net Assets	<u>\$ 1,301,160</u>	<u>\$ (671,402)</u>
Adjustments to Reconcile Change in Net Assets to Net Cash Provided (Used) by Operating Activities		
Depreciation and Amortization	135,755	355,693
Amortization of Operating Lease Right-of-Use Asset	177,967	54,107
Stock Donations	(4,975)	(154,608)
Proceeds from Sale of Stock Donations	5,022	152,040
Net Realized (Gain) Loss on Sales of Donated Stock	(47)	2,568
Net Unrealized and Realized Gain on Investments	(163,099)	(179,661)
Donor-Restricted Endowment Contributions	(3,328)	(214,162)
Changes in Allowance for Uncollectible Amounts	(12,000)	(3,000)
Changes in Assets and Liabilities:		
Grants Receivable	1,221,165	(456,579)
Pledges Receivable	(276,953)	380,602
Accounts Receivable	(115,199)	11,729
Deferred Expenses	(3,012)	1,478,252
Security Deposits	(13,650)	—
Accounts Payable	(1,314,526)	2,080,961
Grants Payable	(41,023)	(303,636)
Accrued Expenses	78,094	(1,487,724)
Accrued Payroll and Related Expenses	113,318	(185,276)
Accrued Vacation	3,249	14,904
Operating Lease Liability	(198,989)	(57,207)
Deferred Revenue	—	(1,465,456)
Total Adjustments	<u>(412,231)</u>	<u>23,547</u>
Net Cash Provided (Used) by Operating Activities	<u>888,929</u>	<u>(647,855)</u>
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of Property and Equipment	(1,188)	(45,518)
Capitalization of Intangible Assets	—	(55,057)
Purchases of Investments	(408,121)	(749,035)
Proceeds from Sales of Investments	<u>471,036</u>	<u>489,279</u>
Net Cash Provided (Used) by Investing Activities	<u>61,727</u>	<u>(360,331)</u>
CASH FLOWS FROM FINANCING ACTIVITIES		
Donor-Restricted Endowment Contributions	<u>3,328</u>	<u>214,162</u>
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS	953,984	(794,024)
Cash and Cash Equivalents, Beginning	<u>3,808,783</u>	<u>4,602,807</u>
CASH AND CASH EQUIVALENTS, ENDING	<u>\$ 4,762,767</u>	<u>\$ 3,808,783</u>
SUPPLEMENTAL DISCLOSURES OF NONCASH OPERATING, INVESTING AND FINANCING ACTIVITIES		
Donated Services	\$ 23,250	\$ 22,700
Rent-Free use of Signage, Furniture, and Accessories	82,490	91,190
Equipment Purchases in Payables	—	5,900
Intangible Assets Acquired Included in Accounts Payable	—	59,600
Donated Special Event Auction Items	<u>121,509</u>	<u>59,005</u>
	<u>\$ 227,249</u>	<u>\$ 238,395</u>
Construction in Progress from the Prior Year Reclassified to		
Office Equipment	\$ 5,458	\$ —
Intangible Assets	<u>—</u>	<u>12,400</u>
	<u>\$ 5,458</u>	<u>\$ 12,400</u>

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 contracts, its annual conference and summit of strength symposiums.

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 (U.S. GAAP) 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 (the Board).

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.

NOTES TO FINANCIAL STATEMENTS

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 periods in which the promises are received. Conditional promises to give are not recorded as receivables, 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 restrictions are reclassified to net assets without donor restrictions 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, current economic conditions, and subsequent collections. 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.

NOTES TO FINANCIAL STATEMENTS

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

REVENUErecognition, GRANTS, PLEDGES AND OTHER RECEIVABLES (Continued)

The Organization's program service fees are comprised of exhibit space sales, tickets and sponsorship 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, crossing two fiscal years. The Organization prorated the revenues and expenses associated with its 2023 annual conference based on the number of days that fell in each of the two fiscal years. The prorated revenue of 40% for the two days of the conference that fell in the June 30, 2024 fiscal year were not reported as revenue for the fiscal year ending June 30, 2023. That amount of \$1,465,456 was reported as deferred revenue at June 30, 2023 on the statements of financial position and recognized in annual conference revenue during the year ended June 30, 2024. Similarly, expenses of \$1,534,091, representing 40% of the total incurred during this conference, were also deferred to and recognized during the fiscal year ending June 30, 2024.

Program service fees recognized over time are \$5,319,249 and \$5,376,949 for the years ended June 30, 2025 and June 30, 2024, 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 \$1,593,049 and \$1,581,564 for the years ended June 30, 2025 and June 30, 2024, 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 also deferred.

