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

FINANCIAL STATEMENTS

JUNE 30, 2023

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Warady & Davis LLP
Certified Public Accountants & Consultants

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, 2023 and 2022, and the related statements of activities, functional expenses and cash flows for the years then ended, and the related notes to the financial statements.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of FAMILIES OF SPINAL MUSCULAR ATROPHY D/B/A CURE SMA as of June 30, 2023 and 2022, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Our responsibilities under those standards are further described in the 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 discussed in Note 1 to the financial statements, the Organization changed its method of accounting for leases for the year ended June 30, 2023 as required by the provisions of FASB Accounting Standards Update ASC 842. Our opinion is not modified with respect to that 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 Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with 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 14, 2023

STATEMENTS OF FINANCIAL POSITION

As of June 30	**2023**	2022
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	**$ 4,602,807**	$ 5,444,777
Grants Receivable, net of Allowances for Uncollectible Amounts of $25,000 and $33,500	**1,826,782**	3,274,577
Pledges Receivable, net of Allowances for Uncollectible Amounts of $27,000 and $16,500	**1,379,535**	486,424
Other Receivables	—	122,677
Deferred Expenses	**1,702,133**	93,219
Total Current Assets	**9,511,257**	9,421,674
PROPERTY AND EQUIPMENT, NET	**253,762**	288,280
NONCURRENT ASSETS		
Pledges Receivable, net of Discount	**726,879**	84,468
Operating Lease Right-of-Use Asset, net of Accumulated Amortization of $52,527 and $-0-	**232,074**	—
Security Deposits and Other Assets	**6,344**	6,344
Intangibles, net of Accumulated Amortization of $1,020,686 and $1,051,050	**131,096**	85,619
Investments	**1,851,892**	1,411,074
	2,948,285	1,587,505
	$ 12,713,304	$ 11,297,459
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts Payable	**$ 515,659**	$ 512,930
Grants Payable	**1,542,929**	2,045,472
Accrued Expenses	**1,488,384**	1,215,548
Accrued Payroll and Related Expenses	**288,729**	81,660
Accrued Vacation	**181,292**	190,882
Current Portion of Operating Lease Liability	**57,207**	—
Deferred Revenue	**1,465,456**	—
Total Current Liabilities	**5,539,656**	4,046,492
LONG-TERM LIABILITIES		
Grants Payable	**181,928**	—
Long-Term Portion of Operating Lease Liability	**198,989**	—
Deferred Rent	—	20,247
Total Long-Term Liabilities	**380,917**	20,247
Total Liabilities	**5,920,573**	4,066,739
NET ASSETS		
Without Donor Restrictions	**1,566,462**	3,294,012
With Donor Restrictions - Time and Purpose	**3,301,558**	2,327,339
With Donor Restrictions - Endowment	**1,924,711**	1,609,369
Total Net Assets	**6,792,731**	7,230,720
	$ 12,713,304	$ 11,297,459

See accompanying notes.

STATEMENTS OF ACTIVITIES

For the Years Ended June 30	2023				2022			
		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	$ 606,915	$ 5,238,584	$ 315,342	$ 6,160,841	$ 1,243,857	$ 6,735,504	$ 137,735	$ 8,117,096
In-Kind Contributions	217,731			217,731	80,408			80,408
	824,646	5,238,584	315,342	6,378,572	1,324,265	6,735,504	137,735	8,197,504
Chapter Events								
Special Events Revenue	3,572,220			3,572,220	2,399,532			2,399,532
Donated Special Event Auction Items	84,870			84,870	69,333			69,333
Less: Event Expenses	(390,606)			(390,606)	(315,497)			(315,497)
	3,266,484			3,266,484	2,153,368			2,153,368
Program Revenues								
Summit of Strength Symposiums	677,500			677,500	500,000			500,000
Industry Sponsored Research	1,138,250			1,138,250	350,000			350,000
Annual Conference	2,166,179			2,166,179	2,678,616			2,678,616
	3,981,929			3,981,929	3,528,616			3,528,616
Other Revenues and Losses								
Payroll Protection Program Loan and Interest Forgiveness				—	963,515			963,515
Grant Forfeitures	48,777			48,777				—
Employee Retention Credit Interest	48,224			48,224	11,140			11,140
Investment Income (Loss)	(2,658)	125,476		122,818	13	(198,295)		(198,282)
Loss on Disposal of Property and Equipment				—	(19,800)			(19,800)
Other Income	38,795			38,795	158,855			158,855
Total Other Revenues and Losses	133,138	125,476		258,614	1,113,723	(198,295)		915,428
Net Assets Released from Restrictions	4,389,841	(4,389,841)		—	7,552,159	(7,552,159)		—
Total Support and Revenues	12,596,038	974,219	315,342	13,885,599	15,672,131	(1,014,950)	137,735	14,794,916
Expenses								
Program Services	11,523,757			11,523,757	11,359,863			11,359,863
Management and General	1,586,641			1,586,641	904,581			904,581
Fundraising	1,213,190			1,213,190	1,919,044			1,919,044
Total Expenses	14,323,588			14,323,588	14,183,488			14,183,488
CHANGE IN NET ASSETS	(1,727,550)	974,219	315,342	(437,989)	1,488,643	(1,014,950)	137,735	611,428
Net Assets, Beginning of Year	3,294,012	2,327,339	1,609,369	7,230,720	1,805,369	3,342,289	1,471,634	6,619,292
NET ASSETS, ENDING	$ 1,566,462	$ 3,301,558	$ 1,924,711	$ 6,792,731	$ 3,294,012	$ 2,327,339	$ 1,609,369	$ 7,230,720

