

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

Form **990**

Department of the Treasury
Internal Revenue Service

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)
Do not enter social security numbers on this form as it may be made public.
Go to www.irs.gov/Form990 for instructions and the latest information.

2024

Open to Public
Inspection

A For the **2024** calendar year, or tax year beginning **JUL 1, 2024** and ending **JUN 30, 2025**

B Check if applicable: ☒ Address change ☐ Name change ☐ Initial return ☐ Final return/terminated ☐ Amended return ☐ Application pending	C Name of organization FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA Doing business as CURE SMA Number and street (or P.O. box if mail is not delivered to street address) Room/suite 50 E COMMERCE DR 90 City or town, state or province, country, and ZIP or foreign postal code SCHAUMBURG, IL 60173 F Name and address of principal officer: KENNETH HOBBY SAME AS C ABOVE	D Employer identification number 36-3320440 E Telephone number 847-709-6318 G Gross receipts \$ 16,238,049. H(a) Is this a group return for subordinates? Yes ☒ No H(b) Are all subordinates included? Yes No If "No," attach a list. See instructions H(c) Group exemption number
I Tax-exempt status: ☒ 501(c)(3) 501(c) () (insert no.) 4947(a)(1) or 527		
J Website: WWW.CURESMA.ORG		
K Form of organization: ☒ Corporation Trust Association Other		L Year of formation: 1984 M State of legal domicile: IL

Part I Summary

1	Briefly describe the organization's mission or most significant activities: TO DRIVE RESEARCH FOR TREATMENTS AND A CURE FOR SMA, AND TO SUPPORT AND EMPOWER EVERYONE IMPACTED BY		
2	Check this box if the organization discontinued its operations or disposed of more than 25% of its net assets.		
3	Number of voting members of the governing body (Part VI, line 1a)	3	24
4	Number of independent voting members of the governing body (Part VI, line 1b)	4	24
5	Total number of individuals employed in calendar year 2024 (Part V, line 2a)	5	53
6	Total number of volunteers (estimate if necessary)	6	6800
7a	Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
7b	Net unrelated business taxable income from Form 990-T, Part I, line 11	7b	0.
8	Contributions and grants (Part VIII, line 1h)	8	7,517,231.
9	Program service revenue (Part VIII, line 2g)	9	6,958,513.
10	Investment income (Part VIII, column (A), lines 3, 4, and 7d)	10	133,015.
11	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	11	176,476.
12	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	12	14,785,235.
13	Grants and similar amounts paid (Part IX, column (A), lines 1-3)	13	2,062,306.
14	Benefits paid to or for members (Part IX, column (A), line 4)	14	0.
15	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	15	5,757,663.
16a	Professional fundraising fees (Part IX, column (A), line 11e)	16a	0.
b	Total fundraising expenses (Part IX, column (D), line 25)	b	1,878,580.
17	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	17	7,801,896.
18	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	18	15,621,865.
19	Revenue less expenses. Subtract line 18 from line 12	19	-836,630.
20	Total assets (Part X, line 16)	20	10,703,968.
21	Total liabilities (Part X, line 26)	21	4,582,639.
22	Net assets or fund balances. Subtract line 21 from line 20	22	6,121,329.

Part II Signature Block

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

Sign Here	Signature of officer KENNETH HOBBY, PRESIDENT Type or print name and title	Date 11/12/2025
Paid Preparer Use Only	Preparer's name KOSTA G. TCHOBANOV Preparer's signature Date 12/03/25 Check if self-employed ☐ PTIN P01302744 Firm's name WARADY & DAVIS LLP Firm's address 1717 DEERFIELD RD SUITE 300S DEERFIELD, IL 60015 Firm's EIN 36-2170602 Phone no. (847) 267-9600	

May the IRS discuss this return with the preparer shown above? See instructions ☒ Yes ☐ No

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

Form 990 (2024)

36-3320440

Page 2

Part III Statement of Program Service AccomplishmentsCheck if Schedule O contains a response or note to any line in this Part III ☒

1 Briefly describe the organization's mission:

OUR MISSION IS TO DRIVE RESEARCH FOR TREATMENTS AND A CURE FOR SMA,
AND TO SUPPORT AND EMPOWER EVERYONE IMPACTED BY SMA TODAY.

2 Did the organization undertake any significant program services during the year which were not listed on the
prior Form 990 or 990-EZ? ☐ Yes ☒ No

If "Yes," describe these new services on Schedule O.

3 Did the organization cease conducting, or make significant changes in how it conducts, any program services? ☐ Yes ☒ No

If "Yes," describe these changes on Schedule O.

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses.

Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and
revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 4,835,026. including grants of \$ 196,619.) (Revenue \$ 245,468.)

INDIVIDUALS WITH SMA NEED SPECIALIZED CARE AND EQUIPMENT, WHICH CAN PUT
ENORMOUS LOGISTICAL AND FINANCIAL PRESSURE ON FAMILIES. CURE SMA IS
COMMITTED TO MAKING SURE THAT FAMILIES HAVE THE BEST, MOST ACCURATE
INFORMATION ABOUT SMA AND WHAT IT MEANS FOR THEM, AND TO MAKING SURE
THAT THEY UNDERSTAND ALL THE OPTIONS AND RESOURCES AVAILABLE TO THEM
FROM DAY-TO-DAY CARE TO THE CHANGING LANDSCAPE OF RESEARCH
BREAKTHROUGHS AND TREATMENTS.

THIS INCLUDES OUR CARE SERIES BOOKLETS, WHICH ARE SENT OUT AS PART OF
INFORMATIONAL PACKETS AVAILABLE AT NO COST TO ANYONE WHO REQUESTS ONE.
DEVELOPED BY MEDICAL EXPERTS AND REVIEWED BY FAMILIES, THESE BOOKLETS
COVER TOPICS SUCH AS BREATHING, NUTRITION, PALLIATIVE CARE, GENETICS,

4b (Code:) (Expenses \$ 5,416,203. including grants of \$ 2,368,243.) (Revenue \$ 1,650,318.)

CURE SMA FOCUSES ON THREE DIFFERENT YET EQUALLY CRITICAL AND
INTERDEPENDENT RESEARCH AREAS: BASIC RESEARCH, TO UNDERSTAND THE CAUSE
AND BIOLOGY OF SMA; DRUG DISCOVERY, TO CONVERT BASIC RESEARCH IDEAS
INTO PRACTICAL NEW DRUG CANDIDATES; AND CLINICAL & REGULATORY RESEARCH,
TO PROVIDE THE INFRASTRUCTURE TO TEST THE DRUG CANDIDATES. DURING THIS
PERIOD CURE SMA FUNDED SIX NEW AND SIX ONGOING BASIC RESEARCH GRANTS.
WE ALSO FUNDED AND EXECUTED MULTIPLE CLINICAL AND REGULATORY FOCUSED
PROJECTS, TO INCREASE SMA CLINICAL TRIAL SITE CAPACITY AND READINESS,
TO PROVIDE REGULATORY AUTHORITIES WITH DATA ON THE SMA POPULATION AND
THEIR REPORTED UNMET NEEDS, AND TO COLLECT DATA TO UNDERSTAND THE
PATIENT EXPERIENCE WITH SMA.

4c (Code:) (Expenses \$ 588,940. including grants of \$) (Revenue \$ 5,330,919.)

WE HOSTED THE 2025 ANNUAL SMA CONFERENCE IN ANAHEIM, CA WITH OVER 2,739
REGISTERED ATTENDEES. OUR ANNUAL CONFERENCE IS AN INVALUABLE RESOURCE
FOR THE ENTIRE SMA COMMUNITY. THE CONFERENCE IS THE LARGEST IN THE
WORLD FOCUSED SPECIFICALLY ON SMA. THE RESEARCHER AND CLINICAL CARE
CONFERENCE ATTRACTED THE TOP SCIENTISTS AND COMPANIES IN THE FIELD.

THE COMMUNITY CONFERENCE INCLUDES A VARIETY OF WORKSHOPS, KEYNOTE
SESSIONS WITH LEADING EXPERTS, AND MORE-PLUS GREAT EVENTS SUCH AS OUR
TEEN AND ADULTS WITH SMA SOCIALS, THE FAMILY FRIENDLY RESEARCHER POSTER
SESSION AND OUR MEET & GREET, WITH A FAMILY FUN FEST. THE RESEARCHER
AND CLINICAL CARE CONFERENCE CREATES OPEN COMMUNICATION OF EARLY,
UNPUBLISHED SCIENTIFIC DATA, ACCELERATING THE PACE OF RESEARCH. THE

4d Other program services (Describe on Schedule O.)

(Expenses \$ including grants of \$) (Revenue \$)

4e Total program service expenses 10,840,169.

Form 990 (2024)

**FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Form 990 (2024)

36-3320440 Page **3**

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i>	1 X	
2 Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? See instructions	2 X	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>		X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i>	4 X	
5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? <i>If "Yes," complete Schedule C, Part III</i>		X
6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i>		X
7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>		X
9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i>		X
10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i>	10 X	
11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X, as applicable.		
a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i>	11a X	
b Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII</i>		X
c Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i>		X
d Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i>		X
e Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>	11e X	
f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>	11f X	
12a Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i>	12a X	
b Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i>		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>	13	X
14a Did the organization maintain an office, employees, or agents outside of the United States?	14a	X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i>	14b X	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i>	15 X	
16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i>		X
17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I. See instructions</i>		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i>	18 X	
19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>		X
20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>	20a	X
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?	20b	
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>	21 X	

**FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Form 990 (2024)

36-3320440 Page **4**

Part IV Checklist of Required Schedules (continued)

	Yes	No
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	22 X	
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>	23 X	
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>	24a	X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?	24b	
c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?	24c	
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?	24d	
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>	25a	X
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>	25b	X
26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part II</i>	26	X
27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>	27	X
28 Was the organization a party to a business transaction with one of the following parties? (See the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions):		
a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>	28a	X
b A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>	28b	X
c A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>	28c	X
29 Did the organization receive more than \$25,000 in noncash contributions? <i>If "Yes," complete Schedule M</i>	29 X	
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>	30	X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>	31	X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>	32	X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>	33	X
34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>	34	X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?	35a	X
b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>	35b	
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>	36	X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>	37	X
38 Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19?	38 X	

Note: All Form 990 filers are required to complete Schedule O

Part V Statements Regarding Other IRS Filings and Tax Compliance

Check if Schedule O contains a response or note to any line in this Part V ☐

	Yes	No
1a Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable	1a 33	
b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable	1b 0	
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?	1c	

**FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Form 990 (2024)

36-3320440

Page **5**

Part V **Statements Regarding Other IRS Filings and Tax Compliance** (continued)