NOTES TO FINANCIAL STATEMENTS

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

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.

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 \$105,740, comprised of \$23,250 of donated professional accounting services, included in professional services, and \$82,490 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, 2025. 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 expense for the year ended June 30, 2024. 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 \$121,509 and \$59,005 for the years ended June 30, 2025 and 2024, 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, 2025 and 2024.

A number of unpaid volunteers and members of the Board 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 most of the donor-restricted and board-designated endowment net assets that are included in the investment portfolio, investments are classified as noncurrent.

NOTES TO FINANCIAL STATEMENTS

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

PROPERTY AND EQUIPMENT

Property and equipment purchases of \$1,000 or more are recorded at cost (increased to \$2,500 or more, effective July 1, 2024). 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 estimated 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 \$32,059 for the year ended June 30, 2025 and \$219,049 for the year ended June 30, 2024. Amortization expense for the year ending June 30, 2026 will be \$1,588.

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.

During the year ended June 30, 2025, the Organization restructured their programs and departments to better align with their broader strategic plan, consolidating the prior “research” and “patient services” programs into a single category. The two prior programs are presented separately on the statement of functional expenses for the year ended June 30, 2024. Their consolidated new program is presented as “research” on the statement of functional expenses for the year ended June 30, 2025. In addition, the former “awareness” program has been renamed to “advocacy” on the statement of functional expenses for the year ended June 30, 2025.

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.

NOTES TO FINANCIAL STATEMENTS

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 payable by the lessor 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. GAAP.

ALLOWANCE FOR DOUBTFUL ACCOUNTS AND CREDIT LOSSES

Grants receivable, pledges receivable, and accounts receivable are each stated net of an allowance for uncollectible accounts, at the amount management expects to collect from outstanding balances based on historical data, factoring any changes in current conditions, subsequent receipts, and reasonable and supportable future forecasts. Management provides for probable uncollectible amounts through a charge to bad debt expense and a credit to a valuation allowance. Balances that are still outstanding after management has used reasonable collection efforts are written off through a charge to the valuation allowance and a credit to the appropriate receivable. As of June 30, 2025, the allowance on grants receivable, pledges receivable, and accounts receivable is \$9,000, \$20,000, and \$8,000, respectively. As of June 30, 2024, the allowance on grants receivable, pledge receivable, and accounts receivable is \$22,000, \$19,000, and \$8,000, respectively.

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:

	2025	2024
Cash and Cash Equivalents.....	\$ 4,762,767	\$ 3,808,783
Grants Receivable, net	1,078,196	2,286,361
Pledges Receivable, net	1,476,374	1,200,421
Accounts Receivable, net.....	628,861	513,662
Investments.....	2,391,493	2,291,309
Less: Net Assets with Donor Restrictions – Time and Purpose	(2,670,455)	(2,558,327)
Less: Net Assets with Donor Restrictions – Endowment.....	<u>(2,142,201)</u>	<u>(2,138,873)</u>
	<u>\$ 5,525,035</u>	<u>\$ 5,403,336</u>

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.

NOTES TO FINANCIAL STATEMENTS

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:

	2025	2024
Less than One Year	\$ 819,750	\$ 374,728
One to Five Years	<u>492,000</u>	600,000
More than Five Years	<u>300,000</u>	400,000
	<u>1,611,750</u>	<u>1,374,728</u>
Less: Discount to Net Present Value.....	115,376	155,307
Less: Allowance for Doubtful Accounts	<u>20,000</u>	19,000
	<u>135,376</u>	<u>174,307</u>
Net Pledges Receivable	1,476,374	1,200,421
Less: Current Portion, net of Allowance for Doubtful Accounts.....	<u>799,750</u>	<u>355,728</u>
Long-Term Portion	<u>\$ 676,624</u>	<u>\$ 844,693</u>

The discount rates used in determining the net present value of long-term pledges receivable as of June 30, 2025 and 2024 ranged from 4.5% to 5.3%.

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

NOTES TO FINANCIAL STATEMENTS

NOTE 5—PROPERTY AND EQUIPMENT

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

	2025	2024
Office Equipment.....	\$ 54,473	\$ 48,944
Office Furniture	39,999	47,246
Medical Equipment	760,629	1,197,488
Construction in Process.....	-	5,458
	855,101	1,299,136
Less: Accumulated Depreciation	<u>796,016</u>	<u>1,137,543</u>
 Total.....	 <u>\$ 59,085</u>	 <u>\$ 161,593</u>

Depreciation expense was \$103,696 for the year ended June 30, 2025 and \$136,644 for the year ended June 30, 2024.