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES

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	$ 969,148	$ 720,801	$ —	$ 4,573,610
Payroll Taxes	52,958	64,847	55,930	27,773	201,508	67,723	50,369	—	319,600
Employee Benefits	74,677	91,443	78,869	39,164	284,153	95,499	71,027	—	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	20,300	7,268	—	56,645
Miscellaneous	—	—	—	—	—	648	—	389	1,037
Occupancy	14,870	18,208	15,704	7,797	56,579	19,016	14,143	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	7,419	5,518	—	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	14,332	10,659	—	67,635
Travel	33,038	40,456	34,893	17,327	125,714	42,250	31,423	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	1,586,641	1,213,190	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	$ 1,586,641	$ 1,213,190	$ —	$ 14,323,588

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES (Continued)

For the Year Ended June 30, 2022

	Research	Patient Services	Community Support	Awareness	Total Program Services	Management and General	Fundraising	Event Expenses	Total
Salaries	$ 722,702	$ 767,427	$ 710,162	$ 315,999	$ 2,516,290	$ 438,888	$ 1,224,706	$ —	$ 4,179,884
Payroll Taxes	49,619	52,690	48,758	21,695	172,762	30,133	84,086	—	286,981
Employee Benefits	76,137	80,849	74,816	33,290	265,092	46,237	129,023	—	440,352
Advertising	83,906	41,953	55,937	41,953	223,749	20,137	41,953	—	285,839
Bad Debt Expense	—	—	—	—	—	30,000	—	—	30,000
Bank Charges, Credit Card and Other Fees	—	—	—	—	—	65,197	40,590	—	105,787
Conferences and Meetings	1,607,518	470,573	967,190	71,495	3,116,776	17,965	—	113,516	3,248,257
Depreciation and Amortization	8,770	95,837	216,458	16,966	338,031	1,885	7,540	—	347,456
Dues and Subscriptions/Publications	—	—	—	—	—	16,451	5,900	—	22,351
Equipment Grants and Care Packages	—	—	144,872	—	144,872	—	—	—	144,872
Equipment Rental	—	—	—	—	—	17,329	—	—	17,329
Insurance Expense	6,884	7,310	6,764	3,011	23,969	12,881	11,666	—	48,516
Miscellaneous	4,457	—	—	—	4,457	30,253	—	3,316	38,026
Occupancy	46,469	45,526	36,455	21,079	149,529	25,669	39,243	22,471	236,912
Office Expenses	7,706	2,477	5,503	3,578	19,264	1,926	6,330	12,553	40,073
Prizes and Promotional Items	26,192	—	—	—	26,192	5,452	194	159,905	191,743
Professional Services	409,833	181,505	23,418	14,544	629,300	65,414	77,183	—	771,897
Research Grants	1,870,773	838,944	—	—	2,709,717	—	—	—	2,709,717
Shipping Expense	20,681	51,704	93,066	10,341	175,792	10,342	20,681	—	206,815
Staff Development/Training	11,534	3,707	8,238	5,356	28,835	2,883	9,474	—	41,192
Stationery and Printing	47,661	71,491	83,406	23,830	226,388	—	11,915	—	238,303
Technology	119,348	38,362	85,248	55,412	298,370	29,837	98,036	—	426,243
Telephone and Internet	19,414	6,240	13,868	9,014	48,536	4,854	15,948	—	69,338
Travel	39,232	41,660	38,552	17,154	136,598	23,825	66,484	3,736	230,643
Website	7,023	7,023	49,160	42,138	105,344	7,023	28,092	—	140,459
	5,185,859	2,805,278	2,661,871	706,855	11,359,863	904,581	1,919,044	315,497	14,498,985
Less Event Expenses on Statement of Activities	—	—	—	—	—	—	—	(315,497)	(315,497)
TOTALS	$ 5,185,859	$ 2,805,278	$ 2,661,871	$ 706,855	$ 11,359,863	$ 904,581	$ 1,919,044	$ —	$ 14,183,488

