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

FINANCIAL STATEMENTS

JUNE 30, 2020

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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

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, 2020 and 2019, 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, 2020 and 2019, 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.

Emphasis of Matter

As discussed in Note 1 to the financial statements, FAMILIES OF SPINAL MUSCULAR ATROPHY d/b/a CURE SMA adopted the new accounting guidance in ASU No. 2018-08, *Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made* as required by accounting principles generally accepted in the United States of America. This accounting principle was applied on a modified prospective basis. Our opinion is not modified with respect to this matter.

Warady & Davis LLP

October 20, 2020

STATEMENTS OF FINANCIAL POSITION

As of June 30	2020	2019
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	**$ 6,593,442**	$ 4,382,614
Grants Receivable, net of Allowance for Uncollectible Amounts of $18,000 and $13,000	**1,056,025**	2,485,432
Pledges Receivable, net of Allowance for Uncollectible Amounts of $8,000 and $23,300	**268,714**	1,040,398
Other Receivables	**—**	108,319
Prepaid Expenses	**176,850**	90,394
Total Current Assets	**8,095,031**	8,107,157
PROPERTY AND EQUIPMENT, NET	**412,831**	337,177
NONCURRENT ASSETS		
Pledges Receivable	**50,000**	200,001
Security Deposits and Other Assets	**15,402**	23,342
Intangibles, net of Accumulated Amortization of $739,015 and $440,638	**300,823**	507,000
Investments	**1,277,887**	1,201,609
	1,644,112	1,931,952
	$ 10,151,974	$ 10,376,286
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts Payable	**$ 311,589**	$ 532,566
Grants Payable	**2,185,799**	2,630,934
Accrued Expenses	**18,636**	1,292,140
Accrued Payroll and Related Expenses	**196,330**	233,203
Accrued Vacation	**161,991**	138,128
Deferred Rent	**6,835**	6,839
Total Current Liabilities	**2,881,180**	4,833,810
LONG-TERM LIABILITIES		
Grants Payable	**396,250**	425,001
Paycheck Protection Program Loan	**769,100**	—
Deferred Rent	**6,514**	12,669
Deferred Revenue	**21,000**	—
Total Long-Term Liabilities	**1,192,864**	437,670
Total Liabilities	**4,074,044**	5,271,480
NET ASSETS		
Without Donor Restrictions	**1,427,936**	462,362
Without Donor Restrictions - Board-Designated Endowment	**35,931**	35,613
With Donor Restrictions - Time and Purpose	**3,371,596**	3,440,835
With Donor Restrictions - Endowment	**1,242,467**	1,165,996
Total Net Assets	**6,077,930**	5,104,806
	$ 10,151,974	$ 10,376,286

See accompanying notes.

STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS

For the Years Ended June 30	2020				2019			
		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 and Grants	$ 1,892,650	$ 5,032,168	$ 66,864	$ 6,991,682	$ 1,087,755	$ 7,318,726	$ 63,994	$ 8,470,475
Chapter Events								
Special Events Revenue	2,140,723	1,632,400		3,773,123	3,389,424	898,257		4,287,681
Less: Event Expenses	(377,501)			(377,501)	(607,074)			(607,074)
	1,763,222	1,632,400		3,395,622	2,782,350	898,257		3,680,607
Annual Conference	1,640,500			1,640,500	649,343	1,358,070		2,007,413
Other Revenues								
Investment Income	2,981	31,233	9,607	43,821	22,455	25,994	25,873	74,322
Other Income	31,591			31,591	45,183			45,183
Total Other Revenues	34,572	31,233	9,607	75,412	67,638	25,994	25,873	119,505
Net Assets Released from Restrictions	6,765,040	(6,765,040)		—	8,682,909	(8,682,909)		—
Total Support and Revenues	12,095,984	(69,239)	76,471	12,103,216	13,269,995	918,138	89,867	14,278,000
Expenses								
Program Services	8,902,759			8,902,759	11,696,028			11,696,028
Management and General	858,845			858,845	1,010,788			1,010,788
Fundraising	1,368,488			1,368,488	1,422,300			1,422,300
Total Expenses	11,130,092			11,130,092	14,129,116			14,129,116
CHANGE IN NET ASSETS	965,892	(69,239)	76,471	973,124	(859,121)	918,138	89,867	148,884
Net Assets, Beginning of Year	497,975	3,440,835	1,165,996	5,104,806	1,357,096	2,522,697	1,076,129	4,955,922
NET ASSETS, ENDING	$ 1,463,867	$ 3,371,596	$ 1,242,467	$ 6,077,930	$ 497,975	$ 3,440,835	$ 1,165,996	$ 5,104,806