NOTE 6—INVESTMENTS

Investments at June 30 consist of the following:

	2025	2024
Mutual Funds and Exchange Traded Funds (ETF)		
Equity Funds		
Mid Cap	\$ 215,325	\$ 198,568
Index	740,594	684,681
Large Cap	16,413	63,424
Small Cap	98,175	95,933
International Large Growth	52,395	138,539
International Large Value.....	<u>158,417</u>	<u>54,737</u>
Total Equity Funds.....	<u>1,281,319</u>	<u>1,235,882</u>
Alternative Investments – Mutual Funds	<u>138,028</u>	<u>132,869</u>
Money Market Funds	<u>122,526</u>	<u>131,587</u>
Fixed Income Funds – Intermediate Term Bond Fund	<u>849,620</u>	<u>790,971</u>
Total Investments	<u>\$ 2,391,493</u>	<u>\$ 2,291,309</u>

NOTES TO FINANCIAL STATEMENTS

NOTE 6—INVESTMENTS (Continued)

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

	2025	2024
Net Realized Gain.....	\$ 56,557	\$ 14,032
Net Unrealized Gain.....	106,589	165,228
Interest and Dividends.....	152,657	58,529
Less: Investment Expenses.....	(18,750)	(15,593)
 Total Investment Income, net.....	 \$ 297,053	 \$ 222,196

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.

NOTES TO FINANCIAL STATEMENTS

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, 2025 and 2024.

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 net asset value, 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 SMA. 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.

Research grant expense for the year ended June 30, 2025 was \$2,368,243 and \$1,960,710 for the year ended June 30, 2024.

Some of 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 was 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 was responsible for all costs incurred or committed at the time of termination.

As of June 30, 2025, the Organization's unconditional grants payable obligations have terms expiring through March 2027. Long-term grants are discounted to net present value. As of June 30, 2025, grants payable obligations amounted to \$1,380,198 with a discount on long-term grants payable of \$4,474, netted in that total at June 30, 2025. The discount rate used in determining the net present value of long-term grants payable at June 30, 2025 was 2.5%. 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 the long-term grants payable of \$4,396, netted in that total. The discount rate used in determining the net present value of long-term grants payable at June 30, 2024 was 2.5%.

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

NOTES TO FINANCIAL STATEMENTS

NOTE 9—NET ASSETS WITH DONOR RESTRICTIONS

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

	2025	2024
Purpose and Time Restrictions:		
Research.....	\$ 951,624	\$ 1,044,693
Annual Chapter Meeting	244,494	233,398
Equipment Pool and Care Packages	186,458	244,805
Directions Newsletter.....	—	45,000
Industry Collaboration.....	608,154	467,768
Policy and Advocacy	25,000	—
Annual Conference Meeting.....	85,038	—
Real World Evidence Collaboration.....	—	189,440
Technology Program.....	24,834	63,064
Virtual Resources	97,500	—
Other.....	85,000	—
Fundraising Support Staff	120,000	120,000
Accumulated Endowment Fund Earnings	<u>242,353</u>	<u>150,159</u>
Total Purpose and Time Restricted Net Assets.....	<u>\$ 2,670,455</u>	<u>\$ 2,558,327</u>
Donor Restricted Endowment – In Perpetuity	<u>\$ 2,142,201</u>	<u>\$ 2,138,873</u>

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

	2025	2024
Research.....	\$ 780,681	\$ 746,354
Annual Chapter Meeting	288,904	291,602
Scholarships.....	—	215,000
Equipment Pool and Care Packages	315,244	92,653
Directions Newsletter.....	45,000	22,500
Walk-n-Roll	407,500	257,500
Gala/Dinners.....	28,500	—
Third Party Events.....	40,000	—
Industry Collaboration.....	1,579,613	1,357,540
Congressional Dinner.....	95,000	130,000
Continuing Medical Education	—	50,000
Policy and Advocacy	190,000	70,000
Pediatric Neuromuscular Clinical Research Network	25,000	—
Children's Programs.....	—	35,000
Real World Evidence Collaboration.....	189,440	1,697,586
Technology Program.....	38,230	6,936
Care Center Network	—	117,000
Virtual Resources	32,500	—
Fundraising Support Staff	120,000	—
Other.....	30,000	67,663
Appropriation of Endowment Assets for Expenditure	<u>126,088</u>	<u>—</u>
Total.....	<u>\$ 4,331,700</u>	<u>\$ 5,157,334</u>

NOTES TO FINANCIAL STATEMENTS

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 SMA. During the fiscal year ended 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 the Board, 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. During the year ended June 30, 2025, \$115,732 from the endowment fund was used to support a PNCR center.