See accompanying notes.

STATEMENTS OF CASH FLOWS

For the Years Ended June 30	**2023**	2022
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in Net Assets	**$ (437,989)**	$ 611,428
Adjustments to Reconcile Change in Net Assets to Net Cash Used by Operating Activities		
Donated Medical Equipment	**—**	(9,300)
Depreciation	**184,666**	232,998
Amortization	**53,333**	114,458
Payroll Protection Program (PPP) Loan and Interest Forgiveness	**—**	(963,515)
Noncash PPP Interest Expense	**—**	4,048
Loss on Disposal of Property and Equipment	**—**	19,800
Stock Donations	**(132,407)**	(9,510)
Proceeds from Sale of Stock Donations	**132,407**	9,541
Realized (Gain) Loss on Sales of Donated Stocks	**—**	(31)
Unrealized and Realized (Gain) Loss on Investments	**(95,246)**	225,787
Donor Restricted Endowment Contributions	**(315,342)**	(137,735)
Change in Allowance for Uncollectible Amounts	**2,000**	30,000
Changes in		
Grants Receivable	**1,456,295**	(2,454,743)
Pledges Receivable	**(1,546,022)**	(281,892)
Other Receivables	**122,677**	(122,677)
Deferred Expenses	**(1,608,914)**	137,255
Operating Lease Right of Use Asset	**(232,074)**	—
Security Deposits	**—**	9,058
Accounts Payable	**2,729**	384,574
Grants Payable	**(320,615)**	(19,215)
Accrued Expenses	**272,836**	1,168,617
Accrued Payroll and Related Expenses	**207,069**	(146,084)
Accrued Vacation	**(9,590)**	44,559
Operating Lease Liability	**256,196**	—
Deferred Revenue	**1,465,456**	(13,000)
Deferred Rent	**(20,247)**	13,733
Total Adjustments	**(124,793)**	(1,763,274)
Net Cash Used by Operating Activities	**(562,782)**	(1,151,846)
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of Property and Equipment	**(164,288)**	(148,486)
Capitalization of Intangibles	**(84,670)**	(49,831)
Purchases of Investments	**(647,050)**	(551,304)
Proceeds from Sales of Investments	**301,478**	392,933
Net Cash Used by Investing Activities	**(594,530)**	(356,688)
CASH FLOWS FROM FINANCING ACTIVITIES		
Donor Restricted Endowment Contributions	**315,342**	137,735
NET DECREASE IN CASH AND CASH EQUIVALENTS	**(841,970)**	(1,370,799)
Cash and Cash Equivalents, Beginning	**5,444,777**	6,815,576
CASH AND CASH EQUIVALENTS, ENDING	**$ 4,602,807**	$ 5,444,777
SUPPLEMENTAL DISCLOSURES OF CASH FLOW INFORMATION		
Noncash Activities		
Donated Services	**$ 131,571**	$ 11,950
Donated Medical Equipment	**—**	9,300
Donated Goods and Supplies	**85,460**	58,056
Donated Medical Devices Granted to Program Recipients	**700**	1,102
Donated Special Event Auction Items	**84,870**	69,333
	$ 302,601	$ 149,741
Construction in Progress from 2022 Reclassified as Intangibles	**$ 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 revenue are contributions, grants and program service fees from its annual conference and Summit of Strength symposiums. There were no concentrations of revenue from individual donors during the year ended June 30, 2023, however receivables from two corporations and one foundation accounted for approximately 55% of total receivables. During the year ended June 30, 2022, 26% of total support and revenues was received from two corporations and at June 30, 2022, receivables from three corporations accounted for approximately 72% 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 financial statements 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, restricted 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 and nature of fund-raising activity. 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 ASC 958-605. The remaining ERC receivable as of June 30, 2023 and 2022 totals $294,268 and $898,711, respectively, and is included in grants receivable on the statements of financial position. Management considers the remaining receivable to be fully collectible, as the amount is established following statutory rules and it is due from the U.S. Department of Treasury.

