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

FINANCIAL STATEMENTS

JUNE 30, 2021



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

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INDEPENDENT AUDITORS' REPORT

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

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, 2021 and 2020, 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, 2021 and 2020, 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 Accounting Standards Update (ASU) No. 2014-09 (Topic 606): *Revenue from Contracts with Customers* as required by accounting principles generally accepted in the United States of America. Our opinion is not modified with respect to this matter.

Warady & Davis LLP

October 16, 2021

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

As of June 30		
	2021	2020
ASSETS		
CURRENT ASSETS		
Cash and Cash Equivalents	\$ 6,815,576	\$ 6,593,442
Grants Receivable, net of Allowance for	040 004	1 050 005
Uncollectible Amounts of \$13,000 and \$18,000 Pledges Receivable, net of Allowance for	840,334	1,056,025
Uncollectible Amounts of \$7,000 and \$8,000	298,500	268,714
Prepaid Expenses	230,474	176,850
Total Current Assets	 8,184,884	8,095,031
DDODEDTV AND FOLIDMENT NET	<u> </u>	419 091
PROPERTY AND EQUIPMENT, NET	 383,292	412,831
NONCURRENT ASSETS		
Pledges Receivable	_	50,000
Security Deposits and Other Assets	15,402	15,402
Intangibles, net of Accumulated Amortization	150 0 40	000.000
of \$936,592 and \$739,015 Investments	150,246	300,823
mvestments	 $\frac{1,478,490}{1,644,138}$	$\frac{1,277,887}{1,644,112}$
	1,011,100	1,011,112
	\$ 10,212,314	\$ 10,151,974
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts Payable		
•	\$ 128,356	
Grants Payable	\$ 1,742,736	2,185,799
Grants Payable Accrued Expenses	\$ $1,\!742,\!736\\46,\!931$	2,185,799 18,636
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses	\$ $1,742,736\\46,931\\227,744$	2,185,799 18,636 196,330
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation	\$ $1,742,736\\46,931\\227,744\\146,323$	2,185,799 $18,636$ $196,330$ $161,991$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue	\$ $1,742,736\\46,931\\227,744\\146,323\\13,000$	$\begin{array}{c} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000 \end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans	\$ $1,742,736\\46,931\\227,744\\146,323\\13,000\\959,467$	$\begin{array}{c} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue	\$ $1,742,736\\46,931\\227,744\\146,323\\13,000$	2,185,799 18,636 196,330
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities	\$ $1,742,736\\46,931\\227,744\\146,323\\13,000\\959,467\\6,514$	$\begin{array}{r} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities LONG-TERM LIABILITIES	\$ $1,742,736 \\ 46,931 \\ 227,744 \\ 146,323 \\ 13,000 \\ 959,467 \\ 6,514 \\ 3,271,071 \\ \end{array}$	$\begin{array}{r} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\\ \hline 3,671,280\end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities LONG-TERM LIABILITIES Grants Payable	\$ $1,742,736\\46,931\\227,744\\146,323\\13,000\\959,467\\6,514$	$\begin{array}{c} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\\ \hline 3,671,280\\ \end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities LONG-TERM LIABILITIES Grants Payable Deferred Rent	\$ 1,742,73646,931227,744146,32313,000959,4676,5143,271,071321,951-	$\begin{array}{c} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\\ \overline{3,671,280}\\ \end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities LONG-TERM LIABILITIES Grants Payable	\$ $1,742,736 \\ 46,931 \\ 227,744 \\ 146,323 \\ 13,000 \\ 959,467 \\ 6,514 \\ 3,271,071 \\ \end{array}$	$\begin{array}{c} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\\ 3,671,280\\ \end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities LONG-TERM LIABILITIES Grants Payable Deferred Rent Total Long-Term Liabilities Total Liabilities	\$ 1,742,73646,931227,744146,32313,000959,4676,5143,271,071321,951	$\begin{array}{c} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\\ \overline{3,671,280}\\ \end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities LONG-TERM LIABILITIES Grants Payable Deferred Rent Total Long-Term Liabilities NET ASSETS	\$ 1,742,736 46,931 227,744 146,323 13,000 959,467 6,514 3,271,071 321,951 321,951 3,593,022	$\begin{array}{r} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\\ 3,671,280\\ \end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities LONG-TERM LIABILITIES Grants Payable Deferred Rent Total Long-Term Liabilities Total Liabilities	\$ 1,742,73646,931227,744146,32313,000959,4676,5143,271,071321,951	$\begin{array}{c} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\\ \hline 3,671,280\\ \hline 396,250\\ 6,514\\ \hline 402,764\\ \hline 4,074,044\\ \hline 1,427,936\end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities LONG-TERM LIABILITIES Grants Payable Deferred Rent Total Long-Term Liabilities Total Liabilities	\$ 1,742,736 46,931 227,744 146,323 13,000 959,467 6,514 3,271,071 321,951 321,951 3,593,022	$\begin{array}{c} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\\ \hline 3,671,280\\ \end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities LONG-TERM LIABILITIES Grants Payable Deferred Rent Total Long-Term Liabilities Total Liabilities NET ASSETS Without Donor Restrictions Without Donor Restrictions - Board-Designated Endowment	\$ 1,742,736 46,931 227,744 146,323 13,000 959,467 6,514 3,271,071 321,951 3,593,022 1,805,369	$\begin{array}{c} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\\ 3,671,280\\ \end{array}$
Grants Payable Accrued Expenses Accrued Payroll and Related Expenses Accrued Vacation Deferred Revenue Paycheck Protection Program Loans Deferred Rent Total Current Liabilities LONG-TERM LIABILITIES Grants Payable Deferred Rent Total Long-Term Liabilities Total Liabilities NET ASSETS Without Donor Restrictions Without Donor Restrictions - Board-Designated Endowment With Donor Restrictions - Time and Purpose	\$ 1,742,736 46,931 227,744 146,323 13,000 959,467 6,514 3,271,071 321,951 321,951 3,593,022 1,805,369 3,342,289	$\begin{array}{c} 2,185,799\\ 18,636\\ 196,330\\ 161,991\\ 21,000\\ 769,100\\ 6,835\\ 3,671,280\\ \end{array}\\\\ \begin{array}{c} 396,250\\ 6,514\\ 402,764\\ 4,074,044\\ \end{array}\\\\ 1,427,936\\ 35,931\\ 3,371,596\\ \end{array}$