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES

For the Year Ended June 30, 2020

	Research	Patient Services	Family Support	Awareness	Total Program Services	Management and General	Fundraising	Event Expenses	Total
Salaries	$ 814,830	$ 811,232	$ 715,275	$ 385,825	$ 2,727,162	$ 451,794	$ 819,228	$ —	$ 3,998,184
Payroll Taxes	56,263	56,015	49,389	26,641	188,308	31,196	56,567	—	276,071
Employee Benefits	77,167	76,826	67,739	36,539	258,271	42,787	77,584	—	378,642
Advertising	108,630	34,917	77,592	50,435	271,574	34,381	89,232	—	395,187
Bad Debt Expense	—	—	—	—	—	2,700	—	—	2,700
Bank Charges, Credit Card and Other Fees	—	—	12,737	12,737	25,474	37,545	35,028	—	98,047
Conferences and Meetings	434,600	90,200	262,401	32,800	820,001	—	—	166,090	986,091
Depreciation and Amortization	5,030	292,159	161,191	25,186	483,566	5,030	15,109	—	503,705
Dues and Subscriptions/Publications	—	—	—	—	—	—	19,394	—	19,394
Equipment Grants and Care Packages	—	—	398,392	—	398,392	—	—	—	398,392
Equipment Rental	—	—	—	—	—	21,144	—	—	21,144
Insurance Expense	5,920	5,894	5,197	2,804	19,815	8,229	5,952	—	33,996
Interest Expense	—	—	—	—	—	1,064			1,064
Miscellaneous	2,400	—	—	—	2,400	9,242	—	288	11,930
Occupancy	48,622	47,635	38,144	22,056	156,457	26,858	41,061	30,327	254,703
Office Expenses	8,987	2,889	6,419	4,172	22,467	2,247	7,382	6,664	38,760
Prizes and Promotional Items	18,937	—	—	—	18,937	2,282	—	173,135	194,354
Professional Services	319,153	94,815	22,594	14,687	451,249	51,340	25,984	—	528,573
Research Grants	1,696,807	561,315	—	—	2,258,122	—	—	—	2,258,122
Shipping Expense	20,388	51,896	75,990	9,267	157,541	11,119	16,681	—	185,341
Staff Development/Training	11,647	3,744	8,320	5,408	29,119	2,912	9,568	—	41,599
Stationery and Printing	33,640	58,870	58,870	8,410	159,790	—	8,410	—	168,200
Technology	92,930	29,870	66,378	43,146	232,324	23,233	76,335	—	331,892
Telephone and Internet	11,133	3,578	7,952	5,168	27,831	2,783	9,145	—	39,759
Temporary Labor	—	—	—	—	—	65,947	—	—	65,947
Travel	36,473	36,312	32,017	17,270	122,072	20,222	36,670	997	179,961
Website	4,790	4,830	33,528	28,739	71,887	4,790	19,158	—	95,835
	3,808,347	2,262,997	2,100,125	731,290	8,902,759	858,845	1,368,488	377,501	11,507,593
Less Event Expenses on Statements of Activities	—	—	—	—	—	—	—	(377,501)	(377,501)
TOTALS	$ 3,808,347	$ 2,262,997	$ 2,100,125	$ 731,290	$ 8,902,759	$ 858,845	$ 1,368,488	$ —	$ 11,130,092

See accompanying notes.