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 following 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. Program service fees recognized over time are $2,843,679 and $3,178,616 for the years ended June 30, 2023 and June 30, 2022, respectively.

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. Program service fees recognized at a point in time are $1,138,250 and $350,000 for the years ended June 30, 2023 and June 30, 2022, 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 re received. There are no contracts which contain variable consideration and there are very few, if any, contract modifications.

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 in accordance with generally accepted accounting principles.

Other receivables reported on the statements of financial position consist primarily of commissions earned based on negotiated percentage of eligible expenses incurred during the Organization's 2022 annual conference, with the related revenue recorded as part of other income on the statements of activities for the year ended June 30, 2022. There was no similar agreement, and therefore no such receivable and revenue recorded during the fiscal year ended June 30, 2023.

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 as the 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 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 included in advertising expense, $10,250 of donated accounting, 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. The Organization received donated in-kind contributions comprised of medical equipment of $9,300, donated goods and supplies of $57,796 included in stationery and printing, medical devices received and granted to program recipients of $1,102 included in equipment grants and care packages, $260 included in special event expense and $11,950 of donated accounting, included in professional services on the statements of functional expenses for the year ended June 30, 2022. During the year ended June 30, 2022, the donated medical equipment of $9,300 was capitalized and is utilized in the Organization’s programs. The medical devices received were granted to program participants as part of the Organization’s family support program. The remaining donated services, goods and supplies were utilized by the Organization’s various programs and supporting services.

Donated special event auction items are valued at the gross selling price received and totaled $84,870 and $69,333 for the years ended June 30, 2023 and June 30, 2022, 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, 2023 and 2022.

A number of unpaid volunteers and members of the Boards 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 Financial Accounting Standards Board (FASB) Codification topic related to accounting for contributions received and made.

CASH AND CASH EQUIVALENTS

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

NOTES TO FINANCIAL STATEMENTS

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

INVESTMENTS

The Organization follows the provisions of the Financial Accounting Standards Board (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 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, the investments have been classified as noncurrent.

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 years 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 three years using the straight-line method. Amortization expense was $53,333 for the year ended June 30, 2023 and $114,458 for the year ended June 30, 2022.

Amortization expense for the next three years is:

Year Ending June 30	
2024	$ 57,603
2025	47,541
2026	25,952
	$ 131,096

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.

NOTES TO FINANCIAL STATEMENTS

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

NEW ACCOUNTING STANDARDS ON LEASES

In February 2016, the FASB issued ASU 2016-02, *Leases (Topic 842)*, which supersedes existing guidance for accounting for leases under *Topic 840, Leases*. The FASB subsequently issued additional ASUs, which further amend and clarify Topic 842. The most significant change in the new leasing guidance is the requirement to recognize right-of-use (ROU) assets and lease liabilities for operating and financing leases on the statements of financial position.

The Organization elected to adopt these ASUs effective July 1, 2022 using the modified retrospective effective method, and utilized all of the available practical expedients. The adoption has a material impact on the Organization's statements of financial position but no significant impact on the statements of activities and changes in net assets. The most significant impact was the recognition of an operating lease ROU asset and an operating lease liability. Adoption of the standard resulted in an increase in operating lease ROU asset of $284,601 and an increase in operating lease liability of $304,848 at July 1, 2022.

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 ROU asset, current portion of operating lease liability, and long-term portion of operating lease liability.

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 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.

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 expense 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, were previously reported as deferred rent on the statements of financial position. As of the adoption date of the lease ASUs, deferred rent is no longer reported on the statements of financial position.

The lease agreements do not contain any material residual value guarantees or material restrictive covenants.