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

STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS

For the Years Ended June 30	2021					2020								
		it Donor ictions	ar	With Donor Time nd Purpose	E	rictions ndowment Perpetuity	Total		ithout Donor Restrictions		Vith Donor Time I Purpose	E	rictions ndowment Perpetuity	Total
SUPPORT AND REVENUE Contributions and Grants Chapter Events	\$	801,587	\$	4,732,476	\$	5,475	\$ 5,539,538	\$	1,205,150	<u>\$</u>	5,032,168	\$	66,864	\$ 6,304,182
Special Events Revenue Less: Event Expenses		2,497,004 (71,102) 2,425,902					2,497,004 (71,102) 2,425,902		$2,140,723 \\ (377,501) \\ 1,763,222$		1,632,400 1,632,400			3,773,123 (377,501)
Program Revenues	2	<u>, , , , , , , , , , , , , , , , , , , </u>									1,632,400			3,395,622
Summit of Strength Symposiums Annual Conference		485,000 ,142,325 ,627,325					485,000 <u>1,142,325</u> <u>1,627,325</u>	_	$\begin{array}{r} 687,500 \\ 1,640,500 \\ 2,328,000 \end{array}$					$ \begin{array}{r} $
Other Revenues Payroll Protection Program Loan and Interest Forgiveness		775,125					775,125							
Grant Forfeitures Investment Income Other Income		126,488 9 33,326		41,692		223,692	126,488 265,393 33,326		$2,981 \\ 31,591$		31,233		9,607	43,821 31,591
Total Other Revenues		934,948		41,692		223,692	1,200,332		34,572		31,233		9,607	75,412
Net Assets Released from Restrictions	4	1,803,475		(4,803,475)					6,765,040	((6,765,040)			
Total Support and Revenues	1(),593,237		(29,307)		229,167	10,793,097		12,095,984		(69, 239)		76,471	12,103,216
Expenses Program Services Management and General Fundraising Total Expenses	1	7,772,710 658,317 ,820,708),251,735					$7,772,710 \\ 658,317 \\ 1,820,708 \\ 10,251,735 \\ \hline$		$\begin{array}{r} 8,902,759\\ 858,845\\ 1,368,488\\ 11,130,092\end{array}$					8,902,759 $858,845$ $1,368,488$ $11,130,092$
CHANGE IN NET ASSETS		341,502		(29,307)		229,167	541,362		965,892		(69,239)		76,471	973,124
Net Assets, Beginning of Year	1	1,463,867		3,371,596		1,242,467	6,077,930		497,975	:	3,440,835		1,165,996	5,104,806
NET ASSETS, ENDING	\$ 1	1,805,369	\$	3,342,289	\$	1,471,634	\$ 6,619,292	\$	1,463,867	\$ 3	3,371,596	\$	1,242,467	\$ 6,077,930