STATEMENTS OF FUNCTIONAL EXPENSES (Continued)

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	5,650	382	3,090	10,302
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
Temporary Labor	—	—	—	—	—	1,311	—	—	1,311
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
	5,155,498	3,313,869	2,462,687	763,974	11,696,028	1,010,788	1,422,300	607,074	14,736,190
Less Event Expenses on Statement 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

STATEMENTS OF CASH FLOWS

For the Years Ended June 30	**2020**	2019
CASH FLOWS FROM OPERATING ACTIVITIES		
Change in Net Assets	**$ 973,124**	$ 148,884
Adjustments to Reconcile Change in Net Assets to Net Cash Provided by Operating Activities		
Donated Medical Equipment	**(38,000)**	(8,900)
Depreciation	**205,328**	126,254
Amortization	**298,377**	200,448
Loss on Disposition of Property and Equipment	**361**	—
Stock Donations	**(56,550)**	—
Proceeds from Sale of Stock Donations	**57,050**	—
Unrealized and Realized Gain on Investments	**(13,765)**	(37,559)
Donor Restricted Endowment Contributions	**(66,864)**	(63,994)
Change in Allowance for Uncollectible Amounts	**(10,300)**	3,300
Changes in		
Grants Receivable	**1,424,407**	(1,413,846)
Pledges Receivable	**936,985**	(1,048,903)
Other Receivables	**108,319**	169,763
Prepaid Expenses	**(86,456)**	4,126
Security Deposits	**7,940**	—
Accounts Payable	**(220,977)**	(19,105)
Grants Payable	**(473,886)**	1,563,438
Accrued Expenses	**(1,273,504)**	308,443
Accrued Payroll and Related Expenses	**(36,873)**	136,016
Accrued Vacation	**23,863**	23,917
Deferred Rent	**(6,159)**	(4,585)
Deferred Revenue	**21,000**	—
Total Adjustments	**800,296**	(61,187)
Net Cash Provided by Operating Activities	**1,773,420**	87,697
CASH FLOWS FROM INVESTING ACTIVITIES		
Purchases of Equipment	**(243,343)**	(284,216)
Capitalization of Intangibles	**(92,200)**	(228,833)
Purchases of Investments	**(447,447)**	(591,175)
Reinvested Dividends	**(242)**	(21,378)
Proceeds from Sales of Investments	**384,676**	559,365
Net Cash Used by Investing Activities	**(398,556)**	(566,237)
CASH FLOWS FROM FINANCING ACTIVITIES		
Donor Restricted Endowment Contributions	**66,864**	63,994
Funds Received from PPP Loan	**769,100**	—
Net Cash Provided by Financing Activities	**835,964**	63,994
NET INCREASE (DECREASE) IN CASH AND CASH EQUIVALENTS	**2,210,828**	(414,546)
Cash and Cash Equivalents, Beginning	**4,382,614**	4,797,160
CASH AND CASH EQUIVALENTS, ENDING	**$ 6,593,442**	$ 4,382,614
SUPPLEMENTAL DISCLOSURES OF CASH FLOW INFORMATION		
Noncash Activities		
Donated Services	**$ 19,325**	$ 15,700
Donated Goods and Supplies	**$ 39,656**	$ 118,075
Intangibles Acquired Included in Payables	**$ —**	$ 68,000

See accompanying notes.

NOTES TO FINANCIAL STATEMENTS

NATURE OF ORGANIZATION

Families of Spinal Muscular Atrophy d/b/a Cure SMA (the “Organization”) is an Illinois not-for-profit organization. The Organization’s efforts include advancing research, to provide patient and family support, and to promote public awareness with regard to the disease Spinal Muscular Atrophy (“SMA’). The Organization’s major sources of revenue are contributions and grants. During the year ended June 30, 2020, 73% of total revenues was received from three donors/grantors and at June 30, 2020, receivables from three grantors accounted for approximately 80% of total receivables. 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.