NOTES TO FINANCIAL STATEMENTS

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 statement of financial position date, are comprised of the following at June 30:

	2023	2022
Cash and Cash Equivalents	**$ 4,602,807**	$ 5,444,777
Grants Receivable, net	**1,826,782**	3,274,577
Pledges Receivable, net	**2,106,414**	570,892
Other Receivables	**—**	122,677
Investments	**1,851,892**	1,411,074
Less: Net Assets with Donor Restrictions – Time and Purpose	**(3,301,558)**	(2,327,339)
Less: Net Assets with Donor Restrictions – Endowment	**(1,924,711)**	(1,609,369)
	$ 5,161,626	$ 6,887,289

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 maintains its accounts in financial institutions with high credit ratings and has not experienced any losses in such accounts. Thus, management believes they are not exposed to any significant credit risk on cash or cash equivalents.

Credit risk associated with grants, pledges, and other 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 Internal Revenue Service.

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:

	2023	2022
Less than One Year	**$ 1,406,535**	$ 502,924
One to Five Years	**500,000**	84,468
More than Five Years	**400,000**	—
	2,306,535	587,392
Less: Discount to Net Present Value	**173,121**	—
Less: Allowance for Uncollectible Accounts	**27,000**	16,500
	200,121	16,500
Net Pledges Receivable	**2,106,414**	570,892
Less Current Portion, net of Allowance for Uncollectible Amounts	**1,379,535**	486,424
Long-Term Portion	**$ 726,879**	$ 84,468

Management has not discounted the long-term portion of pledges receivable as of June 30, 2022, as the discount was not deemed significant.

The discount rate used in determining the net present value of long-term pledges receivable was 4.5%.

NOTE 5—PROPERTY AND EQUIPMENT

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

	2023	2022
Office Equipment	**$ 41,716**	$ 72,563
Office Furniture	**47,246**	47,246
Medical Equipment	**1,157,773**	1,040,698
Construction in Process	**12,400**	14,140
	1,259,135	1,174,647
Less Accumulated Depreciation	**1,005,373**	886,367
Total	**$ 253,762**	$ 288,280

Depreciation expense was $184,666 for the year ended June 30, 2023 and $232,998 for the year ended June 30, 2022.

NOTE 6—INVESTMENTS

Investments at June 30 consisted of the following:

	2023	2022
Mutual Funds and Exchange Traded Funds (ETF)		
Equity Funds		
Mid Cap	**$ 139,124**	$ 76,349
Index	**462,990**	376,743
Large Cap	**34,797**	66,092
Small Cap	**80,526**	57,921
International Large Growth	**100,393**	104,743
International Large Value	**49,402**	42,571
Total Equity Funds	**867,232**	724,419
Alternative Investments – Mutual Funds	**151,938**	126,764
Money Market	**330,748**	105,781
Fixed Income Funds		
Short-Term US Treasury ETF	**—**	32,810
Intermediate Term Bond Fund	**501,974**	421,300
Total Fixed Income Funds	**501,974**	454,110
Total Investments	**$ 1,851,892**	$ 1,411,074

Investment Income (Loss) is comprised of the following for the year ended June 30:

	2023	2022
Net Realized Gains (Losses)	**$ (1,218)**	$ 1,758
Net Unrealized Gains (Losses)	**96,464**	(227,514)
Interest and Dividends	**38,783**	39,213
Investment Expenses	**(11,211)**	(11,739)
Total Investment Income (Loss)	**$ 122,818**	$ (198,282)

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.

Following is a description of the valuation methodologies used for assets measured at fair value. There have been no changes in the methodologies used at June 30, 2023 and 2022.

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, technical, or commercially feasible. The Organization is responsible for all costs incurred or committed at the time of termination. Research grant expense for the year ended June 30, 2023, was $3,045,491 and $2,709,717 for June 30, 2022.

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 long-term grants payable of $4,548, netted in that total at June 30, 2023. The discount rate used in determining the net present value of long-term grants payable at June 30, 2023 was 2.50%. As of June 30, 2022, all grants payable obligations are current and there is no discount to present value. As of June 30, 2022, grants payable obligations amounted to $2,045,472.

NOTE 9—CONDITIONAL GRANTS PAYABLE

The Organization makes some of its grants conditional on the grantees having to overcome certain measurable performance-related barriers or other measurable obstacles. These obligations are not accrued since conditional promises to give are not recognized until the conditions are substantially met by the grantees.