STATEMENTS OF FUNCTIONAL EXPENSES

For the Year Ended June 30, 2021

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

STATEMENTS OF FUNCTIONAL EXPENSES (Continued)

For the Year Ended June 30, 2020

	Research	Patient Services	Family Support	Awareness	Total Program Services	Management and General	Fundraising	Event Expenses	Total
							0		
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									
Statement 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

STATEMENTS OF CASH FLOWS

For the Years Ended June 30		2021		2020
CASH FLOWS FROM OPERATING ACTIVITIES				
Change in Net Assets	\$	541,362	\$	973,124
Adjustments to Reconcile Change in Net Assets				
to Net Cash Provided (Used) by Operating Activities				
Donated Medical Equipment		(10,000)		(38,000)
Depreciation		252,582		205,328
Amortization		197,577		298,377
Payroll Protection Program (PPP) Loan and Interest Forgiveness		(775,125)		· · · · ·
Noncash PPP Interest Expense		9,009		1,064
Loss on Disposition of Property and Equipment		_		361
Stock Donations		(14,785)		(56, 550)
Proceeds from Sale of Stock Donations		14,768		57,050
Realized (Gain) Loss on Sales of Donated Stocks		17		(500)
Unrealized and Realized Gain on Investments		(246,740)		(13,265)
Donor Restricted Endowment Contributions		(5,475)		(66,864)
Change in Allowance for Uncollectible Amounts		(6,000)		(10,300)
Changes in		(0,000)		(10,000)
Grants Receivable		220,691		1,424,407
Pledges Receivable		21,214		936,985
Other Receivables		21,214		108,319
Prepaid Expenses		(53,624)		(86,456)
		(55,024)		7,940
Security Deposits		(100 000)		
Accounts Payable		(183,233)		(220,977)
Grants Payable		(517,362)		(473,886)
Accrued Expenses		25,311		(1,274,568)
Accrued Payroll and Related Expenses		31,414		(36,873)
Accrued Vacation		(15,668)		23,863
Deferred Rent		(6,835)		(6, 159)
Deferred Revenue		(8,000)		21,000
Total Adjustments		(1,070,264)		800,296
Net Cash Provided (Used) by Operating Activities		(528,902)		1,773,420
CASH FLOWS FROM INVESTING ACTIVITIES				
Purchases of Property and Equipment		(213,043)		(243, 343)
Capitalization of Intangibles		(47,000)		(92,200)
Purchases of Investments		(590,902)		(447,447)
Reinvested Dividends		(461)		(242)
Proceeds from Sales of Investments		637,500		384,676
Net Cash Used by Investing Activities		(213,906)		(398,556)
CASH FLOWS FROM FINANCING ACTIVITIES				
Donor Restricted Endowment Contributions		5,475		66,864
Funds Received from PPP Loan		959,467		769,100
		555,101		705,100
Net Cash Provided by Financing Activities		964,942		835,964
NET INCREASE IN CASH AND CASH EQUIVALENTS		222,134		2,210,828
Cash and Cash Equivalents, Beginning		6,593,442		4,382,614
CASH AND CASH EQUIVALENTS, ENDING	\$	6,815,576	\$	6,593,442
SUPPLEMENTAL DISCLOSURES OF CASH FLOW INFORMATION Noncash Activities				
Donated Services	\$	194,730	\$	19,325
Donated Goods and Supplies	Ψ	1,236	Ψ	39,656
		1,200		55,000

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, 2021, 48% of total support and revenues was received from three donors/grantors and at June 30, 2021, receivables from four grantors accounted for approximately 95% of total receivables. During the year ended June 30, 2020, 57% of total support and revenues was received from three grantors accounted for approximately 80% of total receivables.

