

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

FINANCIAL STATEMENTS

JUNE 30, 2019



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INDEPENDENT AUDITORS' REPORT

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

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, 2019 and 2018, and the related statements of activities, functional expenses, and cash flows for the years then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes 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.

Auditors' Responsibility

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

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, 2019 and 2018, 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.

Warady & Davis LLP

December 17, 2019

FAMILIES OF SPINAL MUSCULAR ATROPHY d/b/a CURE SMA

STATEMENTS OF FINANCIAL POSITION

As of June 30	2019	2018
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	\$ 4,382,614	\$ 4,797,160
Grants Receivable, net of Allowance for Uncollectible Amounts of \$13,000 and \$20,000	2,485,432	1,064,586
Pledges Receivable, net of Allowance for Uncollectible Amounts of \$23,300 and \$9,000	1,040,398	205,796
Other Receivables, net of Allowance for Uncollectible Amounts of \$-0- and \$4,000	108,319	274,082
Prepaid Expenses	90,394	94,520
Total Current Assets	<u>8,107,157</u>	<u>6,436,144</u>
PROPERTY AND EQUIPMENT, NET	<u>337,177</u>	<u>170,315</u>
NONCURRENT ASSETS		
Pledges Receivable	200,001	—
Security Deposits and Other Assets	23,342	23,342
Intangibles, net of Accumulated Amortization of \$440,638 and \$240,191	507,000	410,615
Investments	1,201,609	1,110,862
	<u>1,931,952</u>	<u>1,544,819</u>
	<u>\$ 10,376,286</u>	<u>\$ 8,151,278</u>
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts Payable	\$ 532,566	\$ 483,671
Grants Payable	2,630,934	1,098,747
Accrued Expenses	1,292,140	983,697
Accrued Payroll and Related Expenses	233,203	97,187
Accrued Vacation	138,128	114,211
Deferred Rent	6,839	4,585
Total Current Liabilities	<u>4,833,810</u>	<u>2,782,098</u>
LONG-TERM LIABILITIES		
Grants Payable	425,001	393,750
Deferred Rent	12,669	19,508
Total Long-Term Liabilities	<u>437,670</u>	<u>413,258</u>
Total Liabilities	<u>5,271,480</u>	<u>3,195,356</u>
NET ASSETS		
Without Donor Restrictions	462,362	1,322,363
Without Donor Restrictions - Board Designated Endowment	35,613	34,733
With Donor Restrictions - Time and Purpose	3,440,835	2,522,697
With Donor Restrictions - Endowment	1,165,996	1,076,129
Total Net Assets	<u>5,104,806</u>	<u>4,955,922</u>
	<u>\$ 10,376,286</u>	<u>\$ 8,151,278</u>

See accompanying notes.

STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS

For the Years Ended June 30	2019				2018			
	Without Donor Restrictions	With Donor Restrictions Time and Purpose	With Donor Restrictions Endowment	Total	Without Donor Restrictions	With Donor Restrictions Time and Purpose	With Donor Restrictions Endowment	Total
SUPPORT AND REVENUE								
Contributions								
Contributions and Grants	\$ 1,087,755	\$ 7,318,726	\$ 63,994	\$ 8,470,475	\$ 1,977,685	\$ 5,636,556	\$ 48,571	\$ 7,662,812
Chapter Events								
Special Events Revenue	3,389,424	898,257		4,287,681	3,300,837			3,300,837
Less: Event Expenses	(607,074)			(607,074)	(829,363)			(829,363)
	<u>2,782,350</u>	<u>898,257</u>		<u>3,680,607</u>	<u>2,471,474</u>			<u>2,471,474</u>
Total Direct Public Support	<u>3,870,105</u>	<u>8,216,983</u>	<u>63,994</u>	<u>12,151,082</u>	<u>4,449,159</u>	<u>5,636,556</u>	<u>48,571</u>	<u>10,134,286</u>
Annual Conference	<u>649,343</u>	<u>1,358,070</u>		<u>2,007,413</u>	<u>1,159,409</u>			<u>1,159,409</u>
Other Revenues								
Investment Income	22,455	25,994	25,873	74,322	10,313	27,187	28,960	66,460
Other Income	45,183			45,183	132,100			132,100
Total Other Revenues	<u>67,638</u>	<u>25,994</u>	<u>25,873</u>	<u>119,505</u>	<u>142,413</u>	<u>27,187</u>	<u>28,960</u>	<u>198,560</u>
Net Assets Released from Restrictions	<u>8,682,909</u>	<u>(8,682,909)</u>		<u>—</u>	<u>4,079,505</u>	<u>(4,079,505)</u>		<u>—</u>
Total Support and Revenues	<u>13,269,995</u>	<u>918,138</u>	<u>89,867</u>	<u>14,278,000</u>	<u>9,830,486</u>	<u>1,584,238</u>	<u>77,531</u>	<u>11,492,255</u>
Expenses								
Program Services	11,696,028			11,696,028	8,000,769			8,000,769
Management and General	1,010,788			1,010,788	669,278			669,278
Fundraising	1,422,300			1,422,300	1,015,466			1,015,466
Total Expenses	<u>14,129,116</u>			<u>14,129,116</u>	<u>9,685,513</u>			<u>9,685,513</u>
CHANGE IN NET ASSETS	<u>(859,121)</u>	<u>918,138</u>	<u>89,867</u>	<u>148,884</u>	<u>144,973</u>	<u>1,584,238</u>	<u>77,531</u>	<u>1,806,742</u>
Net Assets, Beginning of Year, as Previously Reported	1,357,096	2,522,697	1,076,129	4,955,922	1,212,123	484,392	998,598	2,695,113
Prior Period Adjustment						454,067		454,067
Net Assets, Beginning of Year, as Restated	<u>1,357,096</u>	<u>2,522,697</u>	<u>1,076,129</u>	<u>4,955,922</u>	<u>1,212,123</u>	<u>938,459</u>	<u>998,598</u>	<u>3,149,180</u>
NET ASSETS, ENDING	<u>\$ 497,975</u>	<u>\$ 3,440,835</u>	<u>\$ 1,165,996</u>	<u>\$ 5,104,806</u>	<u>\$ 1,357,096</u>	<u>\$ 2,522,697</u>	<u>\$ 1,076,129</u>	<u>\$ 4,955,922</u>