The Organization has also awarded care center network grants with terms expiring on various dates through December 31, 2023, which are conditional on new patients being enrolled in the program and patient data being upload at each care center, at a rate of $600 per patient with no maximum per grantee. Based on the Organization’s projections, as of June 30, 2023, the Organization expects that it would have to recognize as grant expense and pay approximately $189,600 during the fiscal year ending June 30, 2024 to seventeen such care centers. Any payments subsequent to June 30, 2023 are conditional on future enrollment of new patients during the remainder of these care centers’ award periods and the transfer of patient-related date. As the awards are not limited by maximum amounts that each care center could become eligible for, the actual amounts paid under the existing conditional grants could exceed the total projected by the Organization’s management.

NOTE 10—PAYROLL PROTECTION PROGRAM LOANS

On January 14, 2021, the Organization applied for and was approved for a second installment of a PPP loan from the SBA of additional $959,467. The loan accrues interest at a fixed rate of 1.00% per annum, but payments are not required to begin for ten months after the end of the loan forgiveness covered period. The Organization could become eligible for up to 100% forgiveness of the loan amount plus accrued interest and any amount of principal and interest not forgiven by the SBA would mature on January 14, 2026. The Organization applied for and was granted forgiveness of the entire loan amount, plus the accrued interest of $4,048 on October 5, 2021. The loan and accrued interest forgiveness totaling $963,515 is included under other revenues and losses on the statements of activities.

As permitted under U.S. Generally Accepted Accounting Principles, the Organization accounted for the PPP loan as debt under FASB ASC 470. Under this standard, the proceeds from the loan remained reported as a liability on the statements of financial position until the SBA legally forgave the loan.

NOTES TO FINANCIAL STATEMENTS

NOTE 11—NET ASSETS WITH DONOR RESTRICTIONS

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

	2023	2022
Research	**$ 1,232,715**	$ 482,770
Annual Chapter Meeting	**225,000**	225,000
Scholarships	**140,000**	—
Equipment and Wagons	**50,000**	—
Directions Newsletter	**22,500**	22,500
Industry Collaboration	**325,309**	418,173
Congressional Dinner	**57,500**	25,000
Care and Support Packages	**10,029**	152,253
Walk-n-Roll Program	**12,500**	—
Continuing Medical Education (CME)	**50,000**	—
Real World Evidence Collaboration	**1,081,824**	1,167,965
Technology Program	**40,000**	—
Children's Programs	**10,000**	—
Info Packets	—	31,973
Care Center Network	**117,000**	—
Underwater Endowments	**(72,819)**	(198,295)
	$ 3,301,558	$ 2,327,339

NOTE 11—NET ASSETS WITH DONOR RESTRICTIONS (Continued)

Releases of restriction for the years ended June 30, were as follows:

	2023	2022
Research	**$ 647,270**	$ 75,000
Support Programs	**—**	180,000
Annual Chapter Meeting	**225,000**	225,000
Scholarships	**75,000**	34,327
Equipment and Wagons	**129,534**	361,446
Directions Newsletter	**45,000**	90,000
Walk-n-Roll	**170,000**	112,500
Industry Collaboration	**1,357,537**	2,028,571
Congressional Dinner	**102,500**	120,000
Care and Support Packages	**36,623**	437,639
Newborn Screening	**—**	193,605
Pediatric Neuromuscular Clinical Research (PNCR) Network	**335,000**	1,130,000
Real World Evidence Collaboration	**986,142**	956,936
Technology Program	**10,262**	—
Employee Retention Credit	**—**	1,120,082
Info Packets	**31,973**	262,092
Care Center Network	**123,000**	6,856
Virtual Resources	**20,000**	—
Other	**95,000**	218,105
Total	**$ 4,389,841**	$ 7,552,159

NOTE 12—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.

NOTE 12—ENDOWMENT FUNDS (Continued)

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 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.

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, 2023 is as follows:

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

NOTES TO FINANCIAL STATEMENTS

NOTE 12—ENDOWMENT FUNDS (Continued)

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, 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 and Losses	—	97,905	—	97,905
Endowment Net Assets, End of Year	$ —	$ (72,819)	$ 1,924,711	$ 1,851,892

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 has 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.

At June 30, 2022, one fund with an original gift value of $65,581 and fair value of $57,009 had such a deficiency of $8,572, which is reported in the net assets with time and purpose restriction. As of June 30, 2022, the second endowment fund had $1,543,788 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 has a fair value of $1,354,065 as of June 30, 2022, and a deficiency of $189,723, which is also reported in the net assets with time and purpose restriction.

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, 2023 and 2022.

