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

FINANCIAL STATEMENTS

JUNE 30, 2022

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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, 2022 and 2021, 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, 2022 and 2021, 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.

Auditor's Responsibilities for the Audit of the Financial Statements

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

In performing an audit in accordance with generally accepted auditing standards, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.

- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of 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

October 7, 2022

STATEMENTS OF FINANCIAL POSITION

As of June 30	**2022**	2021
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	**$ 5,444,777**	$ 6,815,576
Grants Receivable, net of Allowances for Uncollectible Amounts of $33,500 and $13,000	**3,274,577**	840,334
Pledges Receivable, net of Allowances for Uncollectible Amounts of $16,500 and $7,000	**486,424**	298,500
Other Receivables	**122,677**	—
Prepaid Expenses	**93,219**	230,474
Total Current Assets	**9,421,674**	8,184,884
PROPERTY AND EQUIPMENT, NET	**288,280**	383,292
NONCURRENT ASSETS		
Pledges Receivable	**84,468**	—
Security Deposits and Other Assets	**6,344**	15,402
Intangibles, net of Accumulated Amortization of $1,051,050 and $936,592	**85,619**	150,246
Investments	**1,411,074**	1,478,490
	1,587,505	1,644,138
	$ 11,297,459	$ 10,212,314
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts Payable	**$ 512,930**	$ 128,356
Grants Payable	**2,045,472**	1,742,736
Accrued Expenses	**1,215,548**	46,931
Accrued Payroll and Related Expenses	**81,660**	227,744
Accrued Vacation	**190,882**	146,323
Deferred Revenue	—	13,000
Paycheck Protection Program Loans	—	959,467
Deferred Rent	—	6,514
Total Current Liabilities	**4,046,492**	3,271,071
LONG-TERM LIABILITIES		
Grants Payable	—	321,951
Deferred Rent	**20,247**	—
Total Long-Term Liabilities	**20,247**	321,951
Total Liabilities	**4,066,739**	3,593,022
NET ASSETS		
Without Donor Restrictions	**3,294,012**	1,805,369
With Donor Restrictions - Time and Purpose	**2,327,339**	3,342,289
With Donor Restrictions - Endowment	**1,609,369**	1,471,634
Total Net Assets	**7,230,720**	6,619,292
	$ 11,297,459	$ 10,212,314

See accompanying notes.

STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS

For the Years Ended June 30	2022				2021			
		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	**$ 547,365**	**$ 6,735,504**	**$ 137,735**	**$ 7,420,604**	$ 562,040	$ 4,732,476	$ 5,475	$ 5,299,991
In-Kind Contributions	**80,408**			**80,408**	239,547			239,547
	627,773	**6,735,504**	**137,735**	**7,501,012**	801,587	4,732,476	5,475	5,539,538
Chapter Events								
Special Events Revenue	**3,165,357**			**3,165,357**	2,497,004			2,497,004
Less: Event Expenses	**(315,497)**			**(315,497)**	(71,102)			(71,102)
	2,849,860			**2,849,860**	2,425,902			2,425,902
Program Revenues								
Summit of Strength Symposiums	**500,000**			**500,000**	485,000			485,000
Industry Sponsored Research	**350,000**			**350,000**				—
Annual Conference	**2,678,616**			**2,678,616**	1,142,325			1,142,325
	3,528,616			**3,528,616**	1,627,325			1,627,325
Other Revenues and Losses								
Payroll Protection Program Loan and Interest Forgiveness	**963,515**			**963,515**	775,125			775,125
Grant Forfeitures	**—**			**—**	126,488			126,488
Employee Retention Credit Interest	**11,140**			**11,140**				
Investment Income (Loss)	**13**	**(198,295)**		**(198,282)**	9	41,692	223,692	265,393
Loss on Disposal of Property and Equipment	**(19,800)**			**(19,800)**				—
Other Income	**158,855**			**158,855**	33,326			33,326
Total Other Revenues and Losses	**1,113,723**	**(198,295)**		**915,428**	934,948	41,692	223,692	1,200,332
Net Assets Released from Restrictions	**7,552,159**	**(7,552,159)**		**—**	4,803,475	(4,803,475)		—
Total Support and Revenues	**15,672,131**	**(1,014,950)**	**137,735**	**14,794,916**	10,593,237	(29,307)	229,167	10,793,097
Expenses								
Program Services	**11,359,863**			**11,359,863**	7,772,710			7,772,710
Management and General	**904,581**			**904,581**	658,317			658,317
Fundraising	**1,919,044**			**1,919,044**	1,820,708			1,820,708
Total Expenses	**14,183,488**			**14,183,488**	10,251,735			10,251,735
CHANGE IN NET ASSETS	**1,488,643**	**(1,014,950)**	**137,735**	**611,428**	341,502	(29,307)	229,167	541,362
Net Assets, Beginning of Year	**1,805,369**	**3,342,289**	**1,471,634**	**6,619,292**	1,463,867	3,371,596	1,242,467	6,077,930
NET ASSETS, ENDING	**$ 3,294,012**	**$ 2,327,339**	**$ 1,609,369**	**$ 7,230,720**	$ 1,805,369	$ 3,342,289	$ 1,471,634	$ 6,619,292