		Yes	No
2a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return	2a 53		
b If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	2b	X	
3a Did the organization have unrelated business gross income of \$1,000 or more during the year?	3a		X
b If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation on Schedule O</i>	3b		
4a At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?	4a		X
b If "Yes," enter the name of the foreign country See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).			
5a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?	5a		X
b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?	5b		X
c If "Yes" to line 5a or 5b, did the organization file Form 8886-T?	5c		
6a Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?	6a		X
b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?	6b		
7 Organizations that may receive deductible contributions under section 170(c).			
a Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?	7a	X	
b If "Yes," did the organization notify the donor of the value of the goods or services provided?	7b	X	
c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?	7c		X
d If "Yes," indicate the number of Forms 8282 filed during the year	7d		
e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	7e		X
f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?	7f		X
g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?	7g		
h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?	7h		
8 Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?	8		
9 Sponsoring organizations maintaining donor advised funds.			
a Did the sponsoring organization make any taxable distributions under section 4966?	9a		
b Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?	9b		
10 Section 501(c)(7) organizations. Enter:			
a Initiation fees and capital contributions included on Part VIII, line 12	10a		
b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b		
11 Section 501(c)(12) organizations. Enter:			
a Gross income from members or shareholders	11a		
b Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b		
12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a		
b If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b		
13 Section 501(c)(29) qualified nonprofit health insurance issuers.			
a Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O.	13a		
b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans	13b		
c Enter the amount of reserves on hand	13c		
14a Did the organization receive any payments for indoor tanning services during the tax year?	14a		X
b If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation on Schedule O</i>	14b		
15 Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see the instructions and file Form 4720, Schedule N.	15		X
16 Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.	16		X
17 Section 501(c)(21) organizations. Did the trust, or any disqualified or other person engage in any activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953? If "Yes," complete Form 6069.	17		

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

Form 990 (2024)

36-3320440

Page 6

Part VI Governance, Management, and Disclosure. For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions.

Check if Schedule O contains a response or note to any line in this Part VI

☒**Section A. Governing Body and Management**

		Yes	No
1a Enter the number of voting members of the governing body at the end of the tax year	24		
If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O.			
b Enter the number of voting members included on line 1a, above, who are independent	24		
2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?	2		X
3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person?	3		X
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?	4		X
5 Did the organization become aware during the year of a significant diversion of the organization's assets?	5		X
6 Did the organization have members or stockholders?	6		X
7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?	7a		X
b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?	7b		X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:			
a The governing body?	8a	X	
b Each committee with authority to act on behalf of the governing body?	8b	X	
9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O	9		X

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)

	Yes	No
10a Did the organization have local chapters, branches, or affiliates?	X	
b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes?	X	
11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	X	
b Describe on Schedule O the process, if any, used by the organization to review this Form 990.		
12a Did the organization have a written conflict of interest policy? If "No," go to line 13	X	
b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	X	
c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done	X	
13 Did the organization have a written whistleblower policy?	X	
14 Did the organization have a written document retention and destruction policy?	X	
15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?		
a The organization's CEO, Executive Director, or top management official	X	
b Other officers or key employees of the organization	X	
If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions.		
16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year?		X
b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?		

Section C. Disclosure

17 List the states with which a copy of this Form 990 is required to be filed IL, AL, AK, AZ, CA, CO, CT, DE, FL, GA, IN, IA

18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
☒ Own website ☐ Another's website ☒ Upon request ☐ Other (explain on Schedule O)

19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.

20 State the name, address, and telephone number of the person who possesses the organization's books and records
MARLINE PAGAN - 847-709-6318
50 E COMMERCE DR, 90, SCHAUMBURG, IL 60173

**FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Form 990 (2024)

36-3320440 Page **7**

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

Check if Schedule O contains a response or note to any line in this Part VII ☐

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
 - List all of the organization's **current** key employees, if any. See the instructions for definition of "key employee."
 - List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (box 5 of Form W-2, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.
 - List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
 - List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.
- See the instructions for the order in which to list the persons above.

☐ Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) KENNETH HOBBY PRESIDENT	70.00			X				329,195.	0.	19,611.
(2) JAMIE GIBSON CHIEF DEVELOPMENT OFFICER	60.00				X			266,038.	0.	28,541.
(3) MARLINE PAGAN CHIEF OPERATING OFFICER	60.00				X			208,905.	0.	30,552.
(4) MARY SCHROTH CHIEF MEDICAL OFFICER (THROUGH 3/31/	60.00				X			218,342.	0.	10,202.
(5) COLLEEN MCCARTHY O'TOOLE SR VICE PRESIDENT, COMMUNI	60.00					X		175,435.	0.	27,061.
(6) MAYNARD FRIESZ VICE PRESIDENT, POLICY	50.00					X		149,595.	0.	13,548.
(7) MARY CURRY VICE PRESIDENT, CLINICAL RESEARCH &	50.00					X		138,474.	0.	20,241.
(8) JACKIE GLASCOCK VICE PRESIDENT OF RESEARCH	50.00					X		146,346.	0.	7,311.
(9) JESSE AYNES VICE PRESIDENT OF DEVELOPMENT	50.00					X		135,299.	0.	9,819.
(10) ROBERT GRAHAM DIRECTOR	2.00	X						0.	0.	0.
(11) PETER STATILE DIRECTOR	2.00	X						0.	0.	0.
(12) MARK MOORE DIRECTOR	2.00	X						0.	0.	0.
(13) MARC GINSKY DIRECTOR	2.00	X						0.	0.	0.
(14) KAREN MCROY-NEGRIN DIRECTOR	2.00	X						0.	0.	0.
(15) BAKRI ELSHEIKH DIRECTOR	2.00	X						0.	0.	0.
(16) JOE WISEMAN DIRECTOR	2.00	X						0.	0.	0.
(17) ROB LOCKWOOD DIRECTOR	2.00	X						0.	0.	0.

FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA

Form 990 (2024)

36-3320440 Page 8

Part VII Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (continued)

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(18) KELLY JANKOWSKI DIRECTOR	2.00	X						0.	0.	0.
(19) AMY MEDINA DIRECTOR	2.00	X						0.	0.	0.
(20) GILLIAN MULLINS DIRECTOR (THROUGH 12/31/24)	2.00	X						0.	0.	0.
(21) EDMUND LEE DIRECTOR (THROUGH 12/31/24)	2.00	X						0.	0.	0.
(22) DIANA CASTRO DIRECTOR	2.00	X						0.	0.	0.
(23) BRIAN SNYDER DIRECTOR	2.00	X						0.	0.	0.
(24) BRIANNA GROSS DIRECTOR	2.00	X						0.	0.	0.
(25) JACLYN GREENWOOD DIRECTOR	2.00	X						0.	0.	0.
(26) COREY BRAASTAD DIRECTOR	2.00	X						0.	0.	0.
1b Subtotal								1,767,629.	0.	166,886.
c Total from continuation sheets to Part VII, Section A								0.	0.	0.
d Total (add lines 1b and 1c)								1,767,629.	0.	166,886.

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization 16

	Yes	No
3 Did the organization list any former officer, director, trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		X
4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>	X	
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		X

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation
NONE		
2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization	0	

SEE PART VII, SECTION A CONTINUATION SHEETS

Form 990 (2024)

**FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Form 990

36-3320440

Part VII

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees *(continued)*

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (check all that apply)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(27) ALLYSON HENKEL DIRECTOR	2.00	X						0.	0.	0.
(28) COLLIN POLLOCK DIRECTOR (START 4/26/25)	2.00	X						0.	0.	0.
(29) RACHEL BROWN DIRECTOR (START 4/26/25)	2.00	X						0.	0.	0.
(30) TYLER DUKES DIRECTOR (START 4/26/25)	2.00	X						0.	0.	0.
(31) KALEEN ROBINSON DIRECTOR	2.00	X						0.	0.	0.
(32) SPENCER PERLMAN DIRECTOR	2.00	X						0.	0.	0.
(33) NICK FARRELL BOARD CHAIR	5.00	X		X				0.	0.	0.
(34) BRADLEY A. NUNEMAKER TREASURER & VICE CHAIR	5.00	X		X				0.	0.	0.
(35) SHANNON ZERZAN DIRECTOR	5.00	X						0.	0.	0.
(36) JOHN WEBER DIRECTOR (START 10/1/2024)	2.00	X						0.	0.	0.
Total to Part VII, Section A, line 1c										

FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA

Form 990 (2024)

36-3320440 Page **9**

Part VIII Statement of Revenue

Check if Schedule O contains a response or note to any line in this Part VIII ☐

				(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514
Contributions, Gifts, Grants and Other Similar Amounts	1 a Federated campaigns	1a					
	b Membership dues	1b					
	c Fundraising events	1c	2,630,216.				
	d Related organizations	1d					
	e Government grants (contributions)	1e					
	f All other contributions, gifts, grants, and similar amounts not included above ...	1f	5,043,027.				
	g Noncash contributions included in lines 1a-1f	1g	\$ 126,484.				
	h Total. Add lines 1a-1f						
Program Service Revenue			Business Code				
	2 a ANNUAL CONFERENCE		900099	4,504,249.	4,504,249.		
	b INDUSTRY SPONSORED RESEARCH		900099	1,593,049.	1,593,049.		
	c SUMMIT OF STRENGTH SYMPOSIUMS		900099	815,000.	815,000.		
	d						
	e						
	f All other program service revenue						
	g Total. Add lines 2a-2f			6,912,298.			
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			152,824.			152,824.
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
			(i) Real (ii) Personal				
	6 a Gross rents	6a					
	b Less: rental expenses ...	6b					
	c Rental income or (loss)	6c					
	d Net rental income or (loss)						
			(i) Securities (ii) Other				
	7 a Gross amount from sales of assets other than inventory	7a	476,058.				
	b Less: cost or other basis and sales expenses	7b	419,501.				
	c Gain or (loss)	7c	56,557.				
	d Net gain or (loss)			56,557.			56,557.
	8 a Gross income from fundraising events (not including \$ 2,630,216. of contributions reported on line 1c). See Part IV, line 18	8a	709,219.				
	b Less: direct expenses	8b	604,578.				
c Net income or (loss) from fundraising events			104,641.			104,641.	
9 a Gross income from gaming activities. See Part IV, line 19	9a						
b Less: direct expenses	9b						
c Net income or (loss) from gaming activities							
10 a Gross sales of inventory, less returns and allowances	10a						
b Less: cost of goods sold	10b						
c Net income or (loss) from sales of inventory							
Miscellaneous Revenue			Business Code				
	11 a HOTEL COMMISSIONS		900099	159,514.	159,514.		
	b LEASE CANCELLATION		900099	112,500.	112,500.		
	c STORE MERCHANDISE		900099	24,454.	24,454.		
	d All other revenue		900099	17,939.	17,939.		
	e Total. Add lines 11a-11d			314,407.			
12 Total revenue. See instructions			15,213,970.	7,226,705.	0.	314,022.	