The coronavirus (COVID-19) outbreak in the United States commenced prior to the Organization's June 30, 2020 fiscal year-end and has directly impacted fundraising efforts since early spring 2020 as a result of no in-person events being held through current year-end, 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 restrictions - Net assets that are not subject to donor-imposed stipulations plus those resources for which donor-imposed stipulations have been satisfied. Net assets without donor restrictions may otherwise be designated for specific purposes by action of the Board of Directors.

Net assets with donor restrictions – Net assets subject to donor-imposed stipulations that may or will be met either by actions of the organization (purpose restrictions) and/or the passage of time (time restrictions). As the restrictions are satisfied, net assets with donor restrictions are reclassified to net assets without donor restrictions and are reported in the accompanying financial statements as net assets released from restrictions.

Additionally, net assets with donor restrictions may be stipulated by donors to be maintained in perpetuity. Investment income, including realized and unrealized gains and losses, are classified as time restricted net assets until those amounts are appropriated for expenditure by the Organization in a manner consistent with the standard of prudence prescribed by the Uniform Prudent Management of Institutional Funds Act (UPMIFA).

Revenues are reported as increases in net assets without donor restrictions unless use of the related asset is limited by donor-imposed restrictions. Expenses are reported as net assets without donor restrictions.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

USE OF ESTIMATES

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

PUBLIC SUPPORT REVENUE RECOGNITION, GRANTS AND PLEDGES RECEIVABLE

Contributions, including organization grants, and corporate and individual donations, are available for general use unless specifically restricted by the donor. Unconditional promises to give due in the next year are reflected as current pledges receivable and are recorded at their net realizable value. Unconditional promises to give due in future years are reflected as long-term pledges and are recorded at their net present value, using interest discount rates applicable to the years in which the promises are received. Conditional promises to give are not recorded as a receivable or recognized as revenue until the conditions are met.

Grants and contributions of cash and other assets are reported as restricted support if they are received with donor stipulations that limit the use of the donated assets. When a grantor or donor restriction expires, that is, when a stipulated time restriction ends or purpose restriction is satisfied, restricted net assets with donor restriction are reclassified to net assets without donor restriction and reported in the statements of activities as net assets released from restrictions.

An allowance for uncollectible receivables is provided based upon management's judgment, including such factors as prior collection history, type of revenue and nature of fund-raising activity. 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 received donated in-kind contributions comprised of medical equipment of \$10,000, donated auction items of \$11,081 included in special events, medical devices received and granted to program recipients of \$22,500 included in equipment grants and care packages, donated good and supplies of \$1,236 included in stationary and printing and \$194,730 of donated professional services for the year ended June 30, 2021. The Organization received 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 statif development for the year ended June 30, 2020.

A number of unpaid volunteers and members of the Boards of Directors donate their time to ensure success of the Organization's activities. The value of these services is not reflected in these financial statements since they do not meet the criteria for recognition under the Financial Accounting Standards Board (FASB) Codification topic related to accounting for contributions received and made.

CASH AND CASH EQUIVALENTS

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

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

INVESTMENTS

The Organization follows the provisions of the Financial Accounting Standards Board (FASB) Codification for accounting for investments held by not-for-profit organizations. This standard requires that investments in marketable securities be accounted for at fair value. Fair value is based on quoted market prices. Realized gains and losses are the differences between the proceeds received and the cost of investments sold. Unrealized gains and losses are the differences between the fair value and the cost of investments and are included in investment income. Due to the longterm 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

1.

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 \$197,577 for the year ended June 30, 2021 and \$298,377 for the year ended June 30, 2020.

Amortization expense for the next three years is:

00

Year Ending June 30	
2022\$	112,452
2023	29,722
2024	8,072
—	
<u>\$</u>	150,246

FUNCTIONAL ALLOCATION OF EXPENSES

The costs of providing program and support services have been reported on a functional basis in the statements of activities. Expenses are charged directly to programs, management and general, or fundraising categories based upon specific identifications. Accordingly, certain costs have been allocated among the programs and supporting services benefited, based on direct charges or appropriate methods determined by management. These methods include an allocation of personnel, and any other related costs based on estimates of time and effort spent by employees on the different functional categories, and allocation of occupancy and related costs using space utilization percentages occupied by the various functions.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

ACCOUNTING PRONOUNCEMENTS

In 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 Organization's management adopted the ASU effective July 1, 2020 using the modified retrospective application method. The Organization determined that there was no cumulative effect of applying the new standard to the opening balance of net assets without donor restrictions and there is no impact to change in the net assets without donor restrictions currently or in the future.