In 2019, the Organization entered into an agreement with a donor to establish another 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. During the year ended June 30, 2025, \$10,356 from this endowment fund was used for support to the Care Center Network.

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 Board. 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.

NOTES TO FINANCIAL STATEMENTS

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, 2025 is as follows:

	With Donor Restrictions			Total
	Without Donor Restrictions	Time and Purpose Restrictions	Endowment in Perpetuity	Endowment Net Assets
Donor-Restricted				
Endowment Funds	\$ 242,353		\$ 2,142,201	\$ 2,384,554

Changes in endowment net assets for the year ended June 30, 2025 are as follows:

	With Donor Restrictions			Total
	Without Donor Restrictions	Time and Purpose Restrictions	Endowment in Perpetuity	Endowment Net Assets
Endowment Net Assets,				
Beginning of Year	\$ —	\$ 150,159	\$ 2,138,873	\$ 2,289,032
Contributions and Grants	—	—	3,328	3,328
Appropriation of Endowment				
Assets for Expenditure	—	(126,088)	—	(126,088)
Investment Income, net of Fees	—	55,209	—	55,209
Net Realized and Unrealized Gain	—	163,073	—	163,073
Endowment Net Assets, End of Year	\$ —	\$ 242,353	\$ 2,142,201	\$ 2,384,554

NOTES TO FINANCIAL STATEMENTS

NOTE 10—ENDOWMENT FUNDS (Continued)

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

	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>		
	Time and Purpose Restrictions	Endowment in Perpetuity	Total Endowment Net Assets	
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:

	<u>Without Donor Restrictions</u>	<u>With Donor Restrictions</u>		
	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

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 \$140,335 and \$134,936 for the years ended June 30, 2025 and 2024.

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, 2025 and 2024, there were 37 active chapters located throughout the United States. Fundraising 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.

NOTES TO FINANCIAL STATEMENTS

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. In 2024 the 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 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 contingent on the surrender of the premises by the Organization before that day. As of June 30, 2025, the Organization has received the first 50% of the compensation fee and that \$112,500 is reported as lease cancellation income on the statements of activities. The Organization moved out of the office in early July, 2025, thus meeting the condition for the second half of the compensation fee. That second 50% of the fee will be recognized as revenue during the year ended June 30, 2026, when the condition of the Organization's early surrendering of the premises was met.

The Organization entered into a new five-year lease agreement for office space in Schaumburg, Illinois, commencing August 1, 2025 through July 30, 2030. The lease calls for monthly base rent payments with annual increases ranging from \$5,733 to \$6,825, plus a pro rata share of property taxes and operating costs. The lease requires a security deposit of \$13,650 and allows one, five-year renewal option at the prevailing at that time market rental rate.

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, another 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.

The Organization also leases warehouse storage on a month-to-month basis.

NOTES TO FINANCIAL STATEMENTS

NOTE 14—OPERATING LEASES (Continued)

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 lease payments under the warehouse storage and office leases are included in occupancy on the statements of functional expenses. 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:

	2025	2024
Fixed Lease Cost.....	\$ 66,890	\$ 78,079
Variable Operating Lease Expense	<u>58,397</u>	<u>54,952</u>
Total Operating Lease Cost (Rent)	<u>\$ 125,287</u>	<u>\$ 133,031</u>

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 short-term 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.

Future minimum lease payments of the above operating leases as of June 30, 2025 are as follows:

Year Ending June 30		
2026	\$ 74,440	
2027	82,182	
2028	76,805	
2029	78,351	
2030	81,627	
2031	<u>6,825</u>	
		<u>\$ 400,230</u>

The ROU asset and lease liability balances are as follows for the years ended June 30:

	2025	2024
Operating Lease Right-of-Use Asset	<u>\$ —</u>	<u>\$ 177,967</u>
Operating Lease Liability	<u>\$ —</u>	<u>\$ 198,989</u>
Less: Current Portion	<u>—</u>	<u>60,816</u>
Long-Term Portion	<u>\$ —</u>	<u>\$ 138,173</u>
Weighted-Average Remaining Lease Term (Years)	<u>—</u>	3.1
Weighted Average Discount Rate	<u>—</u>	2.9%
Cash Paid for Amounts Included in Measuring Operating Lease Liability		
Operating Cash Flows from Operating Lease.....	<u>\$ 65,755</u>	<u>\$ 63,840</u>

NOTES TO FINANCIAL STATEMENTS

NOTE 15—SUBSEQUENT EVENTS

Management has evaluated subsequent events through November 11, 2025, the date on which the financial statements were available for issuance. Other than as previously disclosed elsewhere, there were no subsequent events which require disclosure.