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

Form 990 (2024)

36-3320440 Page 10

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

Check if Schedule O contains a response or note to any line in this Part IX ☐

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21	1,802,574.	1,802,574.		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	196,619.	196,619.		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	565,669.	565,669.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	1,168,801.	541,662.	188,361.	438,778.
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages	3,747,629.	2,323,971.	552,700.	870,958.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	98,683.	62,575.	14,285.	21,823.
9 Other employee benefits	319,066.	194,954.	45,848.	78,264.
10 Payroll taxes	348,964.	204,319.	52,414.	92,231.
11 Fees for services (nonemployees):				
a Management				
b Legal	4,425.		4,425.	
c Accounting	36,050.		36,050.	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees	18,750.		18,750.	
g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Sch O.)	550,314.	527,293.	5,371.	17,650.
12 Advertising and promotion	33,092.	23,820.	4,806.	4,466.
13 Office expenses	384,534.	324,550.	18,238.	41,746.
14 Information technology	451,247.	315,874.	31,586.	103,787.
15 Royalties				
16 Occupancy	123,018.	72,028.	18,476.	32,514.
17 Travel	204,728.	119,869.	30,749.	54,110.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	3,412,351.	3,268,889.	115,465.	27,997.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	135,755.	120,930.	5,372.	9,453.
23 Insurance	43,929.	19,130.	16,163.	8,636.
24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule O.)				
a BANK CHARGES, CREDIT CARD	127,631.		87,298.	40,333.
b WEBSITE	114,664.	85,998.	5,733.	22,933.
c PROMOTIONAL ITEMS	41,402.	37,245.	4,157.	
d DUES AND SUBSCRIPTIONS/	28,910.	11,475.	10,338.	7,097.
e All other expenses	60,594.	20,725.	34,065.	5,804.
25 Total functional expenses. Add lines 1 through 24e	14,019,399.	10,840,169.	1,300,650.	1,878,580.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here ☐ if following SOP 98-2 (ASC 958-720)				

FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA

Form 990 (2024)

36-3320440 Page **11**

Part X Balance Sheet

Check if Schedule O contains a response or note to any line in this Part X ☐

		(A) Beginning of year		(B) End of year
Assets	1 Cash - non-interest-bearing	3,808,783.	1	4,762,767.
	2 Savings and temporary cash investments		2	
	3 Pledges and grants receivable, net	4,000,444.	3	3,183,431.
	4 Accounts receivable, net		4	
	5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		5	
	6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	223,881.	9	226,893.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	855,101.		
	b Less: accumulated depreciation	796,016.		
	11 Investments - publicly traded securities	161,593.	10c	59,085.
	12 Investments - other securities. See Part IV, line 11	2,291,309.	11	2,391,493.
	13 Investments - program-related. See Part IV, line 11		12	
	14 Intangible assets	33,647.	13	1,588.
	15 Other assets. See Part IV, line 11	184,311.	14	19,994.
16 Total assets. Add lines 1 through 15 (must equal line 33)	10,703,968.	15	10,645,251.	
Liabilities	17 Accounts payable and accrued expenses	10,703,968.	16	10,645,251.
	18 Grants payable	2,962,429.	17	1,842,564.
	19 Deferred revenue	1,245,367.	18	1,201,221.
	20 Tax-exempt bond liabilities		19	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		20	
	22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		21	
	23 Secured mortgages and notes payable to unrelated third parties		22	
	24 Unsecured notes and loans payable to unrelated third parties		23	
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D	374,843.	24	178,977.
	26 Total liabilities. Add lines 17 through 25	4,582,639.	25	3,222,762.
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here ☒ and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	1,424,129.	26	2,609,833.
	28 Net assets with donor restrictions	4,697,200.	27	4,812,656.
	Organizations that do not follow FASB ASC 958, check here ☐ and complete lines 29 through 33.			
	29 Capital stock or trust principal, or current funds		28	
	30 Paid-in or capital surplus, or land, building, or equipment fund		29	
	31 Retained earnings, endowment, accumulated income, or other funds		30	
	32 Total net assets or fund balances	6,121,329.	31	7,422,489.
	33 Total liabilities and net assets/fund balances	10,703,968.	32	10,645,251.

Form **990** (2024)

FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA

Form 990 (2024)

36-3320440 Page 12

Part XI Reconciliation of Net Assets

Check if Schedule O contains a response or note to any line in this Part XI ☐

1	Total revenue (must equal Part VIII, column (A), line 12)	1	15,213,970.
2	Total expenses (must equal Part IX, column (A), line 25)	2	14,019,399.
3	Revenue less expenses. Subtract line 2 from line 1	3	1,194,571.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	6,121,329.
5	Net unrealized gains (losses) on investments	5	106,589.
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	7,422,489.

Part XII Financial Statements and Reporting

Check if Schedule O contains a response or note to any line in this Part XII ☒

	Yes	No
1 Accounting method used to prepare the Form 990: ☐ Cash ☒ Accrual ☐ Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O.		
2a Were the organization's financial statements compiled or reviewed by an independent accountant? _____ If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: ☐ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis		☒
b Were the organization's financial statements audited by an independent accountant? _____ If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: ☒ Separate basis ☐ Consolidated basis ☐ Both consolidated and separate basis	☒	
c If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? _____ If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	☒	
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F? _____		☒
b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits _____		

Form 990 (2024)

Department of the Treasury
Internal Revenue Service

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2024

Open to Public Inspection

Employer identification number
36-3320440

Part I	Reason for Public Charity Status. (All organizations must complete this part.) See instructions.
---------------	---

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1 ☐ A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i).**
- 2 ☐ A school described in **section 170(b)(1)(A)(ii).** (Attach Schedule E (Form 990).)
- 3 ☐ A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii).**
- 4 ☐ A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii).** Enter the hospital's name, city, and state: _____
- 5 ☐ An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv).** (Complete Part II.)
- 6 ☐ A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v).**
- 7 ☒ An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
- 8 ☐ A community trust described in **section 170(b)(1)(A)(vi).** (Complete Part II.)
- 9 ☐ An agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: _____
- 10 ☐ An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2).** (Complete Part III.)
- 11 ☐ An organization organized and operated exclusively to test for public safety. See **section 509(a)(4).**
- 12 ☐ An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2).** See **section 509(a)(3).** Check the box on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
- a ☐ **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
- b ☐ **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
- c ☐ **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
- d ☐ **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
- e ☐ Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.

f Enter the number of supported organizations

g Provide the following information about the supported organization(s).

g. Provide the following information about the supported organization(s):						
(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
Total						

FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA

Schedule A (Form 990) 2024

36-3320440 Page 2

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	7340383.	9516614.	9356093.	7517231.	7673243.	41403564.
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	7340383.	9516614.	9356093.	7517231.	7673243.	41403564.
5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)						17150594.
6 Public support. Subtract line 5 from line 4.						24252970.

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
7 Amounts from line 4	7340383.	9516614.	9356093.	7517231.	7673243.	41403564.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	29,302.	50,353.	87,007.	118,983.	152,824.	438,469.
9 Net income from unrelated business activities, whether or not the business is regularly carried on						
10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)	33,326.	139,055.	87,572.	65,715.	314,407.	640,075.
11 Total support. Add lines 7 through 10						42482108.
12 Gross receipts from related activities, etc. (see instructions)					12 28,365,428.	
13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here						

Section C. Computation of Public Support Percentage

14 Public support percentage for 2024 (line 6, column (f), divided by line 11, column (f))	14	57.09 %
15 Public support percentage from 2023 Schedule A, Part II, line 14	15	55.78 %
16a 33 1/3% support test - 2024. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		
		☒
b 33 1/3% support test - 2023. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization		
		☐
17a 10% -facts-and-circumstances test - 2024. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization		
		☐
b 10% -facts-and-circumstances test - 2023. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here. Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization		
		☐
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions		
		☐

Schedule A (Form 990) 2024

FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA

Schedule A (Form 990) 2024

36-3320440 Page 3

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2020	(b) 2021	(c) 2022	(d) 2023	(e) 2024	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						

14 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here** ☐

Section C. Computation of Public Support Percentage

15 Public support percentage for 2024 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2023 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2024 (line 10c, column (f), divided by line 13, column (f))	17	%
18 Investment income percentage from 2023 Schedule A, Part III, line 17	18	%

19a 33 1/3% support tests - 2024. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization ☐

b 33 1/3% support tests - 2023. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization ☐

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions ☐

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

	Yes	No
1 Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i>		
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer lines 3b and 3c below.</i>		
b Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>		
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>		
4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.</i>		
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i>		
c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <i>If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i>		
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>		
b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If "Yes," provide detail in Part VI.</i>		
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>		
9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If "Yes," provide detail in Part VI.</i>		
b Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i>		
c Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i>		
10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If "Yes," answer line 10b below.</i>		
b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		

**FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Schedule A (Form 990) 2024

36-3320440 Page 5

Part IV Supporting Organizations (continued)

	Yes	No
11 Has the organization accepted a gift or contribution from any of the following persons?		
a A person who directly or indirectly controls, either alone or together with persons described on lines 11b and 11c below, the governing body of a supported organization?		
b A family member of a person described on line 11a above?		
c A 35% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide detail in Part VI .		

Section B. Type I Supporting Organizations

	Yes	No
1 Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.		
2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.		

Section C. Type II Supporting Organizations

	Yes	No
1 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).		

Section D. All Type III Supporting Organizations

	Yes	No
1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?		
2 Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).		
3 By reason of the relationship described on line 2, above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.		

Section E. Type III Functionally Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).			
a ☐ The organization satisfied the Activities Test. Complete line 2 below.			
b ☐ The organization is the parent of each of its supported organizations. Complete line 3 below.			
c ☐ The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions).			
2 Activities Test. Answer lines 2a and 2b below.			
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.			
b Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.			
3 Parent of Supported Organizations. Answer lines 3a and 3b below.			
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? If "Yes" or "No," provide details in Part VI .			
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.			

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule A (Form 990) 2024

DBA CURE SMA

36-3320440 Page 6

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

- 1 ☐ Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (*explain in Part VI*). **See instructions.**
All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	1	
2	Recoveries of prior-year distributions	2	
3	Other gross income (see instructions)	3	
4	Add lines 1 through 3.	4	
5	Depreciation and depletion	5	
6	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6	
7	Other expenses (see instructions)	7	
8	Adjusted Net Income (subtract lines 5, 6, and 7 from line 4)	8	

Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	Total (add lines 1a, 1b, and 1c)	1d	
e	Discount claimed for blockage or other factors (<i>explain in detail in Part VI</i>):		
2	Acquisition indebtedness applicable to non-exempt-use assets	2	
3	Subtract line 2 from line 1d.	3	
4	Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).	4	
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6	Multiply line 5 by 0.035.	6	
7	Recoveries of prior-year distributions	7	
8	Minimum Asset Amount (add line 7 to line 6)	8	

Section C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, column A)	1	
2	Enter 0.85 of line 1.	2	
3	Minimum asset amount for prior year (from Section B, line 8, column A)	3	
4	Enter greater of line 2 or line 3.	4	
5	Income tax imposed in prior year	5	
6	Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6	
7	☐ Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).		