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES

For the Year Ended June 30, 2022

	Research	Patient Services	Family 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 Statements 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 FUNCTIONAL EXPENSES (Continued)

For the Year Ended June 30, 2021

	Research	Patient Services	Family Support	Awareness	Total Program Services	Management and General	Fundraising	Event Expenses	Total
Salaries	$ 745,705	$ 741,773	$ 615,522	$ 252,108	$ 2,355,108	$ 343,748	$ 1,234,190	$ —	$ 3,933,046
Payroll Taxes	50,127	49,863	41,376	16,947	158,313	23,107	82,964	—	264,384
Employee Benefits	72,343	71,961	59,713	24,458	228,475	33,348	119,733	—	381,556
Advertising	91,655	29,462	65,472	42,557	229,146	32,713	75,293	—	337,152
Bank Charges, Credit Card and Other Fees	—	—	—	—	—	51,255	27,654	—	78,909
Conferences and Meetings	89,520	18,579	54,049	6,756	168,904	—	—	3,064	171,968
Depreciation and Amortization	6,080	168,711	232,805	27,362	434,958	3,040	12,161	—	450,159
Dues and Subscriptions/Publications	—	—	—	—	—	—	22,100	—	22,100
Equipment Grants and Care Packages	—	—	452,933	—	452,933	—	—	—	452,933
Equipment Rental	—	—	—	—	—	18,594	—	—	18,594
Insurance Expense	5,257	5,230	4,340	1,778	16,605	7,368	8,702	—	32,675
Interest Expense	—	—	—	—	—	9,009		—	9,009
Miscellaneous	5,026	—	—	—	5,026	1,259	—	5	6,290
Occupancy	51,707	50,657	40,564	23,456	166,384	28,562	43,666	292	238,904
Office Expenses	3,908	1,256	2,792	1,815	9,771	977	3,211	1,404	15,363
Prizes and Promotional Items	26,665	—	—	—	26,665	2,953	—	66,306	95,924
Professional Services	519,053	118,714	51,160	33,254	722,181	58,605	58,834	—	839,620
Research Grants	1,508,236	648,665	—	—	2,156,901	—	—	—	2,156,901
Shipping Expense	22,974	58,479	85,631	10,443	177,527	12,531	18,797	—	208,855
Staff Development/Training	4,115	1,323	2,940	1,911	10,289	1,029	3,381	—	14,699
Stationery and Printing	27,259	47,702	47,703	6,815	129,479	—	6,815	—	136,294
Technology	80,810	25,974	57,721	37,519	202,024	20,202	66,379	—	288,605
Telephone and Internet	15,721	5,053	11,229	7,299	39,302	3,930	12,913	—	56,145
Travel	2,284	2,273	1,886	772	7,215	1,053	3,781	31	12,080
Website	5,034	5,034	35,234	30,202	75,504	5,034	20,134	—	100,672
	3,333,479	2,050,709	1,863,070	525,452	7,772,710	658,317	1,820,708	71,102	10,322,837
Less Event Expenses on Statement of Activities	—	—	—	—	—	—	—	(71,102)	(71,102)
TOTALS	$ 3,333,479	$ 2,050,709	$ 1,863,070	$ 525,452	$ 7,772,710	$ 658,317	$ 1,820,708	$ —	$ 10,251,735

See accompanying notes.