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES

For the Year Ended June 30, 2019

	Research	Patient Services	Family Support	Awareness	Total Program Services	Management and General	Fundraising	Event Expenses	Total
Salaries	\$ 755,734	\$ 719,023	\$ 595,910	\$ 358,955	\$ 2,429,622	\$ 446,470	\$ 832,124	\$ —	\$ 3,708,216
Payroll Taxes	53,226	50,640	41,970	25,281	171,117	31,446	58,606	—	261,169
Employee Benefits	76,384	72,673	60,230	36,280	245,567	45,127	84,104	—	374,798
Advertising	91,064	29,270	65,045	42,280	227,659	40,484	74,802	—	342,945
Bad Debt Expense	—	—	—	—	—	18,134	—	—	18,134
Bank Charges, Credit Card and Other Fees	—	—	—	—	—	72,748	47,786	—	120,534
Conferences and Meetings	1,386,243	373,147	836,975	104,622	2,700,987	106,026	—	270,639	3,077,652
Depreciation and Amortization	4,179	189,445	103,825	18,804	316,253	2,091	8,358	—	326,702
Dues and Subscriptions/Publications	—	—	—	—	—	—	23,878	—	23,878
Equipment Grants and Care Packages	—	1,671	361,968	—	363,639	—	—	—	363,639
Equipment Rental	—	—	—	—	—	19,783	—	—	19,783
Insurance Expense	4,910	4,671	3,872	2,332	15,785	7,847	5,406	—	29,038
Miscellaneous	472	152	337	219	1,180	6,961	382	3,090	11,613
Occupancy	47,094	46,138	36,945	21,363	151,540	26,013	39,770	75,015	292,338
Office Expenses	12,540	4,030	8,957	5,822	31,349	3,135	10,300	17,066	61,850
Prizes and Promotional Items	—	—	—	—	—	5,780	—	216,373	222,153
Professional Services	384,890	203,206	22,389	14,553	625,038	97,041	25,748	17,635	765,462
Research Grants	2,091,503	1,387,184	—	—	3,478,687	—	—	—	3,478,687
Shipping Expense	22,519	56,364	82,155	10,215	171,253	12,439	19,017	—	202,709
Staff Development/Training	11,968	3,847	8,549	5,556	29,920	2,992	9,831	—	42,743
Stationery and Printing	44,101	77,177	77,177	11,025	209,480	—	11,025	2,872	223,377
Technology	89,608	28,803	64,006	41,604	224,021	22,402	73,607	—	320,030
Telephone and Internet	14,346	4,611	10,247	6,661	35,865	3,587	11,784	—	51,236
Travel	59,710	56,810	47,084	28,362	191,966	35,275	65,746	2,832	295,819
Website	5,007	5,007	35,046	30,040	75,100	5,007	20,026	1,552	101,685
	<u>5,155,498</u>	<u>3,313,869</u>	<u>2,462,687</u>	<u>763,974</u>	<u>11,696,028</u>	<u>1,010,788</u>	<u>1,422,300</u>	<u>607,074</u>	<u>14,736,190</u>
Less Event Expenses on Statements of Activities	—	—	—	—	—	—	—	(607,074)	(607,074)
TOTALS	\$ 5,155,498	\$ 3,313,869	\$ 2,462,687	\$ 763,974	\$ 11,696,028	\$ 1,010,788	\$ 1,422,300	\$ —	\$ 14,129,116

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES (Continued)

For the Year Ended June 30, 2018

	Research	Patient Services	Family Support	Awareness	Total Program Services	Management and General	Fundraising	Total
Salaries	\$ 692,402	\$ 431,428	\$ 525,011	\$ 300,524	\$ 1,949,365	\$ 261,530	\$ 574,309	\$ 2,785,204
Payroll Taxes	52,444	32,678	39,766	22,763	147,651	19,809	43,500	210,960
Employee Benefits	70,231	43,760	53,253	30,483	197,727	26,527	58,253	282,507
Advertising	94,294	20,964	25,461	15,140	155,859	12,568	27,831	196,258
Annual Campaign	—	—	2,003	11,760	13,763	—	26,098	39,861
Bad Debt Expense	—	—	—	—	—	47,030	—	47,030
Bank Charges, Credit Card and Other Fees	—	—	—	—	—	43,367	42,781	86,148
Conferences and Meetings	754,921	379,497	346,928	31,100	1,512,446	1,927	16,206	1,530,579
Depreciation and Amortization	5,497	139,825	5,830	26,236	177,388	2,915	11,661	191,964
Dues and Subscriptions/Publications	154	50	110	171	485	14,514	127	15,126
Equipment Grants and Care Packages	—	4,689	29,113	—	33,802	—	—	33,802
Insurance Expense	4,025	2,508	3,052	1,747	11,332	6,466	3,338	21,136
Miscellaneous	3,594	2,033	476	378	6,481	2,175	1,065	9,721
Occupancy	58,804	18,901	42,003	27,302	147,010	14,692	48,306	210,008
Office Expenses	28,809	6,321	14,046	9,132	58,308	5,074	14,945	78,327
Professional Services	334,746	69,709	21,159	20,412	446,026	89,841	26,285	562,152
Research Grants	2,549,627	—	—	—	2,549,627	—	—	2,549,627
Shipping Expense	13,862	16,493	40,892	8,657	79,904	2,950	14,026	96,880
Staff Development/Training	8,062	4,472	5,795	4,267	22,596	3,477	6,165	32,238
Stationery and Printing	17,896	33,842	39,636	2,440	93,814	—	1,249	95,063
Technology	12,577	59,001	9,167	5,959	86,704	4,126	11,187	102,017
Telephone and Internet	10,043	3,230	7,440	4,753	25,466	2,511	8,358	36,335
Travel	33,603	64,932	26,793	19,874	145,202	99,180	45,880	290,262
Website	15,014	15,299	58,921	50,579	139,813	8,599	33,896	182,308
TOTALS	\$ 4,760,605	\$ 1,349,632	\$ 1,296,855	\$ 593,677	\$ 8,000,769	\$ 669,278	\$ 1,015,466	\$ 9,685,513