Schedule A (Form 990) 2024

**FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Schedule A (Form 990) 2024

36-3320440 Page 7

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Section D - Distributions		Current Year
1 Amounts paid to supported organizations to accomplish exempt purposes	1	
2 Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2	
3 Administrative expenses paid to accomplish exempt purposes of supported organizations	3	
4 Amounts paid to acquire exempt-use assets	4	
5 Qualified set-aside amounts (prior IRS approval required - <i>provide details in Part VI</i>)	5	
6 Other distributions (describe in Part VI). See instructions.	6	
7 Total annual distributions. Add lines 1 through 6.	7	
8 Distributions to attentive supported organizations to which the organization is responsive (<i>provide details in Part VI</i>). See instructions.	8	
9 Distributable amount for 2024 from Section C, line 6	9	
10 Line 8 amount divided by line 9 amount	10	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2024	(iii) Distributable Amount for 2024
1 Distributable amount for 2024 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2024 (reasonable cause required - <i>explain in Part VI</i>). See instructions.			
3 Excess distributions carryover, if any, to 2024			
a From 2019			
b From 2020			
c From 2021			
d From 2022			
e From 2023			
f Total of lines 3a through 3e			
g Applied to under distributions of prior years			
h Applied to 2024 distributable amount			
i Carryover from 2019 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2024 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2024 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2024, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
6 Remaining underdistributions for 2024. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
7 Excess distributions carryover to 2025. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2020			
b Excess from 2021			
c Excess from 2022			
d Excess from 2023			
e Excess from 2024			

Schedule A (Form 990) 2024

Part VI

Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information.
(See instructions.)

**Schedule B
(Form 990)**

(Rev. December 2024)
Department of the Treasury
Internal Revenue Service

Schedule of Contributors

Attach to Form 990, 990-EZ, or 990-PF.
Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

Name of the organization

**FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Employer identification number

36-3320440

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

☒ 501(c)(3) (enter number) organization

☐ 4947(a)(1) nonexempt charitable trust **not** treated as a private foundation

☐ 527 political organization

Form 990-PF

☐ 501(c)(3) exempt private foundation

☐ 4947(a)(1) nonexempt charitable trust treated as a private foundation

☐ 501(c)(3) taxable private foundation

Check if your organization is covered by the **General Rule** or a **Special Rule**.

Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

☐ For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

Special Rules

☒ For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of **(1)** \$5,000; or **(2)** 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.

☐ For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III.

☐ For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year \$ _____

Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990), but it **must** answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990).

Name of organization

FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA

Employer identification number

36-3320440

Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>1</u>		\$ <u>864,766.</u>	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
<u>2</u>		\$ <u>764,177.</u>	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
<u>3</u>		\$ <u>797,766.</u>	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
<u>4</u>		\$ <u>450,181.</u>	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
<u>5</u>		\$ <u>892,614.</u>	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)
<u>6</u>		\$ <u>250,000.</u>	Person ☒ Payroll ☐ Noncash ☐ (Complete Part II for noncash contributions.)

Employer identification number

36-3320440

Part II

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
	_____ _____ _____ _____	\$ _____	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
	_____ _____ _____ _____	\$ _____	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
	_____ _____ _____ _____	\$ _____	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
	_____ _____ _____ _____	\$ _____	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
	_____ _____ _____ _____	\$ _____	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
	_____ _____ _____ _____	\$ _____	_____
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
	_____ _____ _____ _____	\$ _____	_____

Name of organization	Employer identification number
FAMILIES OF SPINAL MUSCULAR ATROPHY	
DBA CURE SMA	36-3320440

Part III Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this info. once.) \$ _____
Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	(e) Transfer of gift		
	Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	(e) Transfer of gift		
	Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	(e) Transfer of gift		
	Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	(e) Transfer of gift		
	Transferee's name, address, and ZIP + 4		Relationship of transferor to transferee

SCHEDULE C
(Form 990)

Department of the Treasury
Internal Revenue Service

Political Campaign and Lobbying Activities

For Organizations Exempt From Income Tax Under Section 501(c) and Section 527
Complete if the organization is described below. Attach to Form 990 or Form 990-EZ.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2024

Open to Public
Inspection

If the organization answered "Yes" on Form 990, Part IV, line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then:

- Section 501(c)(3) organizations: Complete Parts I-A and I-B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and I-C below. Do not complete Part I-B.
- Section 527 organizations: Complete Part I-A only.

If the organization answered "Yes" on Form 990, Part IV, line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then:

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B.
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B. Do not complete Part II-A.

If the organization answered "Yes" on Form 990, Part IV, line 5 (Proxy Tax) (see separate instructions), or Form 990-EZ, Part V, line 35c (Proxy Tax) (see separate instructions), then:

- Section 501(c)(4), (5), or (6) organizations: Complete Part III.

Name of organization	FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA	Employer identification number (EIN)	36-3320440
----------------------	---	--------------------------------------	------------

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

1 Provide a description of the organization's direct and indirect political campaign activities in Part IV.

2 Political campaign activity expenditures	\$	
3 Volunteer hours for political campaign activities		

Part I-B Complete if the organization is exempt under section 501(c)(3).

- | | | |
|---|--|--|
| 1 Enter the amount of any excise tax incurred by the organization under section 4955 | \$ | |
| 2 Enter the amount of any excise tax incurred by organization managers under section 4955 | \$ | |
| 3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? | ☐ Yes ☐ No | |
| 4a Was a correction made? | ☐ Yes ☐ No | |
| b If "Yes," describe in Part IV. | | |

Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).

- | | | |
|--|--|--|
| 1 Enter the amount directly expended by the filing organization for section 527 exempt function activities | \$ | |
| 2 Enter the amount of the filing organization's funds contributed to other organizations for section 527 exempt function activities | \$ | |
| 3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL, line 17b | \$ | |
| 4 Did the filing organization file Form 1120-POL for this year? | ☐ Yes ☐ No | |
| 5 Enter the names, addresses, and EINs of all section 527 political organizations to which the filing organization made payments. For each organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC). If additional space is needed, provide information in Part IV. | | |

(a) Name	(b) Address	(c) EIN	(d) Amount paid from filing organization's funds. If none, enter -0-.	(e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-.

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule C (Form 990) 2024

Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).

- A** Check ☐ if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).
- B** Check ☐ if the filing organization checked box A and "limited control" provisions apply.

Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.)		(a) Filing organization's totals	(b) Affiliated group totals												
1a Total lobbying expenditures to influence public opinion (grassroots lobbying)															
b Total lobbying expenditures to influence a legislative body (direct lobbying)															
c Total lobbying expenditures (add lines 1a and 1b)															
d Other exempt purpose expenditures															
e Total exempt purpose expenditures (add lines 1c and 1d)															
f Lobbying nontaxable amount. Enter the amount from the following table in both columns.															
<table><thead><tr><th>IF the amount on line 1e, column (a) or (b), is:</th><th>THEN the lobbying nontaxable amount is:</th></tr></thead><tbody><tr><td>not over \$500,000</td><td>20% of the amount on line 1e.</td></tr><tr><td>over \$500,000 but not over \$1,000,000</td><td>\$100,000 plus 15% of the excess over \$500,000.</td></tr><tr><td>over \$1,000,000 but not over \$1,500,000</td><td>\$175,000 plus 10% of the excess over \$1,000,000.</td></tr><tr><td>over \$1,500,000 but not over \$17,000,000</td><td>\$225,000 plus 5% of the excess over \$1,500,000.</td></tr><tr><td>over \$17,000,000</td><td>\$1,000,000.</td></tr></tbody></table>	IF the amount on line 1e, column (a) or (b), is:	THEN the lobbying nontaxable amount is:	not over \$500,000	20% of the amount on line 1e.	over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.	over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.	over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.	over \$17,000,000	\$1,000,000.			
IF the amount on line 1e, column (a) or (b), is:	THEN the lobbying nontaxable amount is:														
not over \$500,000	20% of the amount on line 1e.														
over \$500,000 but not over \$1,000,000	\$100,000 plus 15% of the excess over \$500,000.														
over \$1,000,000 but not over \$1,500,000	\$175,000 plus 10% of the excess over \$1,000,000.														
over \$1,500,000 but not over \$17,000,000	\$225,000 plus 5% of the excess over \$1,500,000.														
over \$17,000,000	\$1,000,000.														
g Grassroots nontaxable amount (enter 25% of line 1f)															
h Subtract line 1g from line 1a. If zero or less, enter -0-															
i Subtract line 1f from line 1c. If zero or less, enter -0-															
j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year?		☐ Yes	☐ No												

4-Year Averaging Period Under Section 501(h)

(Some organizations that made a section 501(h) election do not have to complete all of the five columns below.
See the separate instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2021	(b) 2022	(c) 2023	(d) 2024	(e) Total
2a Lobbying nontaxable amount					
b Lobbying ceiling amount (150% of line 2a, column(e))					
c Total lobbying expenditures					
d Grassroots nontaxable amount					
e Grassroots ceiling amount (150% of line 2d, column (e))					
f Grassroots lobbying expenditures					

Schedule C (Form 990) 2024

Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

For each "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.

	(a)		(b)
	Yes	No	Amount
1 During the year, did the filing organization attempt to influence foreign, national, state, or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a Volunteers?		X	
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)? ...	X		
c Media advertisements?		X	
d Mailings to members, legislators, or the public?		X	
e Publications, or published or broadcast statements?		X	
f Grants to other organizations for lobbying purposes?		X	
g Direct contact with legislators, their staffs, government officials, or a legislative body?		X	
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		X	
i Other activities?	X		308,613.
j Total. Add lines 1c through 1i			308,613.
2a Did the activities in line 1 cause the organization to not be described in section 501(c)(3)?		X	
b If "Yes," enter the amount of any tax incurred under section 4912			
c If "Yes," enter the amount of any tax incurred by organization managers under section 4912			
d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

	Yes	No
1 Were substantially all (90% or more) dues received nondeductible by members?	1	
2 Did the organization make only in-house lobbying expenditures of \$2,000 or less?	2	
3 Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year?	3	

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No," OR (b) Part III-A, line 3, is answered "Yes."

1 Dues, assessments, and similar amounts from members	1	
2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid):		
a Current year	2a	
b Carryover from last year	2b	
c Total	2c	
3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues	3	
4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year?	4	
5 Taxable amount of lobbying and political expenditures. See instructions	5	

Part IV Supplemental Information

Provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, lines 1 and 2 (see instructions); and Part II-B, line 1. Also, complete this part for any additional information.