The coronavirus (COVID-19) outbreak in the United States commenced prior to the Organization’s fiscal year-end and has directly impacted fundraising efforts since early spring 2020 as a result of no in-person events being held during this period of time, and also converting the Annual Conference to a virtual event. While in the near-term, the disruption to fundraising and operations is expected to continue, given considerable uncertainty concerning the duration, consequential effect to the operations and related financial impact cannot be reasonably estimated at this time.

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.

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 $38,000, donated goods of $39,656 which is included in prizes and promotional items, $19,325 of donated professional services of which $3,500 is included in staff development for the year ended June 30, 2020. 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.

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 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 $298,377 for the year ended June 30, 2020 and $200,448 for the year ended June 30, 2019.

Amortization expense for the next three years is:

Year Ending June 30	
2021	$ 189,966
2022	96,785
2023	14,072
	$ 300,823

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.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

ACCOUNTING PRONOUNCEMENTS

In June 2018, the FASB issued Accounting Standards Update (ASU) No. 2018-08, *Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made*. The new guidance applies to all entities that receive or make contributions and clarifies the definition of an exchange transaction. The criteria for evaluating whether contributions are unconditional (and thus recognized immediately as revenue) or conditional (for which revenue recognition is delayed until the condition is met) have been clarified. The focus is whether a gift or grant agreement both (1) specifies a “barrier” that the recipient must overcome to be entitled to the resources and (2) releases the donor from its obligation to transfer resources if the barrier is not achieved. An agreement that includes both is a conditional contribution. The Organization adopted the ASU commencing July 1, 2019 on a modified prospective basis.

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 was to be effective for the Organization’s year ending June 30, 2020 but was delayed as a result of the COVID-19 pandemic. The new guidance will now be effective for the Organization’s year ending June 30, 2021. The ASU permits application of the new revenue recognition guidance to be applied using one of two retrospective application methods. The Organization does not expect 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, 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 and 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:

	2020	2019
Cash	**$ 6,593,442**	$ 4,382,614
Grants Receivable, net	**1,056,025**	2,485,432
Pledges Receivable, net	**318,714**	1,240,399
Other Receivables	**—**	108,319
Investments	**1,277,887**	1,201,609
Less: Net Assets with Donor Restrictions – Time and Purpose	**(3,371,596)**	(3,440,835)
Less: Net Assets with Donor Restrictions – Endowment	**(1,242,467)**	(1,165,996)
Less: Net Assets Without Donor Restrictions – Board-Designated Endowment	**(35,931)**	(35,613)
	$ 4,596,074	$ 4,775,929

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. Although the Organization does not intend to spend its 2020 board-designated endowment net assets of $35,931 and did not spend its $35,613 board-designated net assets in 2019, 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:

	2020	2019
Less than One Year	**$ 276,714**	$ 1,063,698
One to Five Years	**50,000**	200,001
	326,714	1,263,699
Less: Allowance for Uncollectible Accounts	**8,000**	23,300
Net Pledges Receivable	**318,714**	1,240,399
Less Current Portion	**268,714**	1,040,398
Long-Term Portion	**$ 50,000**	$ 200,001

NOTE 4—PLEDGES RECEIVABLE (Continued)

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

NOTE 5—PROPERTY AND EQUIPMENT

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

	2020	2019
Office Equipment	$ 68,063	$ 52,437
Office Furniture	41,396	30,745
Medical Equipment	727,041	497,129
	836,500	580,311
Less Accumulated Depreciation	423,669	243,134
Total	$ 412,831	$ 337,177

Depreciation expense was $205,328 for the year ended June 30, 2020 and $126,254 for the year ended June 30, 2019.