STATEMENTS OF CASH FLOWS

For the Years Ended June 30	2022	2021
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in Net Assets	**$ 611,428**	$ 541,362
Adjustments to Reconcile Change in Net Assets to Net Cash Used by Operating Activities		
Donated Medical Equipment	**(9,300)**	(10,000)
Depreciation	**232,998**	252,582
Amortization	**114,458**	197,577
Payroll Protection Program (PPP) Loan and Interest Forgiveness	**(963,515)**	(775,125)
Noncash PPP Interest Expense	**4,048**	9,009
Loss on Disposal of Property and Equipment	**19,800**	—
Stock Donations	**(9,510)**	(14,785)
Proceeds from Sale of Stock Donations	**9,541**	14,768
Realized (Gain) Loss on Sales of Donated Stocks	**(31)**	17
Unrealized and Realized (Gain) Loss on Investments	**225,787**	(246,740)
Donor Restricted Endowment Contributions	**(137,735)**	(5,475)
Change in Allowance for Uncollectible Amounts	**30,000**	(6,000)
Changes in		
Grants Receivable	**(2,454,743)**	220,691
Pledges Receivable	**(281,892)**	21,214
Other Receivables	**(122,677)**	—
Prepaid Expenses	**137,255**	(53,624)
Security Deposits	**9,058**	—
Accounts Payable	**384,574**	(183,233)
Grants Payable	**(19,215)**	(517,362)
Accrued Expenses	**1,168,617**	25,311
Accrued Payroll and Related Expenses	**(146,084)**	31,414
Accrued Vacation	**44,559**	(15,668)
Deferred Revenue	**(13,000)**	(8,000)
Deferred Rent	**13,733**	(6,835)
Total Adjustments	**(1,763,274)**	(1,070,264)
Net Cash Used by Operating Activities	**(1,151,846)**	(528,902)
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of Property and Equipment	**(148,486)**	(213,043)
Capitalization of Intangibles	**(49,831)**	(47,000)
Purchases of Investments	**(551,304)**	(590,902)
Reinvested Dividends	**—**	(461)
Proceeds from Sales of Investments	**392,933**	637,500
Net Cash Used by Investing Activities	**(356,688)**	(213,906)
CASH FLOWS FROM FINANCING ACTIVITIES		
Donor Restricted Endowment Contributions	**137,735**	5,475
Funds Received from PPP Loan	**—**	959,467
Net Cash Provided by Financing Activities	**137,735**	964,942
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS	**(1,370,799)**	222,134
Cash and Cash Equivalents, Beginning	**6,815,576**	6,593,442
CASH AND CASH EQUIVALENTS, ENDING	**$ 5,444,777**	$ 6,815,576
SUPPLEMENTAL DISCLOSURES OF CASH FLOW INFORMATION		
Noncash Activities		
Donated Services	**$ 11,950**	$ 194,730
Donated Medical Equipment	**9,300**	10,000
Donated Goods and Supplies	**58,056**	1,236
Donated Medical Devices Granted to Program Recipients	**1,102**	22,500
Donated Special Event Auction Items	**—**	11,081
	$ 80,408	$ 239,547

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. 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. During the year ended June 30, 2021, 48% of total support and revenues was received from three corporations and at June 30, 2021, receivables from four corporations accounted for approximately 95% 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 restriction and net assets with donor restriction.

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).

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. During the year ended June 30, 2022, the Organization established its eligibility for ERC. Since it had also incurred allowable expenses and met the rest of the conditions of the grant, the Organization qualified for the ERC totaling $1,120,082. The amount is reported in grants and contributions with donor restriction on the statements of activities for the year ended June 30, 2021. Management considers the remaining ERC receivable as of June 30, 2022, totaling $898,711 to be fully collectible and the amount is reported in grants receivable on the statement of financial position.

NOTES TO FINANCIAL STATEMENTS

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 and the revenues are recorded over the length of the related events, which typically last between one and five days. Program service fees recognized over time were $3,178,616 and $1,627,325 for the years ended June 30, 2022 and June 30, 2021, respectively.

The Organization also has a contract with a pharmaceutical company 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 were $350,000 and $-0- for the years ended June 30, 2022 and June 30, 2021, respectively.

Balances are due prior to the commencement of each event. Amounts received prior to the end of the fiscal year for the next year's annual conference, or summer 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.