PART II-B, LINE 1

THE ORGANIZATION MAINTAINED TWO STAFF MEMBERS SPECIALIZING IN LOBBYING AND GOVERNMENT RELATIONS AND THIS STAFF MEMBERS' COMPENSATION INCLUDES TAXES AND BENEFITS AND TOTALED \$269,947.70 FOR THE FISCAL YEAR ENDED JUNE 30, 2025.

OUR TEAM WORKS WITH PUBLIC POLICY EXPERTS AND ADVOCATES IN WASHINGTON AND IN THE STATE CAPITAL TO KEEP ABREAST OF DEVELOPMENTS IMPACTING THE SMA COMMUNITY.

SCHEDULE D

(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

Complete if the organization answered "Yes" on Form 990,
Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.

Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

**Open to Public
Inspection**

Name of the organization **FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Employer identification number
36-3320440

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate value of contributions to (during year)		
3 Aggregate value of grants from (during year)		
4 Aggregate value at end of year		
5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? ☐ Yes ☐ No		
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? ☐ Yes ☐ No		

Part II Conservation Easements. Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

1 Purpose(s) of conservation easements held by the organization (check all that apply).
☐ Preservation of land for public use (for example, recreation or education) ☐ Preservation of a historically important land area
☐ Protection of natural habitat ☐ Preservation of a certified historic structure
☐ Preservation of open space

2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.

	Held at the End of the Tax Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included on line 2a	2c
d Number of conservation easements included on line 2c acquired after July 25, 2006, and not on a historic structure listed in the National Register	2d

3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year

4 Number of states where property subject to conservation easement is located

5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? ☐ Yes ☐ No

6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year

7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year

8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? ☐ Yes ☐ No

9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.

Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items.

b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items.

(i) Revenue included on Form 990, Part VIII, line 1 \$

(ii) Assets included in Form 990, Part X \$

2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items:

a Revenue included on Form 990, Part VIII, line 1 \$

b Assets included in Form 990, Part X \$

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule D (Form 990) (Rev. 12-2024)

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule D (Form 990) (Rev. 12-2024) DBA CURE SMA

36-3320440 Page 2

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued)

3 Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply).

a ☐ Public exhibition

d ☐ Loan or exchange program

b ☐ Scholarly research

e ☐ Other _____

c ☐ Preservation for future generations

4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.

5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets

to be sold to raise funds rather than to be maintained as part of the organization's collection? ☐ Yes ☐ No

Part IV Escrow and Custodial Arrangements Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1a Is the organization an agent, trustee, custodian, or other intermediary for contributions or other assets not included on Form 990, Part X? ☐ Yes ☐ No

b If "Yes," explain the arrangement in Part XIII and complete the following table:

	Amount
1c	
1d	
1e	
1f	

c Beginning balance

d Additions during the year

e Distributions during the year

f Ending balance

2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? ☐ Yes ☐ No

b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII ☐

Part V Endowment Funds Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance	2,289,032.	1,851,892.	1,411,074.	1,471,634.	1,277,887.
b Contributions	3,328.	214,162.	315,342.	137,735.	5,475.
c Net investment earnings, gains, and losses	218,282.	222,978.	125,476.	-198,295.	265,384.
d Grants or scholarships					
e Other expenditures for facilities and programs	126,088.				41,181.
f Administrative expenses					35,931.
g End of year balance	2,384,554.	2,289,032.	1,851,892.	1,411,074.	1,471,634.

2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

a Board designated or quasi-endowment .0000 %

b Permanent endowment 89.8365 %

c Term endowment 10.1634 %

The percentages on lines 2a, 2b, and 2c should equal 100%.

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

(i) Unrelated organizations?

(ii) Related organizations?

	Yes	No
3a(i)		X
3a(ii)		X
3b		

b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R? ☐

4 Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		815,102.	756,017.	59,085.
e Other		39,999.	39,999.	0.
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B))				59,085.

Schedule D (Form 990) (Rev. 12-2024)

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule D (Form 990) (Rev. 12-2024) **DBA CURE SMA**

36-3320440 Page **3**

Part VII Investments - Other Securities

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1) Financial derivatives		
(2) Closely held equity interests		
(3) Other		
(A)		
(B)		
(C)		
(D)		
(E)		
(F)		
(G)		
(H)		
Total. (Col. (b) must equal Form 990, Part X, line 12, col. (B))		

Part VIII Investments - Program Related.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
Total. (Col. (b) must equal Form 990, Part X, line 13, col. (B))		

Part IX Other Assets

Complete if the organization answered "Yes" on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, line 15, col. (B))	

Part X Other Liabilities

Complete if the organization answered "Yes" on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

1. (a) Description of liability	(b) Book value
(1) Federal income taxes	
(2) GRANTS PAYABLE, LONG-TERM	178,977.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, line 25, col. (B))	178,977.

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII ... ☒

Schedule D (Form 990) (Rev. 12-2024)

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule D (Form 990) (Rev. 12-2024) **DBA CURE SMA**

36-3320440 Page **4**

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements	1	15,407,549.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a	Net unrealized gains (losses) on investments	2a	106,589.
b	Donated services and use of facilities	2b	105,740.
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII.)	2d	
e	Add lines 2a through 2d	2e	212,329.
3	Subtract line 2e from line 1	3	15,195,220.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	18,750.
b	Other (Describe in Part XIII.)	4b	
c	Add lines 4a and 4b	4c	18,750.
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)	5	15,213,970.

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements	1	14,106,389.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
a	Donated services and use of facilities	2a	105,740.
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII.)	2d	
e	Add lines 2a through 2d	2e	105,740.
3	Subtract line 2e from line 1	3	14,000,649.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	18,750.
b	Other (Describe in Part XIII.)	4b	
c	Add lines 4a and 4b	4c	18,750.
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)	5	14,019,399.

Part XIII Supplemental Information

Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

PART V, LINE 4:

THE ENDOWMENT FUND IS INTENDED FOR THE PURPOSE OF LAUNCHING NEW AND MAINTAINING CURRENT TREATMENT AND CARE CENTERS. TO THE EXTENT THAT THE ORGANIZATION HAS ESTABLISHED ALL THE TREATMENT AND CARE CENTERS DEEMED APPROPRIATE BY ITS BOARD OF DIRECTORS, ANY EXCESS ANNUAL FUNDS SHALL THEN BE ALLOCATED TO FUND A PORTION OF THE DIRECT COSTS OF OPERATING ALL TREATMENT AND CARE CENTERS.

PART X, LINE 2:

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.

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule D (Form 990) (Rev. 12-2024) DBA CURE SMA

36-3320440 Page 5

Part XIII Supplemental Information *(continued)*

Supplemental information area with horizontal lines for text entry.

SCHEDULE F
(Form 990)

(Rev. December 2024)
Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.

Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

Employer identification number

36-3320440

Part I General Information on Activities Outside the United States. Complete if the organization answered "Yes" on

Form 990, Part IV, line 14b.

- 1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ☒ **Yes** ☐ **No**

- 2 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

- 3 Activities per Region.** (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in the region	(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region	(f) Total expenditures for and investments in the region
EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIUM	0	0	GRANTS TO RECIPIENTS IN THE REGION.	GRANTS	515,669.
EAST ASIA AND THE PACIFIC	0	0	GRANTS TO RECIPIENTS IN THE REGION.	GRANTS	50,000.
3 a Subtotal	0	0			565,669.
b Total from continuation sheets to Part I	0	0			0.
c Totals (add lines 3a and 3b)	0	0			565,669.

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule F (Form 990) (Rev. 12-2024)

SEE PART V FOR COLUMN (E) DESCRIPTIONS

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule F (Form 990) (Rev. 12-2024) **DBA CURE SMA**

36-3320440

Page **2**

Part II **Grants and Other Assistance to Organizations or Entities Outside the United States.** Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA,	BASIC RESEARCH	147,836.	WIRE TRANSFER	0.		CASH VALUE
		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA,	CLINICAL TRIALS	364,960.	WIRE TRANSFER	0.		CASH VALUE
		EAST ASIA AND THE PACIFIC	BASIC RESEARCH	50,000.	WIRE TRANSFER	0.		CASH VALUE

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter **0**

3 Enter total number of other organizations or entities **6**

Schedule F (Form 990) (Rev. 12-2024)

Schedule F (Form 990) (Rev. 12-2024) **DBA CURE SMA**

Page 3

Part III can be duplicated if additional space is needed.

Schedule F (Form 990) (Rev. 12-2024)

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule F (Form 990) (Rev. 12-2024) **DBA CURE SMA**

36-3320440 Page **4**

Part IV Foreign Forms

- 1** Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see the Instructions for Form 926)* ☐ Yes ☒ No
- 2** Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see the Instructions for Forms 3520 and 3520-A; don't file with Form 990)* ☐ Yes ☒ No
- 3** Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see the Instructions for Form 5471)* ☐ Yes ☒ No
- 4** Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see the Instructions for Form 8621)* ☐ Yes ☒ No
- 5** Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see the Instructions for Form 8865)* ☐ Yes ☒ No
- 6** Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see the Instructions for Form 5713; don't file with Form 990)* ☐ Yes ☒ No

Schedule F (Form 990) (Rev. 12-2024)

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule F (Form 990) (Rev. 12-2024) **DBA CURE SMA**

36-3320440 Page **5**

Part V Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

PART I, LINE 2:

CURE SMA HAS A COMMITTEE THAT EVALUATES ALL GRANT APPLICATIONS AND SELECTS GRANT BASED UPON THE QUALIFICATION OF THE INSTITUTION, RESEARCHER, THE RESEARCH PROJECT'S AND POTENTIAL APPLICABILITY TO SMA. ONCE A GRANT HAS BEEN APPROVED, GRANTEEES ARE REQUIRED TO SUBMIT PROGRESS REPORTS BEFORE ADDITIONAL FUNDING IS AUTHORIZED.

EACH AWARD INCLUDES THE FOLLOWING TERMS:

- INSTITUTE (GRANTEE) SHALL PROVIDE SPONSOR (CURE SMA) WITH REPORTS OF THE WORK PERFORMED UNDER THIS AGREEMENT IN ACCORDANCE WITH THE FOLLOWING SCHEDULE: 1) QUARTERLY WRITTEN PROGRESS REPORTS DUE WITHIN THIRTY (30) DAYS AFTER THE END OF EACH CALENDAR QUARTER. 2) INSTITUTE SHALL SUBMIT TO SPONSOR A COMPREHENSIVE FINAL REPORT WITHIN NINETY (90) DAYS OF TERMINATION OR EXPIRATION OF THE RESEARCH PROJECT. 3) INSTITUTE SHALL ALSO PROVIDE TO SPONSOR A SUCCINCT WRITTEN LAY REPORT OF ANY PUBLICATIONS RESULTING FROM RESEARCH PERFORMED UNDER THIS AGREEMENT CONTAINING A QUOTE FROM THE PRINCIPAL INVESTIGATOR.