The Organization's program service fees are comprised of exhibit space sales, tickets and sponsorships payments for the Organization's annual conference event and summit of strength symposiums. In exchange, the Organization provides exhibit space, access to the events' symposiums and meetings, educational life and recorded webinars and social events, numerous recorded virtual programs, presentations on the latest SMA research, care and support developments, opportunities to host meetings and connect with the SMA families, and opportunities to conduct surveys, polling and Q&A sessions, among others. As all of these benefits are transferred during the days that each event takes place revenues are recorded at that point in time.

Balances are due prior to the commencement of each event. Amounts received prior to the end of the fiscal year for the next year's annual conference, or summer of strength symposiums are reported as deferred revenue on the statements of financial position. All such programs and activities occur typically within the same fiscal year as the payments are received. There are no contracts which contain variable consideration and there are very few, if any, contract modifications. For these reasons, there is not a significant impact as a result of application of the new revenue recognition standard.

Special events revenue, which includes registration fees, sponsorships, and purchases of auction items, is recorded as revenue when the event occurs, equal to the amounts received. If the amount is received in advance, the amount considered a direct benefit is deferred until the event occurs and is presented in deferred revenue on the statements of financial position, while the contribution portion, the excess amount paid over the direct benefit, is recorded when received in accordance with generally accepted accounting principles.

Based on the Organization's evaluation of its contracts with customers, the timing and amount of revenues recognized previously is consistent with how revenues are recognized under the new standard. Thus, the adoption of the ASU did not have a significant impact on the Organization's financial position, results of activities, or cash flows.

NOTE 1—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (Continued)

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

NOTE 2—LIQUIDITY AND AVAILABILITY OF RESOURCES

Financial assets available for general expenditure, that is, without donor or other restrictions limiting their use, within one year of the statement of financial position date, are comprised of the following at June 30:

_	2021	2020
Cash\$	6,815,576	\$ 6,593,442
Grants Receivable, net Pledges Receivable, net	840,334 298,500	$1,056,025\\318,714$
Investments Less: Net Assets with Donor Restrictions – Time and Purpose	1,478,490 (3,342,289)	1,277,887 (3,371,596)
Less: Net Assets with Donor Restrictions – Endowment Less: Net Assets Without Donor Restrictions –	(1,471,634)	(1,242,467)
Board-Designated Endowment		(35,931)
<u>\$</u>	4,618,977	<u>\$ 4,596,074</u>

As part of its liquidity management plan, the Organization attempts to maintain sufficient cash to meet current operating needs. As indicated in the above chart, assuming revenue is consistent in subsequent years, the Organization has sufficient liquid assets to meet at least one year of expenses. In addition, the Organization had available \$35,931 of board-designated endowment net assets as of June 30, 2020 that could be undesignated by the board. The entire amount was undesignated by the board in 2021.

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.

Credit risk associated with grants and pledges receivable is considered to be limited due to high historical collection rates and because substantial portions of the outstanding amounts are due from pharmaceutical corporations supportive of the Organization's mission.

NOTE 3—CONCENTRATIONS OF CREDIT RISK (Continued)

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:

	2021	 2020
Less than One Year\$	305,500	\$ 276,714
One to Five Years		 50,000
	305,500	326,714
Less: Allowance for Uncollectible Accounts	7,000	 8,000
Net Pledges Receivable	298,500	318,714
Less Current Portion	298,500	 268,714
Long-Term Portion		\$ 50,000

Management has not discounted the long-term portion of pledges receivable as of June 30, 2020, as the amount was not deemed significant.

NOTE 5—PROPERTY AND EQUIPMENT

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

_	2021	 2020
Office Equipment\$	71,445	\$ 68,063
Office Furniture	41,396	41,396
Medical Equipment	904,019	727,041
Construction in Process	19,800	
	1,036,660	836,500
Less Accumulated Depreciation	653,368	 423,669
Total <u>\$</u>	383,292	\$ 412,831

Depreciation expense was \$252,582 for the year ended June 30, 2021 and \$205,328 for the year ended June 30, 2020.