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 amount 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, 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 annual conference, with the related revenue recorded as part of other income on the statements of activities.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

IN-KIND CONTRIBUTIONS AND VOLUNTEER SUPPORT

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. Donated special event auction items are valued at the gross selling price received. 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 for the same kind as the donated professional services. 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 professional services for the year ended June 30, 2022. The Organization received donated in-kind contributions comprised of medical equipment of $10,000, donated auction items of $11,081 included in special events, medical devices received and granted to program recipients of $22,500 included in equipment grants and care packages, donated good and supplies of $1,236 included in stationary and printing and $194,730 of donated professional services for the year ended June 30, 2021. There were no donor-imposed restrictions associated with the in-kind contributions received during the years ended June 30, 2022 and 2021.

During the years ended June 30, 2022 and 2021, the donated medical equipment was capitalized and is utilized in the Organization's programs. All donated auction items were monetized. The medical devices received were granted to program participants as part of the Organization's family support program. The remaining donated goods and supplies were utilized by the Organization's various programs and supporting services.

The entire amount of donated professional services for the year ended June 30, 2022 and $9,730 of the donated professional services for the year ended June 30, 2021 consisted of accounting and audit services used in the preparation and audit of the annual financial statements, and in consulting on accounting matters throughout the year. For the year ended June 30, 2021, the Organization also received and utilized donated professional services valued at $65,000 for strategic planning, $120,000 for executive recruitment search.

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.

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 $114,458 for the year ended June 30, 2022 and $197,577 for the year ended June 30, 2021.

Amortization expense for the next three years is:

Year Ending June 30		
2023	$	46,349
2024		24,666
2025		14,604
	$	85,619

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. These methods include an allocation of personnel, and any other related costs based on estimates of time and effort spent by employees on the different functional categories, and allocation of occupancy and related costs using space utilization percentages occupied by the various functions.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

ACCOUNTING PRONOUNCEMENTS

In February 2016, the Financial Accounting Standards Board (FASB) issued ASU No. 2016-02, *Leases,* which will supersede the current lease requirements in ASC 840. The ASU requires lessees to recognize a right-of-use asset and related lease liability for all leases, with a limited exception for short-term leases. Leases will be classified as either finance or operating, with the classification affecting the pattern of expense recognition in the statement of activities. Currently, leases are classified as either capital or operating, with only capital leases recognized on the statements of financial position. The reporting of lease-related expenses in the statements of activities and cash flows will be generally consistent with the current guidance. The new lease guidance will be effective for the Organization's year ending June 30, 2023 and will be applied using a modified retrospective transition method to the beginning of the earliest period presented. The lease standard is expected to increase assets and lease liabilities upon adoption, however there is not expected to be a significant impact on expenses or cash flows.

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:

	2022	2021
Cash	**$ 5,444,777**	$ 6,815,576
Grants Receivable, net	**3,274,577**	840,334
Pledges Receivable, net	**486,424**	298,500
Other Receivables	**122,677**	---
Investments	**1,411,074**	1,478,490
Less: Net Assets with Donor Restrictions – Time and Purpose	**(2,327,339)**	(3,342,289)
Less: Net Assets with Donor Restrictions – Endowment	**(1,609,369)**	(1,471,634)
	$ 6,802,821	$ 4,618,977

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:

	2022	2021
Less than One Year	$ **502,924**	$ 305,500
One to Five Years	**84,468**	—
	587,392	305,500
Less: Allowance for Uncollectible Accounts	**16,500**	7,000
Net Pledges Receivable	**570,892**	298,500
Less Current Portion	**486,424**	298,500
Long-Term Portion	$ **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.

NOTE 5—PROPERTY AND EQUIPMENT

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

	2022	2021
Office Equipment	$ **72,563**	$ 71,445
Office Furniture	**47,246**	41,396
Medical Equipment	**1,040,698**	904,019
Construction in Process	**14,140**	19,800
	1,174,647	1,036,660
Less Accumulated Depreciation	**886,367**	653,368
Total	$ **288,280**	$ 383,292

Depreciation expense was $232,998 for the year ended June 30, 2022 and $252,582 for the year ended June 30, 2021.