FAMILIES OF SPINAL MUSCULAR ATROPHY d/b/a CURE SMA

STATEMENTS OF CASH FLOWS

For the Years Ended June 30	2019	2018
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in Net Assets	<u>\$ 148,884</u>	<u>\$ 1,806,742</u>
Adjustments to Reconcile Change in Net Assets to Net Cash Provided by Operating Activities		
Donated Medical Equipment	(8,900)	—
Depreciation	126,254	62,878
Amortization	200,448	129,086
Unrealized and Realized Gain on Investments	(37,559)	(47,129)
Donor Restricted Endowment Contributions	(63,994)	(48,571)
Change in Allowance for Uncollectible Amounts	3,300	18,167
Changes in		
Grants Receivable	(1,413,846)	(549,242)
Pledges Receivable	(1,048,903)	(42,766)
Other Receivables	169,763	(23,841)
Prepaid Expenses	4,126	(44,675)
Accounts Payable	(19,105)	(605,440)
Grants Payable	1,563,438	502,497
Accrued Expenses	308,443	976,322
Accrued Payroll and Related Expenses	136,016	23,284
Accrued Vacation	23,917	31,897
Deferred Rent	(4,585)	21,336
Total Adjustments	<u>(61,187)</u>	<u>403,803</u>
Net Cash Provided by Operating Activities	<u>87,697</u>	<u>2,210,545</u>
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of Equipment	(284,216)	(89,263)
Capitalization of Intangibles	(228,833)	(331,834)
Purchases of Investments	(591,175)	(375,349)
Reinvested Dividends	(21,378)	(17,520)
Proceeds from Sales of Investments	<u>559,365</u>	<u>225,609</u>
Net Cash Used by Investing Activities	<u>(566,237)</u>	<u>(588,357)</u>
CASH FLOWS FROM FINANCING ACTIVITIES		
Donor Restricted Endowment Contributions	<u>63,994</u>	<u>48,571</u>
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS		
	(414,546)	1,670,759
Cash and Cash Equivalents, Beginning	<u>4,797,160</u>	<u>3,126,401</u>
CASH AND CASH EQUIVALENTS, ENDING	<u>\$ 4,382,614</u>	<u>\$ 4,797,160</u>
SUPPLEMENTAL DISCLOSURES OF CASH FLOW INFORMATION		
Noncash Activities		
Intangibles Acquired Included in Payables	<u><u>\$ 68,000</u></u>	<u><u>\$ 135,840</u></u>

NOTES TO FINANCIAL STATEMENTS

NATURE OF ORGANIZATION

Families of Spinal Muscular Atrophy d/b/a Cure SMA (the “Organization”) is an Illinois not-for-profit organization. The Organization’s efforts include advancing research, to provide patient and family support, and to promote public awareness with regard to the disease Spinal Muscular Atrophy (“SMA”). The Organization’s major sources of revenue are contributions and grants. During the year ended June 30, 2019, 64% of total revenues was received from three donors/grantors and at June 30, 2019, receivables from three grantors accounted for approximately 63% of total receivables. During the year ended June 30, 2018, 39% of total revenues was received from two donors/grantors and at June 30, 2018, receivables from three grantors accounted for approximately 77% 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 restriction - 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 restriction may otherwise be designated for specific purposes by action of the Board of Directors.