PART I, LINE 3, COLUMN (E):

(A) REGION:

EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA, AUSTRIA, BELGIU

(E) SPECIFIC TYPES OF SERVICES IN REGION: GRANTS

.LIST 59 _ 2

AKOTLOVA - 10/23/24 09:18PM WORKSHEET FORM 990 - SCH F (PART I)

1372

SCHEDULE G
(Form 990)

(Rev. December 2024)
Department of the Treasury
Internal Revenue Service

Supplemental Information Regarding Fundraising or Gaming Activities
Complete if the organization answered "Yes" on Form 990, Part IV, line 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.
Attach to Form 990 or Form 990-EZ.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public Inspection

Name of the organization: FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA
Employer identification number: 36-3320440

Part I Fundraising Activities. Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

- 1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.
a Mail solicitations
b Internet and email solicitations
c Phone solicitations
d In-person solicitations
e Solicitation of nongovernment grants
f Solicitation of government grants
g Special fundraising events
2 a Did the organization have a written or oral agreement with any individual...
b If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements...

Table with 6 columns: (i) Name and address of individual or entity (fundraiser), (ii) Activity, (iii) Did fundraiser have custody or control of contributions?, (iv) Gross receipts from activity, (v) Amount paid to (or retained by) fundraiser listed in col. (i), (vi) Amount paid to (or retained by) organization. Includes a Total row at the bottom.

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule G (Form 990) (Rev. 12-2024) DBA CURE SMA

36-3320440 Page 2

Part II Fundraising Events. Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

	(a) Event #1 CURE FOR CASEY (event type)	(b) Event #2 HOPE ON THE HILL (event type)	(c) Other events 48 (total number)	(d) Total events (add col. (a) through col. (c))	
Revenue	1 Gross receipts	265,339.	151,795.	2,922,301.	3,339,435.
	2 Less: Contributions	256,088.	116,568.	2,257,560.	2,630,216.
	3 Gross income (line 1 minus line 2)	9,251.	35,227.	664,741.	709,219.
Direct Expenses	4 Cash prizes				
	5 Noncash prizes	3,259.		77,180.	80,439.
	6 Rent/facility costs		10,461.	38,242.	48,703.
	7 Food and beverages	9,251.	35,227.	109,076.	153,554.
	8 Entertainment	3,250.	682.	27,165.	31,097.
	9 Other direct expenses	40,449.	12,906.	237,430.	290,785.
	10 Direct expense summary. Add lines 4 through 9 in column (d)				604,578.
11 Net income summary. Subtract line 10 from line 3, column (d)				104,641.	

Part III Gaming. Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

	(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
Revenue				
	1 Gross revenue			
Direct Expenses	2 Cash prizes			
	3 Noncash prizes			
	4 Rent/facility costs			
	5 Other direct expenses			
	6 Volunteer labor	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ No	☐ Yes _____ % ☐ No
7 Direct expense summary. Add lines 2 through 5 in column (d)				
8 Net gaming income summary. Subtract line 7 from line 1, column (d)				

9 Enter the state(s) in which the organization conducts gaming activities: _____

a Is the organization licensed to conduct gaming activities in each of these states? ☐ Yes ☐ No

b If "No," explain: _____

10a Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year? ☐ Yes ☐ No

b If "Yes," explain: _____

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule G (Form 990) (Rev. 12-2024) **DBA CURE SMA**

36-3320440 Page **3**

- 11** Does the organization conduct gaming activities with nonmembers? ☐ Yes ☐ No
- 12** Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity formed to administer charitable gaming? ☐ Yes ☐ No
- 13** Indicate the percentage of gaming activity conducted in:
- | | | |
|--------------------------------------|------------|---|
| a The organization's facility | 13a | % |
| b An outside facility | 13b | % |
- 14** Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name _____

Address _____

- 15a** Does the organization have a contract with a third party from whom the organization receives gaming revenue? ☐ Yes ☐ No

b If "Yes," enter the amount of gaming revenue received by the organization \$ _____ and the amount of gaming revenue retained by the third party \$ _____

c If "Yes," enter the name and address of the third party:

Name _____

Address _____

16 Gaming manager information:

Name _____

Gaming manager compensation \$ _____

Description of services provided _____

☐ Director/officer ☐ Employee ☐ Independent contractor

17 Mandatory distributions:

a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? ☐ Yes ☐ No

b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year \$ _____

Part IV Supplemental Information. Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.

[illegible]

**SCHEDULE I
(Form 990)**

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

**Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States**

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

**Open to Public
Inspection**

Name of the organization **FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Employer identification number
36-3320440

Part I General Information on Grants and Assistance

1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? ☒ **Yes** ☐ **No**

2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section (if applicable)	(d) Amount of cash grant	(e) Amount of noncash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
UNIVERSITY OF ROCHESTER 601 ELMWOOD AVENUE, BOX 673 ROCHESTER, NY 14624	16-0743209	501(C)(3)	230,000.	0.			PNCR NETWORK
TRUSTEES OF COLUMBIA UNIVERSITY - NYC - 154 HAVEN AVENUE - NEW YORK, NY 10032	13-5598093	501(C)(3)	306,885.	0.			PNCR NETWORK & BASIC RESEARCH
BOSTON CHILDREN'S HOSPITAL 300 LONGWOOD AVENUE BOSTON, MA 02115	04-2774441	501(C)(3)	346,620.	0.			PNCR NETWORK & BASIC RESEARCH
LELAND STANFORD JUNIOR UNIVERSITY 450 SERRA MALL STANFORD, CA 94305	94-1156365	501(C)(3)	252,500.	0.			PNCR NETWORK
CHILDREN'S HOSPITAL OF PHILADELPHIA - 34TH STREET CIVIC CENTER RD - PHILADELPHIA, PA 19104	52-1654453	501(C)(3)	164,300.	0.			PNCR NETWORK
JOHN HOPKINS UNIVERSITY BANK OF AMERICA N.A, 12529 COLLECTIONS CENTER DRIVE - CHICAGO, IL 60693	52-0595110	501(C)(3)	149,695.	0.			BASIC RESEARCH

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table **9.**

3 Enter total number of other organizations listed in the line 1 table **0.**

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule I (Form 990) (Rev. 12-2024)

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule I (Form 990) (Rev. 12-2024) DBA CURE SMA

36-3320440

Page 2

Part III **Grants and Other Assistance to Domestic Individuals.** Complete if the organization answered "Yes" on Form 990, Part IV, line 22.
Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of noncash assistance
CHILD CARE PACKAGES	155	32,371.	0.	FMV	CARE PACKAGES FOR FAMILIES WITH RECENTLY DIAGNOSED CHILDREN
ADULT CARE PACKAGES	108	6,897.	0.	FMV	CARE PACKAGES FOR TEENS AND ADULTS INDEPENDENCE PACKAGES
EQUIPMENT	9	54,399.	0.	FMV	CAR BED WITH MODIFIED VEST
MEDICAL ID BRACELET SUPPORT PROGRAM	13	0.	0.	FMV	MEDICAL ALERT BRACELET AND KEYCHAIN
LIFEVAC CHOKING AID DEVICE SUPPORT PROGRAM	83	4,680.	0.	FMV	CHOKING AID DEVICE FOR ANY INDIVIDUAL WITH SMA

Part IV **Supplemental Information.** Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

PART I, LINE 2:

DETAILED REQUIREMENTS MADE OF RECIPIENTS IN GRANT CONTRACTS. RECIPIENTS SHALL PROVIDE THE ORGANIZATION WITH REPORTS OF THE WORK PERFORMED UNDER THIS AGREEMENT IN ACCORDANCE WITH THE FOLLOWING SCHEDULE: QUARTERLY WRITTEN PROGRESS REPORTS DUE WITHIN THIRTY (30) DAYS AFTER THE END OF THE QUARTER. RECIPIENTS SHALL ALSO SUBMIT TO THE ORGANIZATION A COMPREHENSIVE FINAL REPORT WITHIN NINETY (90) DAYS OF TERMINATION OF THE RESEARCH PROJECT. FOR THE PURPOSE OF IDENTIFYING PATENTABLE INVENTIONS NOT COVERED BY PRE-EXISTING PATENTS, RECIPIENTS SHALL SUBMIT A COPY OF ALL PROPOSED PUBLICATIONS, PAPERS, AND ANY OTHER WRITTEN DISCLOSURE OF SUCH DATA OR INFORMATION TO THE ORGANIZATION AT LEAST THIRTY (30) DAYS PRIOR TO SUBMISSION FOR PUBLICATION OR DISCLOSURE TO A THIRD PARTY.

SCHEDULE J
(Form 990)

(Rev. December 2024)
Department of the Treasury
Internal Revenue Service

Compensation Information

For certain Officers, Directors, Trustees, Key Employees, and Highest
Compensated Employees
Complete if the organization answered "Yes" on Form 990, Part IV, line 23.
Attach to Form 990.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization	FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA	Employer identification number	36-3320440
--------------------------	---	--------------------------------	------------

Part I Questions Regarding Compensation

1a Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.

- | | |
|--|--|
| ☐ First-class or charter travel | ☐ Housing allowance or residence for personal use |
| ☐ Travel for companions | ☐ Payments for business use of personal residence |
| ☐ Tax indemnification and gross-up payments | ☐ Health or social club dues or initiation fees |
| ☐ Discretionary spending account | ☐ Personal services (such as maid, chauffeur, chef) |

b If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain

2 Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a?

3 Indicate which, if any, of the following the organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.

- | | |
|--|---|
| ☒ Compensation committee | ☐ Written employment contract |
| ☐ Independent compensation consultant | ☒ Compensation survey or study |
| ☐ Form 990 of other organizations | ☒ Approval by the board or compensation committee |

4 During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:

- a Receive a severance payment or change-of-control payment?
- b Participate in or receive payment from a supplemental nonqualified retirement plan?
- c Participate in or receive payment from an equity-based compensation arrangement?
- If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.

5 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:

- a The organization?
- b Any related organization?
- If "Yes" on line 5a or 5b, describe in Part III.

6 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:

- a The organization?
- b Any related organization?
- If "Yes" on line 6a or 6b, describe in Part III.

7 For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III

8 Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III

9 If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?

	Yes	No
1b		
2		
4a		X
4b		X
4c		X
5a		X
5b		X
6a		X
6b		X
7		X
8		X
9		

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule J (Form 990) (Rev. 12-2024)

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule J (Form 990) (Rev. 12-2024) **DBA CURE SMA**

36-3320440

Page **2**

Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that aren't listed on Form 990, Part VII.