NOTE 6—INVESTMENTS

Investments at June 30 consisted of the following:

	2022	2021
Mutual Funds and Exchange Traded Funds (ETF)		
Equity Funds		
Mid Cap	**$ 76,349**	$ 170,110
Index	**376,743**	368,205
Large Cap	**66,092**	75,758
Small Cap	**57,921**	90,142
International Large Growth	**104,743**	79,457
International Large Value	**42,571**	61,955
Total Equity Funds	**724,419**	845,627
Alternative Investments – Mutual Funds	**126,764**	106,305
Money Market	**105,781**	37,638
Fixed Income Funds		
Short-Term US Treasury ETF	**32,810**	23,459
Intermediate Term Bond Fund	**421,300**	465,461
Total Fixed Income Funds	**454,110**	488,920
Total Investments	**$ 1,411,074**	$ 1,478,490

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

	2022	2021
Net Realized Gains	**$ 1,758**	$ 54,037
Net Unrealized Gains (Losses)	**(227,514)**	192,686
Interest and Dividends	**39,213**	29,302
Investment Expenses	**(11,739)**	(10,632)
Total Investment Income (Loss)	**$ (198,282)**	$ 265,393

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, 2022 and 2021.

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, 2022, was $2,709,717 and $2,156,901 for June 30, 2021.

As of June 30, 2022, the Organization's unconditional grants payable obligations have terms expiring through June 2023. Long-term grants, if any, are discounted to net present value. 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 $2,255,472. The discount on long-term grants payable at June 30, 2021 was $8,049. The discount rate used in determining the net present value of long-term grants payable at June 30, 2021 was 2.50%. As of June 30, 2021, grants payable obligations amounted to $2,064,687.

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.

As of June 30, 2022, a conditional promise of $75,000 to one grantee based on research milestones to be reached by the grantee is still outstanding.

The Organization has also awarded first-year care center network grants with terms running from June 1, 2022 through June 30, 2023, which are conditional on achieving specified percentage of patients with Spinal Muscular Atrophy receiving care at the care center to be enrolled in the program, participation by the grantee in specified program-related conferences, meetings and other activities, and at least three consecutive monthly data submissions covering all consented patients followed at the center. As the conditions have not been met as of June 30, 2022, such promises of $30,000 per grantee to seven care centers for a total of $210,000 are still outstanding.

The Organization has also awarded second-year care center network grants with terms expiring on various dates through June 30, 2023, which are conditional on new patients being enrolled in the program 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, 2022, the Organization expects that it would have to recognize as grant expense and pay approximately $145,000 during the fiscal year ending June 30, 2023 to seventeen such care centers. Any payments subsequent to June 30, 2022 are conditional on future enrollment of new patients during the remainder of these care centers' award periods. 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 May 8, 2020, the Organization applied for and was awarded a Payroll Protection Program (PPP) loan from the U.S. Small Business Administration (SBA) of $769,100. 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 loan matures on May 8, 2022. The Organization is eligible for loan forgiveness up to 100% of the loan, upon meeting certain requirements to the extent of applicable payroll and other covered costs.

NOTE 10—PAYROLL PROTECTION PROGRAM LOANS (Continued)

The amount of loan forgiveness shall be calculated (and may be reduced) in accordance with the requirements of the PPP, including the provisions of Section 1106 of the Coronavirus Aid, Relief, and Economic Security Act (CARES Act). The loan is uncollateralized and is fully guaranteed by the Federal government. The Organization applied for and was granted forgiveness of the entire loan amount, plus the accrued interest of $6,025 on February 23, 2021. The loan and accrued interest forgiveness totaling $775,125 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.

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 has similar terms as the first installment and interest will accrue at 1%. 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.

NOTE 11—NET ASSETS WITH DONOR RESTRICTIONS

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

	2022	2021
Research	**$ 482,770**	$ 175,000
Annual Chapter Meeting	**225,000**	225,000
Scholarships	**—**	34,327
Equipment and Wagons	**—**	273,574
Directions Newsletter	**22,500**	—
Industry Collaboration	**418,173**	991,720
Congressional Dinner	**25,000**	105,000
Care and Support Packages	**152,253**	415,305
Newborn Screening	**—**	193,605
Pediatric Neuromuscular Clinical Research (PNCR) Network	**—**	513,333
Real World Evidence Collaboration	**1,167,965**	333,569
Biomarker Identification and Development	**—**	50,000
Searchable Healthcare Provider Database	**—**	25,000
Info Packets	**31,973**	—
Care Center Network	**—**	6,856
Underwater Endowments	**(198,295)**	—
	$ 2,327,339	$ 3,342,289