Endowment net asset composition by type of fund as of June 30, 2022 is as follows:

	Without Donor Restrictions	With Donor Restrictions: Time and Purpose Restrictions	With Donor Restrictions: Endowment in Perpetuity	Total
Donor-Restricted Endowment Funds	$ —	$ (198,295)	$ 1,609,369	$ 1,411,074
Total	$ —	$ (198,295)	$ 1,609,369	$ 1,411,074

NOTES TO FINANCIAL STATEMENTS

NOTE 12—ENDOWMENT FUNDS (Continued)

Changes in endowment net assets for the year ended June 30, 2022 are as follows:

		With Donor Restrictions		
	Without Donor Restrictions	Time and Purpose Restrictions	Endowment in Perpetuity	Total Endowment Net Assets
Endowment Net Assets, Beginning of Year	$ —	$ —	$ 1,471,634	$ 1,471,634
Contributions and Grants	—	—	137,735	137,735
Investment Income, net of fees	—	27,473	—	27,473
Net Realized and Unrealized Gains and Losses	—	(225,768)	—	(225,768)
Endowment Net Assets, End of Year	$ —	$ (198,295)	$ 1,609,369	$ 1,411,074

NOTE 13—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 $133,899 for 2023 and $128,202 for 2022.

NOTE 14—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, 2023 and 2022, there were 34 active chapters–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 15—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. The Organization believes that it has appropriate support for the positions taken on its returns.

NOTE 16—OPERATING LEASES

In September 2009, the Organization entered into an eight-year lease agreement for office space in Elk Grove Village, Illinois, which was extended in February 2017 and expired in February 2022. Monthly rental payments commenced at $4,740 per month and increase approximately 3% per annum. In February 2022, the lease was extended through July 2027 with rent abatement for the first five months of 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 Additionally, in January 2020 the Organization entered into a two-year lease agreement for a satellite office space located in Chicago, Illinois, with monthly base rental payments commencing at $9,058 per month and increasing 3% per annum, plus monthly charges for the Organization's share of operating expenses, utilities, and real estate taxes. This lease expired in January 2022 and was not renewed. 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 expense 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. Another operating equipment lease was entered into in April 2017 for copier equipment, with sixty-three base rent monthly payments starting at $512 and $541 for the two copiers, plus variable monthly maintenance, insurance and overage charges through June 2022. The base rent payments for the two copiers had annual escalation provisions and during the year ended June 30, 2022, the base rent payments were $643, increasing to $688 for one of the copiers, and $646, increasing to $698 for the other. 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 fixed and variable rental payments under the copier and postage machine leases are reported as equipment rental expense on the statements of functional expenses.

As of June 30, 2022, a deferred rent liability was recognized in the amount of $20,247, for the difference between the actual cash outlay for base rental payments and the straight-line rent expense computed over the term of the office lease in accordance with U.S. principles generally accepted in the United States of America. As of July 1, 2023, the adoption date of the new lease ASUs, deferred rent is no longer reported on the statements of financial position and the June 30, 2022 balance was netted against the operating lease right of use asset, in accordance with the adopted ASUs.

Lease expense consists of a fixed base rent, plus a variable component, which includes operating expenses, utilities and real estate taxes for the office leases, and maintenance, insurance and overage charges for the equipment leases.

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

	2023	2022
Fixed Lease Cost	**$ 47,607**	$ 189,962
Variable Operating Lease Expense	**38,184**	34,743
Total Operating Lease Cost (Rent)	**$ 85,791**	$ 224,705

NOTE 16—OPERATING LEASES (Continued)

When the lease ASUs *(Topic 842)* were adopted on July 1, 2022, the lease ROU asset and liability were calculated utilizing a risk-free rate of return, utilizing a practical expedient permitted under Topic 842. As of June 30, 2023 the ROU assets 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

Future minimum lease payments of the above operating leases as of June 30, 2023 are as follows:

Year Ending June 30	
2024	$ 75,216
2025	77,132
2026	79,104
2027	79,452
2028	7,486
	$ 318,390

Future minimum lease payments of the above operating leases as of June 30, 2022 are as follows:

Year Ending June 30	
2023	$ 68,243
2024	75,216
2025	77,132
2026	79,104
2027	79,452
2028	7,486
	$ 386,633

NOTE 17—RECLASSIFICATIONS

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

NOTE 18—SUBSEQUENT EVENTS

Management has evaluated subsequent events through November 14, 2023, the date through which the financial statements were available for issue. There were no subsequent events which require disclosure.