NOTE 6—INVESTMENTS

Investments at June 30 consisted of the following:

	2020	2019
Mutual Funds and Exchange Traded Funds (ETF)		
Equity Funds		
Mid Cap	$ 130,647	$ 131,844
Index	288,077	280,898
Large Cap	84,943	54,186
Small Cap	61,138	54,581
International Large Growth	58,117	78,755
International Large Value	17,951	–
International Large Cap	26,286	28,962
Total Equity Funds	667,159	629,226
Alternative Investments – Mutual Funds	90,204	85,728
Money Market	39,964	94,261
Fixed Income Funds		
Short-Term US Treasury ETF	25,453	–
Intermediate Term Bond Fund	455,107	392,394
Total Fixed Income Funds	480,560	392,394
Total Investments	$ 1,277,887	$ 1,201,609

NOTE 6—INVESTMENTS (Continued)

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

	2020	2019
Net Realized Gains	$ 4,175	$ 85,840
Net Unrealized Gains (Losses)	9,590	(48,281)
Interest and Dividends	39,285	45,169
Investment Expenses	(9,229)	(8,406)
Total Investment Income	$ 43,821	$ 74,322

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, 2020 and 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.

NOTE 7—FAIR VALUE MEASUREMENTS (Continued)

Level 2 Fair Value Measurements

The Organization has no level 2 fair value measurements.

Level 3 Fair Value Measurements

The Organization has no level 3 fair value measurements.

NOTE 8—GRANTS PAYABLE

The Organization makes grants to various medical and research centers for research in relation to Spinal Muscular Atrophy. Grant agreements are subject to periodic reporting and compliance requirements and can be rescinded by the Organization if it is determined that a research project is no longer academically, technically or commercially feasible. The Organization is responsible for all costs incurred or committed at the time of termination. Research grant expense for the year ended June 30, 2020, was $2,258,122 and $3,478,687 for June 30, 2019.

As of June 30, 2020, the Organization's grants payable obligations have terms expiring through June 2022. Long-term grants should be discounted to net present value. No discount was reflected for the long-term grants payable at June 30, 2020 as the amount was not deemed material. There were no long-term grants payable at June 30, 2019. As of June 30, 2020, grants payable obligations amounted to $2,582,049. As of June 30, 2019, grants payable obligations amounted to $3,055,935.

Future obligations associated with the Organization's grants payable for fiscal years subsequent to June 30, 2020 are as follows:

2021	$ 2,185,799
2022	396,250
	$ 2,582,049

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, 2020, certain milestones were achieved and $175,000 of payments related to two prior year conditional promises were disbursed and are included in research grants in the statements of functional expenses. 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.

As of June 30, 2020, future conditional promises due to two grantees based on the achievement of milestones are estimated to be $250,000. As of June 30, 2019, future conditional promises due to grantees based on the achievement of milestones were estimated to be $425,000.

NOTE 9—PAYROLL PROTECTION PROGRAM LOAN

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 seven months after the funding of the loan. 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. 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.

As permitted under accounting principles U.S. GAAP, the Organization is treating the possible loan forgiveness as a gain contingency under ASC 450-30. Under this standard, the proceeds from the loan and any accrued interest thereof will remain reported as a liability on the statements of financial position until the federal agency lender legally forgives the loan.

NOTE 10—NET ASSETS WITH DONOR RESTRICTIONS

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

	2020	2019
Research	**$ 325,000**	$ 388,850
Annual Conference	–	89,001
Scholarships	**554,242**	70,251
Car Beds	–	14,700
Equipment and Wagons	**642,197**	621,191
Medical ID Bracelets	**30,000**	–
Industry Collaboration Phase IV, V, and VI	**1,158,079**	660,104
Congressional Reception	–	75,000
Local Educational and Networking Conferences	–	253,850
Chapter Meeting	–	225,000
Care Packages	**262,122**	244,745
Newborn Screening	**370,467**	798,143
Biomarker Identification and Development Project	**10,000**	–
Other	**20,000**	–
Underwater Endowment	**(511)**	–
	$ 3,371,596	$ 3,440,835

Net assets of $6,765,040 and $8,682,909 were released from donor restrictions during the years ended June 30, 2020 and 2019, respectively, by incurring expenses satisfying the purpose restrictions.