NOTE 6—INVESTMENTS

Investments at June 30 consisted of the following:

2021	<u>1</u> 2020
Mutual Funds and Exchange Traded Funds (ETF)	
Equity Funds	
Mid Cap	0 \$ 130,647
Index	5 288,077
Large Cap	8 84,943
Small Cap	2 61,138
International Large Growth	
International Large Value	5 17,951
International Large Cap — — —	26,286
Total Equity Funds	7 667,159
	001,100
Alternative Investments – Mutual Funds 106,305	<u>5</u> 90,204
Money Market	<u>8</u> 39,964
Fixed Income Funds	
Short-Term US Treasury ETF	9 25,453
Intermediate Term Bond Fund	· · · · ·
Total Fixed Income Funds	
Total Investments <u>\$ 1,478,490</u>	<u>0 \$ 1,277,887</u>
Investment income is comprised of the following for the year ended June 30:	
2021	<u>1</u> 2020

Net Realized Gains\$	54,037	\$	4,175
Net Unrealized Gains	192,686		9,590
Interest and Dividends	29,302		39,285
Investment Expenses	(10,632)		(9,229)
Total Langety and Langers P	0.CE 909	ው	49 001
Total Investment Income <u>\$</u>	205,393	<u>ð</u>	43,821

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, 2021 and 2020.

Level 1 Fair Value Measurements

All investments of the Organization are measured at level 1. Exchange-traded funds traded on a national exchange or on the national market system of NASDAQ are valued at their last reported sale price or, if there has been no sale on that date, at the closing "bid" price if long, or closing "ask" price if short.

Mutual funds are valued at their market values, which are determined daily and are quoted on a national exchange.

Level 2 Fair Value Measurements

The Organization has no level 2 fair value measurements.

Level 3 Fair Value Measurements

The Organization has no level 3 fair value measurements.

NOTE 8—GRANTS PAYABLE

The Organization makes grants to various medical and research centers for research in relation to Spinal Muscular Atrophy. Grant agreements are subject to periodic reporting and compliance requirements and can be rescinded by the Organization if it is determined that a research project is no longer academically, 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, 2021, was \$2,156,901 and \$2,258,122 for June 30, 2020.

As of June 30, 2021, the Organization's unconditional grants payable obligations have terms expiring through June 2023. Long-term grants are discounted to net present value. The discount on long-term grants payable at June 30, 2021 is \$8,049, which is presented as a reduction of the long-term grants payable on the statement of financial position. The discount rate used in determining the net present value of long-term grants payable is 2.50% for the year ended June 30, 2021. No discount was reflected for the long-term grants payable at June 30, 2020 as the amount was not deemed significant. As of June 30, 2021, grants payable obligations amounted to \$2,064,687. As of June 30, 2020, grants payable obligations amounted to \$2,582,049.

Future obligations associated with the Organization's grants payable for fiscal years subsequent to June 30, 2021 are as follows:

2022\$	1,742,736
2023	330,000
	2,072,736
Less Discount to Net Present Value	8,049
	2,064,687
Less Current Portion	1,742,736
Long-Term Portion	321,951

NOTE 9—CONDITIONAL GRANTS PAYABLE

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. As of June 30, 2021, such promises to two grantees are estimated to be \$175,000.

The Organization has also awarded care center network grants with terms expiring on various dates through September 30, 2022, which are conditional on new patients being enrolled in the program at each care center at a rate of \$500 per patient, capped at \$45,000 maximum award per grantee.

As of June 30, 2021, the Organization has \$627,500 of unrecognized grants to eighteen such care centers, conditional on enrollment of new patients during the remainder of their award periods.

NOTE 10—PAYROLL PROTECTION PROGRAM LOANS

On May 8, 2020, the Organization applied for and was awarded a Payroll Protection Program (PPP) loan from the U.S. Small Business Administration (SBA) of \$769,100. The loan accrues interest at a fixed rate of 1.00% per annum, but payments are not required to begin for ten months after the end of the loan forgiveness covered period. The loan matures on May 8, 2022. The Organization is eligible for loan forgiveness up to 100% of the loan, upon meeting certain requirements to the extent of applicable payroll and other covered costs. The amount of loan forgiveness shall be calculated (and may be reduced) in accordance with the requirements of the PPP, including the provisions of Section 1106 of the Coronavirus Aid, Relief, and Economic Security Act (CARES Act). The loan is uncollateralized and is fully guaranteed by the Federal government. The Organization applied for and was granted forgiveness of the entire loan amount, plus the accrued interest of \$6,025 on February 23, 2021. The loan and accrued interest forgiveness totaling \$775,125 is included in other revenues on the statements of activities.