NOTE 11—NET ASSETS WITH DONOR RESTRICTIONS (Continued)

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

	2022	2021
Research	$ 75,000	$ 165,133
Support Programs	180,000	59,000
Annual Chapter Meeting	225,000	—
Scholarships	34,327	36,742
Equipment and Wagons	361,446	468,027
Directions Newsletter	90,000	116,810
Adult and Family Social Events	—	50,000
Walk-n-Roll	112,500	92,500
Medical ID Bracelets	—	30,000
Industry Collaboration	2,028,571	1,349,330
Congressional Dinner	120,000	—
Care and Support Packages	437,639	1,072,823
Newborn Screening	193,605	546,862
Pediatric Neuromuscular Clinical Research (PNCR) Network	1,130,000	275,000
Real World Evidence Collaboration	956,936	147,698
Biomarker Identification and Development	—	50,000
Employee Retention Credit	1,120,082	—
Info Packets	262,092	96,050
Care Center Network	6,856	—
Physical Therapy and Career Resource Webinars	—	145,000
Other	218,105	102,500
Total	$ 7,552,159	$ 4,803,475

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)

Additionally, in 2012, the board of directors designated $30,000 of net assets without donor restrictions for the endowment fund. During the fiscal year ended June 30, 2021, the board of directors undesignated the entire board-designated endowment.

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 foundations 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, 2022 is as follows:

		With Donor Restrictions		
	Without Donor Restrictions	Time and Purpose 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

NOTE 12—ENDOWMENT FUNDS (Continued)

Changes in endowment net assets for the year ended June 30, 2022 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	$ —	$ —	$ 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

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, 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 year ended June 30, 2022.

Endowment net asset composition by type of fund as of June 30, 2021 is as follows:

	Without Donor Restrictions	With Donor Restrictions: Time and Purpose Restrictions	With Donor Restrictions: Endowment in Perpetuity	Total
Donor-Restricted Endowment Funds	$ —	$ —	$ 1,471,634	$ 1,471,634
Total	$ —	$ —	$ 1,471,634	$ 1,471,634

NOTES TO FINANCIAL STATEMENTS

NOTE 12—ENDOWMENT FUNDS (Continued)

Changes in endowment net assets for the year ended June 30, 2021 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	$ 35,931	$ (511)	$ 1,242,467	$ 1,277,887
Contributions and Grants	—	—	5,475	5,475
Withdrawals	(35,931)	—	—	(35,931)
Investment Income, net of fees	—	3,212	16,961	20,173
Net Realized and Unrealized Gains and Losses	—	38,480	206,731	245,211
Appropriation of Endowment Assets for Expenditure	—	(41,181)	—	(41,181)
Endowment Net Assets, End of Year	$ —	$ —	$ 1,471,634	$ 1,471,634

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 $128,202 for 2022 and $126,407 for 2021.

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, 2022 and 2021, 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 rental payments commence at $5,114 per month and increase on March 1 every year by approximately 3% per annum. Additionally, the Organization entered into a two-year lease agreement for a satellite office located in Chicago, Illinois, with monthly rental payments commencing at $9,058 per month and increasing 3% per annum, which expired in January 2022. This lease was not renewed. The Organization also leases warehouse storage on a month-to-month basis.

Rental expense, and related real estate taxes and operating expenses for the year ended June 30, 2022 were $137,006 and $54,446, respectively, which is included in occupancy on the statements of functional expenses. Rental expense, and related real estate taxes and operating expenses for the year ended June 30, 2021 were $169,649 and $32,335, respectively.

As of June 30, 2022 and 2021, a deferred rent liability was recognized in the amount of $20,247 and $6,514, respectively, for the difference between the actual cash outlay for base rental payments and the straight-line rent expense computed over the term of the lease in accordance with U.S. principles generally accepted in the United States of America.

The minimum future payment on the above lease is as follows:

Year Ending June 30	
2023	$ 56,867
2024	63,840
2025	65,755
2026	67,728
2027	69,069
Thereafter	5,755
	$ 329,014

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 October 7, 2022, the date through which the financial statements were available for issue. There were no subsequent events which require disclosure.