NOTE 11—ENDOWMENT FUNDS

The Organization maintains two endowment funds 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 funds. The majority of the Organization's endowment contributions are subject to a specific agreement with the Organization.

NOTE 11—ENDOWMENT FUNDS (Continued)

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 net assets without donor restrictions for the endowment fund.

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.

NOTE 11—ENDOWMENT FUNDS (Continued)

Endowment net asset composition by type of fund as of June 30, 2020 is as follows:

		With Donor Restrictions		
	Without Donor Restrictions	Time and Purpose Restrictions	Endowment in Perpetuity	Total
Board-Designated Endowment Funds	$ 35,931	$ —	$ —	$ 35,931
Donor-Restricted Endowment Funds	—	(511)	1,242,467	1,241,956
Total	$ 35,931	$ (511)	$ 1,242,467	$ 1,277,887

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, 2020, one fund with an original gift value of $35,581 and fair value of $35,070 had such a deficiency of $511, which is reported in the net assets with time and purpose restriction. This amount has fully recovered subsequent to June 30, 2020 due to favorable market fluctuations.

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 fund during the year ended June 30, 2020.

Changes in endowment net assets for the year ended June 30, 2020 are as follows:

		With Donor Restrictions		
	Without Donor Restrictions	Time and Purpose Restrictions	Endowment in Perpetuity	Total Endowment Net Assets
Endowment Net Assets, Beginning of Year	$ 35,613	$ —	$ 1,165,996	$ 1,201,609
Contributions and Grants	—	—	66,864	66,864
Investment Income, net of fees	850	21,537	6,464	28,851
Net Realized and Unrealized Gains and Losses	413	9,694	3,143	13,250
Appropriation of Endowment Assets for Expenditure	(945)	(31,742)	—	(32,687)
Endowment Net Assets, End of Year	$ 35,931	$ (511)	$ 1,242,467	$ 1,277,887

NOTE 11—ENDOWMENT FUNDS (Continued)

Endowment net asset composition by type of fund as of June 30, 2019 is as follows:

		With Donor Restrictions		
	Without Donor Restrictions	Time and Purpose Restrictions	Endowment In Perpetuity	Total
Board-Designated Endowment Funds	$ 35,613	$ —	$ —	$ 35,613
Donor-Restricted Endowment Funds	—	—	1,165,996	1,165,996
Total	$ 35,613	$ —	$ 1,165,996	$ 1,201,609

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

		With Donor Restrictions		
	Without Donor Restrictions	Time and Purpose Restrictions	Endowment In Perpetuity	Total Endowment Net Assets
Endowment Net Assets, Beginning of Year	$ 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	(794)	(25,994)	—	(26,788)
Endowment Net Assets, End of Year	$ 35,613	$ —	$ 1,165,996	$ 1,201,609

NOTE 12—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 $122,337 for 2020 and $108,509 for 2019.

NOTE 13—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, 2020 and 2019, there were 36 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.

NOTES TO FINANCIAL STATEMENTS

NOTE 14—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 15—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 expired in January 2020 with monthly rental payments commencing at $8,499 per month and increasing 2% per annum. This lease was not renewed as the Organization entered into a new 2 - year lease agreement for office space located in Chicago, Illinois, which expires in January 2022. Monthly payments are $9,058 monthly increasing by 3% per annum. Rental expense, and related real estate taxes and operating expenses for the year ended June 30, 2020 was $162,502 and $48,534, 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, 2019 was $160,017 and $43,208, respectively.

As of June 30, 2020 and 2019, a deferred rent liability was recognized in the amount of $13,349 and $19,508, 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.

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

Year Ending June 30		
2021	$	172,815
2022		107,974
	$	280,789

NOTE 16—RECLASSIFICATIONS

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

NOTE 17—SUBSEQUENT EVENTS

Management has evaluated subsequent events through October 20, 2020, the date through which the financial statements were available for issue.

Except for the recovery of the underwater fund disclosed in Note 11, there were no other subsequent events which require disclosure.