Net assets with donor restriction – 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 restriction are reclassified to net assets without donor restriction and are reported in the accompanying financial statements as net assets released from restrictions

Additionally, net assets with donor restriction 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 restriction unless use of the related asset is limited by donor-imposed restrictions. Expenses are reported as net assets without donor restriction.

NOTES TO FINANCIAL STATEMENTS

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)**USE OF ESTIMATES**

The preparation of financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenue and expenses during the reporting period. Actual results may differ from those estimates.

PUBLIC SUPPORT, REVENUE RECOGNITION, GRANTS AND PLEDGES RECEIVABLE

Contributions, including organization grants, and corporate and individual donations, are generally available for 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. After all attempts to collect a receivable have failed, the receivable is written off against the allowance or bad debt expense.

IN-KIND DONATIONS AND VOLUNTEER SUPPORT

Contributions of non-cash assets are recorded at their fair values in the period 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 Organization had donated in-kind contributions comprised of medical equipment of \$8,900, donated goods of \$118,075 of which \$63,167 is included in stationary and printing expense, \$52,608 is included in chapter events and \$2,300 is included in conference and meetings, and \$15,700 of donated professional services for the year ended June 30, 2019. The Organization had donated goods of \$234,192 included in chapter events for the year ended June 30, 2018. There were no donated services provided for the year ended June 30, 2018.

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 earnings. 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 non-current.

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 \$200,448 for the year ended June 30, 2019 and \$129,086 for the year ended June 30, 2018.

Amortization expense for the next three years is:

Year Ending June 30	
2020	\$ 281,716
2021	159,232
2022	<u>66,052</u>
	<u>\$ 507,000</u>

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 costs deemed to be related to time and efforts expended by employees on the different functional categories and allocation of occupancy and related costs using space utilization percentages occupied by the various functions.

NOTES TO FINANCIAL STATEMENTS

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

ACCOUNTING PRONOUNCEMENTS

The Organization adopted Accounting Standards Update (ASU) No. 2016-14, *Not-for-Profit Entities (Topic 958): Presentation of Financial Statements of Not-for-Profit Entities*, which was issued by the Financial Accounting Standards Board (FASB) in August 2016 and was effective for the Organization's year ended June 30, 2019. ASU No. 2016-14 required significant changes to the financial reporting model of organizations that follow the FASB not-for-profit rules, including changing from three classes of net assets to two classes: net assets with donor restrictions and net assets without donor restrictions; changes in the way certain information is aggregated and reported by the organization, including required disclosures about the liquidity and availability of resources; and a statement of functional expenses with required disclosure of the allocation methodology. The new standard was applied on a retrospective basis. Other than these additional disclosures and name changes, no additional revisions were required.

In May 2014, the Financial Accounting Standards Board (FASB) issued Accounting Standards Update (ASU) No. 2014-09 (*Topic 606): Revenue from Contracts with Customers*, which will supersede the current revenue recognition requirements in Topic 605, *Revenue Recognition*. The ASU is based on the principle that revenue is recognized to depict the transfer of goods or services to customers in an amount that reflects the consideration to which the entity expects to be entitled in exchange for those goods or services. The ASU also requires additional disclosure about the nature, amount, timing, and uncertainty of revenue and cash flows arising from customer contracts, including significant judgments and changes in judgments and assets recognized from costs incurred to obtain or fulfill a contract. The new guidance will be effective for the Organization's year ending June 30, 2020. The ASU permits application of the new revenue recognition guidance to be applied using one of two retrospective application methods. The Organization has determined that the standard will not have a significant impact on the financial statements. The Organization is currently gathering the appropriate information to implement the standard in a timely manner.

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, 2022 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 and there is not expected to be a significant impact on expenses or cash flows.