Note: The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC and/or 1099-NEC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns (B)(i)-(D)	(F) Compensation in column (B) reported as deferred on prior Form 990
		(i) Base compensation	(ii) Bonus & incentive compensation	(iii) Other reportable compensation				
(1) KENNETH HOBBY PRESIDENT	(i)	329,195.	0.	0.	12,244.	7,367.	348,806.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(2) JAMIE GIBSON CHIEF DEVELOPMENT OFFICER	(i)	266,038.	0.	0.	9,619.	18,922.	294,579.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(3) MARLINE PAGAN CHIEF OPERATING OFFICER	(i)	208,905.	0.	0.	9,202.	21,350.	239,457.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(4) MARY SCHROTH CHIEF MEDICAL OFFICER (THROUGH 3/31/	(i)	218,342.	0.	0.	8,841.	1,361.	228,544.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(5) COLLEEN MCCARTHY O'TOOLE SR VICE PRESIDENT, COMMUNI	(i)	175,435.	0.	0.	5,746.	21,315.	202,496.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(6) MAYNARD FRIESZ VICE PRESIDENT, POLICY	(i)	149,595.	0.	0.	5,879.	7,669.	163,143.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(7) MARY CURRY VICE PRESIDENT, CLINICAL RESEARCH &	(i)	138,474.	0.	0.	6,111.	14,130.	158,715.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(8) JACKIE GLASCOCK VICE PRESIDENT OF RESEARCH	(i)	146,346.	0.	0.	6,067.	1,244.	153,657.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							

Schedule J (Form 990) (Rev. 12-2024)

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule J (Form 990) (Rev. 12-2024) DBA CURE SMA

36-3320440

Page 3

Part III Supplemental Information

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

PART I, LINE 3:

APPROVED BY THE BOARD OF DIRECTORS. THE BOARD'S EXECUTIVE COMMITTEE
CONDUCTS A MARKET SURVEY OF THE POSITION USING INDEPENDENT COMPENSATION
SOURCES, AND THEN PRESENTS A RECOMMENDATION TO THE FULL BOARD FOR APPROVAL.

SCHEDULE M
(Form 990)

Department of the Treasury
Internal Revenue Service

Noncash Contributions

Complete if the organizations answered "Yes" on Form 990, Part IV, line 29 or 30.
Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2024

Open to Public
Inspection

Name of the organization **FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA**

Employer identification number
36-3320440

Part I Types of Property

	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1 Art - Works of art				
2 Art - Historical treasures				
3 Art - Fractional interests				
4 Books and publications				
5 Clothing and household goods				
6 Cars and other vehicles				
7 Boats and planes				
8 Intellectual property				
9 Securities - Publicly traded	X	3	4,975.	FAIR MARKET VALUE
10 Securities - Closely held stock				
11 Securities - Partnership, LLC, or trust interests				
12 Securities - Miscellaneous				
13 Qualified conservation contribution - Historic structures				
14 Qualified conservation contribution - Other ...				
15 Real estate - Residential				
16 Real estate - Commercial				
17 Real estate - Other				
18 Collectibles				
19 Food inventory				
20 Drugs and medical supplies				
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other (<u>DONATED AUCTION</u>)	X	199	121,509.	FAIR MARKET VALUE
26 Other ()				
27 Other ()				
28 Other ()				

29 Number of Forms 8283 received by the organization during the tax year for contributions
for which the organization completed Form 8283, Part V, Donee Acknowledgement

29

30a During the year, did the organization receive by contribution any property reported on Part I, lines 1 through 28, that it
must hold for at least 3 years from the date of the initial contribution, and which isn't required to be used for
exempt purposes for the entire holding period?

b If "Yes," describe the arrangement in Part II.

31 Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions?

32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash
contributions?

b If "Yes," describe in Part II.

33 If the organization didn't report an amount in column (c) for a type of property for which column (a) is checked,
describe in Part II.

Yes No

30a		X
31	X	
32a	X	

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule M (Form 990) 2024

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule M (Form 990) 2024

DBA CURE SMA

36-3320440

Page 2

Part II **Supplemental Information.** Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.

SCHEDULE M, PART I, COLUMN (B):

WE ARE REPORTING THE NUMBER OF DONATIONS RECEIVED

SCHEDULE M, PART I, LINE 32B:

THE ORGANIZATION USES PNC TO RECEIVE AND SELL DONATED STOCK.

**SCHEDULE O
(Form 990)**

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on
Form 990 or 990-EZ or to provide any additional information.

Attach to Form 990 or Form 990-EZ.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

**Open to Public
Inspection**

Name of the organization FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA	Employer identification number 36-3320440
---	---

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:
SMA TODAY.

FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:
**MUSCULOSKELETAL ISSUES, AND MORE. IN ADDITION, OUR EQUIPMENT POOL GIVES
FAMILIES ACCESS TO SPECIALIZED ITEMS LIKE CAR BEDS, STROLLERS AND
BATHING SYSTEMS AT NO COST.**

**EVERY NEWLY-DIAGNOSED FAMILY RECEIVES A CARE PACKAGE FROM CURE SMA,
FULL OF TOYS APPROPRIATE TO THE CHILD'S TYPE OF THE DISEASE, IMPARTIAL
INFORMATION FOR PARENTS, AND USEFUL ITEMS SUGGESTED BY OTHER SMA
PARENTS BASED ON THEIR OWN EXPERIENCES. EVERY NEW ADULT TO THE
COMMUNITY RECEIVES A PACKAGES OF SPECIAL INDEPENDENCE RELATED ITEMS.**

**CURE SMA ALSO EDUCATES THE PUBLIC ABOUT SMA, TO STRENGTHEN THE SUPPORT
AVAILABLE TO FAMILIES. THIS INCLUDES DIRECTIONS, A BIANNUAL FAMILY
SUPPORT NEWSLETTER, AND COMPASS, A QUARTERLY UPDATE ON RESEARCH
DEVELOPMENTS**

FORM 990, PART III, LINE 4B, PROGRAM SERVICE ACCOMPLISHMENTS:
**CURRENTLY, THERE ARE THREE APPROVED DRUGS FOR SMA, WITH ANOTHER SEVERAL
DOZEN DRUG PROGRAMS IN DEVELOPMENT, INCLUDING FIVE IN CLINICAL TRIALS.
CURRENTLY, TWO INVESTIGATIONAL DRUGS ARE AWAITING FDA APPROVAL.**

**CURE SMA HAVE THREE PRIMARY DATABASES FOR DATA COLLECTION: A
PATIENT-REPORTED DATABASE WITH DATA FROM OVER 11,000 IMPACTED
INDIVIDUALS WORLDWIDE THAT ALSO INCORPORATES LONGITUDINAL DATA FROM OUR
ANNUAL COMMUNITY UPDATE SURVEY; THE SMA CLINICAL DATA REGISTRY (CDR)
THAT CONTAINS ELECTRONIC MEDICAL RECORD (EMR) SOURCED DATA FROM U.S.
BASED SMA CARE CENTER NETWORK SITES; AND THE NEWBORN SCREENING REGISTRY
WITH DATA FROM PARENTS OF BABIES WITH SMA THAT WERE IDENTIFIED THROUGH
STATEWIDE SMA NEWBORN SCREENING. THE ABOVE DATA SOURCES ARE COMBINED
AND ANALYZED ANNUALLY TO IDENTIFY TRENDS IN DEMOGRAPHICS, DIAGNOSIS,
SMA TREATMENTS, UNMET NEEDS, PATIENT CARE AND OUTCOMES. THE MOST RECENT
ANALYZES WERE PUBLISHED IN THE STATE OF SMA 2024 REPORT AVAILABLE ON
OUR WEBSITE.**

**DATA COLLECTED IS ALSO SHARED IN PEER-REVIEWED LITERATURE. CURE SMA
PUBLISHED "SMA COMMUNITY PRIORITIES FOR FUTURE DRUG THERAPIES:
CROSS-SECTIONAL SURVEY FINDING REPRESENTING 410 ADULTS WITH SMA" IN
NEUROLOGY AND THERAPY IN JUNE 2025. IN ADDITION, CURE SMA SUPPORTS THE
SMA INDUSTRY COLLABORATION. ESTABLISHED IN 2016, THE COLLABORATION IS A
MULTI-FACETED PARTNERSHIP THAT BRINGS TOGETHER PHARMACEUTICAL
COMPANIES, CURE SMA, AND OTHER NONPROFIT ORGANIZATIONS TO SHARE
INFORMATION, IDEAS, AND DATA. THE SMA INDUSTRY COLLABORATION WORKS
TOGETHER TO ADDRESS SCIENTIFIC, CLINICAL, AND REGULATORY TOPICS THAT
ARE CRITICAL TO ADVANCING DRUG DEVELOPMENT IN SMA AND WILL BENEFIT THE
BROADER SMA COMMUNITY.**

**CURE SMA CO-CREATED A NEW HEALTHCARE PROVIDER ENDURING CONTINUING
MEDICAL EDUCATION PROGRAM IN ADDITION TO THE IN-PERSON CURE SMA
CLINICAL CARE SESSION OFFERED IN JUNE 2025. RESOURCES WERE ALSO DEVOTED**

For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule O (Form 990) (Rev. 12-2024)

LHA 432211 01-15-25

Name of the organization	FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA	Employer identification number 36-3320440
--------------------------	---	--

TO MAINTAINING WEBSITE LISTINGS OF SMA NEWBORN SCREENING REFERRAL
CENTERS AND TREATMENT CENTERS THAT PROVIDE FDA-APPROVED SMA TREATMENTS.

FORM 990, PART III, LINE 4C, PROGRAM SERVICE ACCOMPLISHMENTS:

MEETING ALSO FURTHERS RESEARCH BY BUILDING PRODUCTIVE
COLLABORATIONS INCLUDING CROSS-DISCIPLINARY DIALOGUE, PARTNERSHIPS,
INTEGRATION OF NEW RESEARCHERS AND DRUG COMPANIES, AND EDUCATIONAL
OPPORTUNITIES FOR JUNIOR RESEARCHERS. COMMUNITY ATTENDEES HAVE DIRECT
ACCESS TO THE LATEST INFORMATION ABOUT RESEARCH, AND RESEARCHERS HAVE
AN OPPORTUNITY TO BUILD PERSONAL CONNECTIONS WITH THE PATIENTS WHO WILL
BENEFIT FROM THEIR WORK.

FORM 990, PART VI, SECTION B, LINE 11B:

THE FINANCE COMMITTEE OF THE BOARD AND THE PRESIDENT PERFORM AN INITIAL
REVIEW OF FORM 990. AFTER ACCEPTANCE OF FORM 990 BY THE FINANCE COMMITTEE
AND THE PRESIDENT, FORM 990 IS EMAILED TO THE FULL BOARD FOR REVIEW AND
APPROVAL BEFORE IT IS FILED.