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

On January 14, 2021, the Organization applied for and was approved for a second installment of a PPP loan from the SBA of additional \$959,467. The loan has similar terms as the first installment and interest will accrue at 1%. The Organization could become eligible for up to 100% forgiveness of the loan amount plus accrued interest and any amount of principal and interest not forgiven by the SBA would mature on January 14, 2026.

NOTE 11-NET ASSETS WITH DONOR RESTRICTIONS

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

	2021		2020
Research\$	175,000	\$	325,000
Annual Chapter Meeting	225,000		
Scholarships	34,327		554,242
Equipment and Wagons	273,574		642, 197
Medical ID Bracelets			30,000
Industry Collaboration	991,720		1,158,079
Congressional Dinner	105,000		
Care and Support Packages	415,305		262,122
Newborn Screening	193,605		370,467
Pediatric Neuromuscular Clinical Research (PNCR) Network	513,333		
Real World Evidence Collaboration	333,569		
Biomarker Identification and Development	50,000		10,000
Searchable Healthcare Provider Database	25,000		
Other			20,000
Care Center Network	6,856		
Underwater Endowment	·		(511)
<u>\$</u>	3,342,289	<u>\$</u>	3,371,596

NOTE 11-NET ASSETS WITH DONOR RESTRICTIONS (Continued)

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

_	<u>2021</u>	 2020
Research\$	165,133	\$ 264,844
Support Programs	59,000	452,809
Annual Chapter Meeting	·	450,000
Scholarships	36,742	60,317
Equipment and Wagons	468,027	428,259
Directions Newsletter	116,810	92,400
Adult and Family Social Events	50,000	164,500
Walk-n-Roll	92,500	137,500
Awareness	, <u> </u>	30,000
Policy and Advocacy		30,000
Medical ID Bracelets	30,000	,
Industry Collaboration	1,349,330	1,717,325
Congressional Dinner		225,000
Care and Support Packages	1,072,823	346,210
Newborn Screening	546,862	983,376
Pediatric Neuromuscular Clinical Research (PNCR) Network	275,000	·
Real World Evidence Collaboration	147,698	
Biomarker Identification and Development	50,000	
Other	102,500	1,161,350
Info Packets	96,050	101,150
Care Series Booklets	, 	120,000
Physical Therapy and Career Resource Webinars	145,000	
	, <u> </u>	
Total <u>\$</u>	4,803,475	\$ 6,765,040

NOTE 12—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.

The Organization entered into an agreement with a donor to establish an endowment fund for the purpose of providing scholarships to cover the fees to attend the Organization's annual conference for any families of patients newly diagnosed with Spinal Muscular Atrophy. 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, in 2012, the board of directors designated \$30,000 of net assets without donor restrictions for the endowment fund. During the fiscal year ended June 30, 2021 the board of directors undesignated the entire board designated endowment.

NOTE 12—ENDOWMENT FUNDS (Continued)

In 2019, the Organization entered into an agreement with a donor to establish an endowment fund for the purpose of providing support to the Care Center Network. Income earned from investments, including realized and unrealized gains and losses and interest and dividends, is recorded in the net asset class owning the assets, except for net assets with donor restrictions in perpetuity where the income is recorded as with donor restrictions – time and purpose and then reclassified to without donor restrictions upon appropriation for expenditure.

As a result of this interpretation, the Organization classifies as net assets with donor restrictions in perpetuity (1) the original value of gifts donated to the permanent endowment, (2) the original value of subsequent gifts to the permanent endowment and (3) accumulations to the permanent endowment made in accordance with the direction of the applicable donor gift instrument at the time the accumulation is added to the fund.

The Organization's investment guidelines and policies are overseen by members of the finance committee reporting to the Organization's board of directors. The overall investment objective of the Organization is to maximize the return on invested assets while minimizing risk and expenses. This is done through prudent investing and planning, as well as through the maintenance of a diversified portfolio. Investments shall be diversified with a view to minimizing risk. Investments in the equity securities of any one company shall not exceed 5% of the portfolio nor shall the total securities position (debt and equity) in any one company exceed 10% of the portfolio. No more than 25% of the entire portfolio may be invested in the securities of any one sector. The assets of the Organization have a long investment time horizon.