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, 2019:

Cash.....	\$	4,382,614
Grants Receivable, net		2,485,432
Pledges Receivable, net.....		1,240,399
Other Receivables.....		108,319
Investments.....		1,201,609
Less: Net Assets with Donor Restrictions – Time and Purpose		(3,440,835)
Less: Net Assets with Donor Restrictions – Endowment		(1,165,996)
Less: Net Assets Without Donor Restrictions - Board Designated Endowment.....		(35,613)
	\$	<u>4,775,929</u>

As part of its liquidity management plan, the Organization maintains sufficient cash to meet current operating needs. As indicated in the above chart, assuming revenue is consistent in 2020, the Organization has sufficient liquid assets to meet at least one year of expenses. Although the Organization does not intend to spend their board designated endowment net assets of \$35,613, these amounts could be undesignated by the board should the need arise.

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 standings 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.

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:

	<u>2019</u>	<u>2018</u>
Less than One Year	\$ 1,063,698	\$ 214,796
One to Five Years	<u>200,001</u>	—
	1,263,699	214,796
Less: Allowance for Uncollectible Accounts.....	<u>23,300</u>	9,000
Net Pledges Receivable	1,240,399	205,796
Less Current Portion.....	<u>1,040,398</u>	205,796
Long-Term Portion	\$ <u>200,001</u>	\$ —

Management has not discounted the long-term portion of pledges receivable, as the amount was not deemed significant.

NOTES TO FINANCIAL STATEMENTS

NOTE 5—PROPERTY AND EQUIPMENT

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

	<u>2019</u>	<u>2018</u>
Office Equipment.....	\$ 52,437	\$ 47,344
Office Furniture.....	30,745	30,745
Medical Equipment	<u>497,129</u>	<u>209,106</u>
	580,311	287,195
Less Accumulated Depreciation	<u>243,134</u>	<u>116,880</u>
Total.....	<u>\$ 337,177</u>	<u>\$ 170,315</u>

Depreciation expense was \$126,254 for the year ended June 30, 2019 and \$62,878 for the year ended June 30, 2018.

NOTE 6—INVESTMENTS

Investments at June 30 consisted of the following:

	<u>2019</u>	<u>2018</u>
Mutual Funds		
Equity Funds		
Mid Cap	\$ 131,844	122,813
Small Growth	—	43,860
Money Market	94,261	39,211
Index	280,898	—
Large Cap	54,186	—
Foreign Large Growth	78,755	105,812
International Large Cap.....	<u>28,962</u>	<u>—</u>
Total Equity Funds.....	<u>668,906</u>	<u>311,696</u>
Alternative Investments – Mutual Funds.....	<u>85,728</u>	<u>104,582</u>
Fixed Income Funds		
Intermediate Term Bond Fund.....	<u>392,394</u>	<u>364,700</u>
Total Mutual Funds	<u>1,147,028</u>	<u>780,978</u>
Exchange Traded Funds	<u>54,581</u>	<u>329,884</u>
Total Investments	<u>\$ 1,201,609</u>	<u>\$ 1,110,862</u>

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

	<u>2019</u>	<u>2018</u>
Net Realized Gains.....	\$ 85,840	\$ 11,312
Net Unrealized Gains (Losses)	(48,281)	35,817
Interest and Dividends.....	45,169	27,268
Investment Expenses	<u>(8,406)</u>	<u>(7,937)</u>
Total Investment Income	<u>\$ 74,322</u>	<u>\$ 66,460</u>

NOTES TO FINANCIAL STATEMENTS

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, 2019.

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.

NOTES TO FINANCIAL STATEMENTS

NOTE 8—GRANTS PAYABLE

The Organization makes grants to various medical and research centers for research in relation to Spinal Muscular Atrophy. Grant agreements are subject to periodic reporting and compliance requirements and can be rescinded by the Organization if it is determined that a research project is no longer academically, technically or commercially feasible. The Organization is responsible for all costs incurred or committed at the time of termination. Research grant expense for the year ended June 30, 2019, was \$3,478,687 and \$2,549,627 for June 30, 2018.

As of June 30, 2019, the Organization's grants payable obligations have terms expiring through March 2021. As of June 30, 2019, grants payable obligations amounted to \$3,055,935. As of June 30, 2018, grants payable obligations amounted to \$1,492,497.

Future obligations associated with the Organization's grants payable for fiscal years subsequent to June 30, 2019 are as follows:

2020	\$ 2,630,934
2021	<u>425,001</u>
	<u>\$ 3,055,935</u>

Certain grant payments are made to grantees based on research milestones being met. These obligations are not accrued since conditional promises to give are not recognized until the conditions are substantially met. During the year ended June 30, 2019, certain milestones were achieved and \$250,000 of payments related to prior year conditional promises were disbursed and are included in research grants in the statements of functional expenses. During the year ended June 30, 2018, certain milestones were achieved and \$116,500 of payments related to prior year conditional promises were disbursed and are included in research grants in the statements of functional expenses.

As of June 30, 2019, future conditional promises due to grantees based on the achievement of milestones are estimated to be \$425,000. As of June 30, 2018, future conditional promises due to grantees based on the achievement of milestones were estimated to be \$675,000.

NOTES TO FINANCIAL STATEMENTS

NOTE 9—NET ASSETS WITH DONOR RESTRICTIONS

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

	<u>2019</u>	<u>2018</u>
Research	\$ 388,850	\$ 754,550
Annual Conference	89,001	93,431
Scholarships for Adults with SMA and Their Aides	—	3,965
Scholarships	70,251	27,187
Car Beds	14,700	26,033
Equipment and Wagons	621,191	531,483
Equipment Sitters	—	3,867
Mentee Travel	—	42,797
Industry Collaboration Phase III	—	531,870
Industry Collaboration Phase IV	660,104	—
Congressional Reception	75,000	20,000
Local Educational and Networking Conferences	253,850	225,000
Chapter Meeting	225,000	—
Care Packages	244,745	100,887
Newborn Screening	<u>798,143</u>	<u>161,627</u>
	<u>\$ 3,440,835</u>	<u>\$ 2,522,697</u>

Net assets of \$8,682,909 and \$4,079,505 were released from donor restrictions during the years ended June 30, 2019 and 2018, respectively, by incurring expenses satisfying the purpose restrictions.

NOTE 10—ENDOWMENT FUNDS

The Organization maintains one endowment fund consisting of gifts restricted by donors for permanent investment. 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 fund. The majority of the Organization's endowment contributions are subject to a specific agreement with the Organization.

The Organization entered into an agreement with a donor to establish an endowment fund for the purpose of providing scholarships to attend the Organization's annual conference for any families of patients newly diagnosed with Spinal Muscular Atrophy. 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. Additionally, under the terms of the agreement, the board of directors designated \$30,000 of unrestricted net assets for the endowment fund.

NOTES TO FINANCIAL STATEMENTS

NOTE 10—ENDOWMENT FUNDS (Continued)

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, 2019 is as follows:

	<u>Without Donor Restriction</u>	<u>Time and Purpose Restriction</u>	<u>Endowment</u>	<u>Total</u>
Board-Designated				
Endowment Funds	\$ 35,613	\$ —	\$ —	\$ 35,613
Donor-Restricted				
Endowment Funds	<u>—</u>	<u>—</u>	<u>1,165,996</u>	<u>1,165,996</u>
Total	<u>\$ 35,613</u>	<u>\$ —</u>	<u>\$ 1,165,996</u>	<u>\$ 1,201,609</u>

NOTES TO FINANCIAL STATEMENTS

NOTE 10—ENDOWMENT FUNDS (Continued)

Changes in endowment net assets for the year ended June 30, 2019 are as follows:

	Without Donor <u>Restriction</u>	Time and Purpose <u>Restriction</u>	<u>Endowment</u>	Total Endowment Net Assets
Endowment Net Assets, Beginning of Year.....	\$ 34,733	\$ —	\$ 1,076,129	\$ 1,110,862
Contributions and Grants.....			63,994	63,994
Investment Income, net of fees.....	500	7,759	7,723	15,982
Net Realized and Unrealized Gains.....	1,174	18,235	18,150	37,559
Appropriation of Endowment Assets for Expenditure	<u>(794)</u>	<u>(25,994)</u>	<u>—</u>	<u>(26,788)</u>
Endowment Net Assets, End of Year	<u>\$ 35,613</u>	<u>\$ —</u>	<u>\$ 1,165,996</u>	<u>\$ 1,201,609</u>

Endowment net asset composition by type of fund as of June 30, 2018 is as follows:

	Without Donor <u>Restriction</u>	Time and Purpose <u>Restriction</u>	<u>Endowment</u>	<u>Total</u>
Board-Designated Endowment Funds	\$ 34,733	\$ —	\$ —	\$ 34,733
Donor-Restricted Endowment Funds	<u>—</u>	<u>—</u>	<u>1,076,129</u>	<u>1,076,129</u>
Total	<u>\$ 34,733</u>	<u>\$ —</u>	<u>\$ 1,076,129</u>	<u>\$ 1,110,862</u>

Changes in endowment net assets for the year ended June 30, 2018 are as follows:

	Without Donor <u>Restriction</u>	Time and Purpose <u>Restriction</u>	<u>Endowment</u>	Total Endowment Net Assets
Endowment Net Assets, Beginning of Year.....	\$ 33,715	\$ —	\$ 998,598	\$ 1,032,313
Contributions and Grants.....			48,571	48,571
Investment Income, net of fees.....	356	5,112	5,445	10,913
Net Realized and Unrealized Gains.....	1,539	22,075	23,515	47,129
Appropriation of Endowment Assets for Expenditure	<u>(877)</u>	<u>(27,187)</u>	<u>—</u>	<u>(28,064)</u>
Endowment Net Assets, End of Year	<u>\$ 34,733</u>	<u>\$ —</u>	<u>\$ 1,076,129</u>	<u>\$ 1,110,862</u>

NOTES TO FINANCIAL STATEMENTS

NOTE 11—RETIREMENT PLAN

The Organization sponsors a 401(k) retirement plan for all eligible employees immediately upon their date of hire. The plan provides for employer profit-sharing contributions for full-time and part-time employees that are immediately 100% vested. The Organization's contribution to the plan was \$108,509 for 2019 and \$84,035 for 2018.

NOTE 12—CHAPTERS

The Organization has established chapters consisting of volunteers who promote local and regional fund-raising and outreach efforts for the Organization by hosting events in their respective states and regions. As of June 30, 2019 and 2018, there were 36 and 34 active chapters, respectively, throughout the United States. Fund-raising and patient service support activities are coordinated by the staff of the Organization, and revenue and expenses related to all such activities are included in the accompanying statements of activities.

NOTE 13—INCOME TAXES

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

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

NOTE 14—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 now expires in February 2022. Monthly rental payments commenced at \$4,740 per month and increase approximately 3% per annum. Additionally the Organization entered into a sublease commencing in October 2016 for a satellite office located in Chicago, Illinois, which expires in January 2020 with monthly rental payments commencing at \$8,499 per month and increasing 2% per annum. Rental expense and related real estate taxes and operating expenses for the year ended June 30, 2019 was \$160,017 and \$43,208, 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, 2018 was \$174,681 and \$26,299, respectively.

As of June 30, 2019 and 2018, a deferred rent liability was recognized in the amount of \$19,508 and \$24,093, respectively, for the difference between the actual cash outlay for base rental expense 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.

NOTES TO FINANCIAL STATEMENTS

NOTE 14—OPERATING LEASES (Continued)

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

Year Ending June 30		
2020	\$	159,448
2021		62,764
2022		<u>42,667</u>
	\$	<u>264,879</u>

NOTE 15—RECLASSIFICATIONS

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

NOTE 16—SUBSEQUENT EVENTS

Management has evaluated subsequent events through December 17, 2019, the date through which the financial statements were available for issue. There were no subsequent events which require disclosure.