The primary investment objective of the portfolio is to grow the corpus in excess of inflation and to meet the current and future obligations as dictated by the Organization's spending objectives. This objective is to be achieved through the establishment of an optimal portfolio structure and through the retention of quality investment managers capable of meeting the specific performance goals of the Organization. The investment portfolio is expected to achieve the following over rolling five year periods: (a) provide an annualized rate of return that will support the spending policy net of inflation, (b) outperform the return of a hypothetical portfolio composed of indexes weighted according to the target allocation, (c) outperform the median manager in a universe of 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 12—ENDOWMENT FUNDS (Continued)

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

	Without	Time and		
	Donor	Purpose	Endowment	
	Restrictions	Restrictions	in Perpetuity	Total
Donor-Restricted Endowment Funds <u>\$</u>		<u>\$ </u>	<u>\$ 1,471,634</u>	<u>\$ 1,471,634</u>
Total <u>\$</u>		<u>\$ </u>	<u>\$ 1,471,634</u>	<u>\$ 1,471,634</u>

Changes in endowment net assets for the year ended June 30, 2021 are as follows:

	Without Donor <u>Restrictions</u>	Time and Purpose	Restrictions Endowment in Perpetuity	Total Endowment <u>Net Assets</u>
Endowment Net Assets,				
Beginning of Year\$	35,931	\$ (511)	\$ 1,242,467	1,277,887
Contributions and Grants			5,475	5,475
Withdrawals	(35, 931)		—	(35, 931)
Investment Income, net of fees		3,212	16,961	20,173
Net Realized and				
Unrealized Gains and Losses		38,480	206,731	$245,\!211$
Appropriation of Endowment Assets				
for Expenditure		(41,181)		(41,181)
Endowment Net Assets, End of Year §	<u> </u>	<u>\$ </u>	<u>\$ 1,471,634</u>	<u>\$ 1,471,634</u>

NOTE 12—ENDOWMENT FUNDS (Continued)

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

	With Donor Restrictions						
	Without		Time and				
	Donor		Purpose		Endowment		
	Restrictions		Restrictions	I	<u>n Perpetuity</u>		Total
Board-Designated							
Endowment Funds \$	35,931	\$	—	\$	—	\$	35,931
Donor-Restricted							
Endowment Funds			(511)		1,242,467		1,241,956
Total <u>\$</u>	35,931	\$	(511)	\$	1,242,467	<u>\$</u>	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:

	Without Donor <u>Restrictions</u>	With Donor Time and Purpose Restrictions	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	413	9,694	3,143	$13,\!250$
Appropriation of Endowment Assets				
for Expenditure <u></u>	(945)	(31,742)		(32,687)
Endowment Net Assets, End of Year	35,931	<u>\$ (511)</u>	<u>\$ 1,242,467</u>	<u>\$ 1,277,887</u>

NOTE 13—RETIREMENT PLAN

The Organization sponsors a 401(k) retirement plan for all eligible employees immediately upon their date of hire. The plan provides for employer profit-sharing contributions for full-time and parttime employees that are immediately 100% vested. The Organization's contribution to the plan was \$126,407 for 2021 and \$122,337 for 2020.

NOTE 14—CHAPTERS

The Organization has established chapters consisting of volunteers who promote local and regional fund-raising and outreach efforts for the Organization by hosting events in their respective states and regions. As of June 30, 2021 and 2020, there were 34 active chapters-throughout the United States. Fund-raising and patient service support activities are coordinated by the staff of the Organization, and revenue and expenses related to all such activities are included in the accompanying statements of activities.

NOTE 15—INCOME TAXES

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

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

NOTE 16—OPERATING LEASES

In September 2009, the Organization entered into an eight-year lease agreement for office space in Elk Grove Village, Illinois, which was extended in February 2017 and 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 a new, two-year lease agreement for different office space located in Chicago, Illinois, which expires in January 2022. Monthly payments are \$9,058 monthly increasing by 3% per annum. The Organization also leases warehouse storage on a month-to-month basis. Rental expense, and related real estate taxes and operating expenses for the year ended June 30, 2021 were \$169,649 and \$32,335, 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, 2020 were \$166,540 and \$38,827, respectively.

As of June 30, 2021 and 2020, a deferred rent liability was recognized in the amount of \$6,514 and \$13,349, 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:

NOTE 17—RECLASSIFICATIONS

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

NOTE 18—SUBSEQUENT EVENTS

Management has evaluated subsequent events through October 16, 2021, the date through which the financial statements were available for issue. There were no subsequent events which require disclosure.