FORM 990, PART VI, SECTION B, LINE 12C:

MEMBERS OF THE BOARD OF DIRECTORS ARE REQUIRED TO SIGN AN ANNUAL STATEMENT
DISCLOSING ANY POSSIBLE CONFLICTS OF INTEREST. ON AN ANNUAL BASIS, THE
AUDIT AND COMPLIANCE COMMITTEE REVIEWS THE CONFLICT OF INTEREST DISCLOSURE
FORMS FILED BY THE TRUSTEES, OFFICERS AND EMPLOYEES FOR POTENTIAL
CONFLICTS. ADDITIONALLY, ALL COVERED PERSONS HAVE AN ONGOING DUTY TO
DISCLOSE POTENTIAL CONFLICTS TO MANAGEMENT. POTENTIAL CONFLICTS OF INTEREST
ARE PRESENTED TO THE EXECUTIVE COMMITTEE FOR REVIEW. WHERE POTENTIAL
CONFLICT EXIST, A CONFLICT RESOLUTION REPORT IS CREATED AND THE TRUSTEE,
OFFICER OR EMPLOYEE IS NOT ALLOWED TO PARTICIPATE IN ANY VOTE OR DISCUSSION
OF THE DISCLOSED MATTER. AT THE CURRENT TIME, NO POTENTIAL CONFLICTS OF
INTEREST HAVE BEEN IDENTIFIED.

FORM 990, PART VI, SECTION B, LINE 15:

PRESIDENT AND OTHER OFFICER AND KEY EMPLOYEES' COMPENSATION - APPROVED BY
THE BOARD OF DIRECTORS. THE BOARD'S EXECUTIVE COMMITTEE CONDUCTS A MARKET
SURVEY OF THE POSITION USING INDEPENDENT COMPENSATION SOURCES, AND THEN
PRESENTS A RECOMMENDATION TO THE FULL BOARD FOR APPROVAL.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:

IL,AL,AK,AZ,CA,CO,CT,DE,FL,GA,IN,IA,KS,KY,LA,MD,MA,MI,MN,MO,NH,NJ,NM,NY,NC
OH,OR,PA,RI,SC,TN,TX,UT,VT,VA,WA,WV,WI

FORM 990, PART VI, SECTION C, LINE 19:

THE ORGANIZATION'S GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY AND
FINANCIAL STATEMENTS ARE AVAILABLE UPON REQUEST. THE REQUEST FOR DOCUMENTS
CAN BE MADE IN WRITING OR BY PHONE BY CONTACTING THE NATIONAL OFFICE. WHEN
A REQUEST IS MADE FOR DOCUMENTS, THE EXECUTIVE COMMITTEE OF THE BOARD OF
DIRECTORS APPROVES THE RELEASE OF DOCUMENTS.

FORM 990, PART XII, LINE 2C

THE PROCESS HAS NOT CHANGED FROM THE PRIOR YEAR.

TAX RETURN FILING INSTRUCTIONS

ILLINOIS FORM AG990-IL

FOR THE YEAR ENDING

JUNE 30, 2025

PREPARED FOR:

FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA
50 E COMMERCE DR 90
SCHAUMBURG, IL 60173

PREPARED BY:

WARADY & DAVIS LLP
1717 DEERFIELD RD SUITE 300S
DEERFIELD, IL 60015

AMOUNT OF TAX:

BALANCE DUE OF \$15

MAKE CHECK PAYABLE TO:

ILLINOIS CHARITY BUREAU FUND

MAIL TAX RETURN TO:

OFFICE OF THE ATTORNEY GENERAL
CHARITABLE TRUST BUREAU
115 S. LASALLE ST
CHICAGO, IL 60603

RETURN MUST BE MAILED ON OR BEFORE:

DECEMBER 31, 2025

SPECIAL INSTRUCTIONS:

THE REPORT SHOULD BE SIGNED AND DATED BY AN AUTHORIZED
INDIVIDUAL(S).

WE RECOMMEND THAT YOU USE CERTIFIED MAIL WITH POSTMARKED
RECEIPTS FOR PROOF OF TIMELY FILING.

ILLINOIS CHARITABLE ORGANIZATION ANNUAL REPORT

PMT #	_____
AMT	_____
INIT	_____

Illinois Attorney General Kwame Raoul
Charitable Trust Bureau, 115 S. LaSalle St
Chicago, IL 60603

CO # 01-015029

Report for the Fiscal Period:

Beginning 07/01/2024

& Ending 06/30/2025

MO DAY YR

Make Checks
Payable to
Illinois Charity
Bureau Fund

Check all items attached:
☒ Copy of IRS Return
☒ Audited Financial Statements
☐ Reviewed Financial Statements
☐ Copy of Form IFC
☒ \$15 Annual Report Filing Fee
☐ \$100 Late Report Filing Fee

Federal ID # 36-3320440

Are contributions to the organization tax deductible?

☒ Yes ☐ No

Date organization was created: 10/03/1984

MO DAY YR

Legal Name: FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA	YEAR-END AMOUNTS	
Mail Address: 50 E COMMERCE DR, 90	A) ASSETS	A) \$ 10,645,251.
City, State: SCHAUMBURG, IL	B) LIABILITIES	B) \$ 3,222,762.
Zip Code: 60173	C) NET ASSETS	C) \$ 7,422,489.
Email Address: MARLINE@CURESMA.ORG		
I. SUMMARY OF ALL REVENUE ITEMS DURING THE YEAR:	PERCENTAGE	AMOUNT
D) PUBLIC SUPPORT, CONTRIBUTIONS AND PROGRAM SERVICE REV. (GROSS AMTS.)	98.676 %	D) \$ 15,609,167.
E) GOVERNMENT GRANTS AND MEMBERSHIP DUES	%	E) \$
F) OTHER REVENUES	1.324 %	F) \$ 209,381.
G) TOTAL REVENUES, INCOME AND CONTRIBUTIONS RECEIVED (ADD D, E & F)	100 %	G) \$ 15,818,548.
II. SUMMARY OF ALL EXPENDITURES DURING THE YEAR:		
H) OPERATING CHARITABLE PROGRAM EXPENSE	57.932 %	H) \$ 8,471,926.
I) EDUCATION PROGRAM SERVICE EXPENSE	%	I) \$
J) TOTAL CHARITABLE PROGRAM SERVICE EXPENSE (ADD H & I)	57.932 %	J) \$ 8,471,926.
J1) JOINT COSTS ALLOCATED TO PROGRAM SERVICES (INCLUDED IN J)		\$
K) GRANTS TO OTHER CHARITABLE ORGANIZATIONS	16.194 %	K) \$ 2,368,243.
L) TOTAL CHARITABLE PROGRAM SERVICE EXPENDITURE (ADD J & K)	74.126 %	L) \$ 10,840,169.
M) MANAGEMENT AND GENERAL EXPENSE	8.894 %	M) \$ 1,300,650.
N) FUNDRAISING EXPENSE	16.980 %	N) \$ 2,483,158.
O) TOTAL EXPENDITURES THIS PERIOD (ADD L, M & N)	100 %	O) \$ 14,623,977.
III. SUMMARY OF ALL PAID FUNDRAISER & CONSULTANT ACTIVITIES: (Attach Attorney General Report of Individual Fundraising Campaign (Form IFC). One for each PFR.)		
PROFESSIONAL FUNDRAISERS:		
P) TOTAL AMOUNT RAISED BY PAID PROFESSIONAL FUNDRAISERS	100 %	P) \$ 0.
Q) TOTAL FUNDRAISERS FEES AND EXPENSES	%	Q) \$
R) NET RECEIVED BY THE CHARITY (P MINUS Q = R)	%	R) \$
• PROFESSIONAL FUNDRAISING CONSULTANTS:		
S) TOTAL AMOUNT PAID TO PROFESSIONAL FUNDRAISING CONSULTANTS		S) \$ 0.
IV. COMPENSATION TO THE (3) HIGHEST PAID PERSONS DURING THE YEAR:		
T) NAME, TITLE: KENNETH HOBBY, PRESIDENT		T) \$ 368,529.
U) NAME, TITLE: JAMIE GIBSON, CHIEF DEVELOPMENT OFFICER		U) \$ 318,535.
V) NAME, TITLE: MARLINE PAGAN, CHIEF OPERATING OFFICER		V) \$ 247,885.
V. CHARITABLE PROGRAM DESCRIPTION: CHARITABLE PROGRAM (3 HIGHEST BY \$ EXPENDED) CODE CATEGORIES		List on back side of instructions CODE
W) DESCRIPTION: FUNDING RESEARCH OF SPINAL MUSCULAR ATROPHY		W) # 050
X) DESCRIPTION: GRANTS TO OTHER CHARITABLE ORGANIZATIONS		X) # 150
Y) DESCRIPTION:		Y) #

THE QUESTIONS BELOW ARE APPLICABLE TO THE CURRENT REPORTING PERIOD. IF THE ANSWER TO ANY OF THE FOLLOWING QUESTIONS IS YES, ATTACH A DETAILED EXPLANATION:		YES	NO
1. WAS THE ORGANIZATION THE SUBJECT OF ANY COURT ACTION, FINE, PENALTY OR JUDGEMENT?	1.		X
2. DID THE ORGANIZATION MAKE A GRANT AWARD OR CONTRIBUTION TO ANY ORGANIZATION IN WHICH ANY OF ITS OFFICERS, DIRECTORS OR TRUSTEES OWNS AN INTEREST; OR WAS IT A PART TO ANY TRANSACTION IN WHICH ANY OF ITS OFFICERS, DIRECTORS OR TRUSTEES HAS A MATERIAL FINANCIAL INTEREST; OR DID ANY OFFICER, DIRECTOR OR TRUSTEE RECEIVE ANYTHING OF VALUE NOT REPORTED AS COMPENSATION?	2.		X
3. HAS THE ORGANIZATION INVESTED IN ANY CORPORATE STOCK IN WHICH ANY OFFICER, DIRECTOR OR TRUSTEE OWNS MORE THAN 10% OF THE OUTSTANDING SHARES?	3.		X
4. IS ANY PROPERTY OF THE ORGANIZATION HELD IN THE NAME OF OR COMMINGLED WITH THE PROPERTY OF ANY OTHER PERSON OR ORGANIZATION?	4.		X
5. DID THE ORGANIZATION USE THE SERVICES OF A PROFESSIONAL FUNDRAISER? (ATTACH FORM IFC)	5.		X
6a. DID THE ORGANIZATION ALLOCATE THE COST OF ANY SOLICITATION, MAILING, ADVERTISEMENT OR LITERATURE COSTS BETWEEN PROGRAM SERVICE AND FUNDRAISING EXPENSES?	6.		X
6b. IF "YES", ENTER (I) THE AGGREGATE AMOUNT OF THESE JOINT COSTS \$ _____ ; (II) THE AMOUNT ALLOCATED TO PROGRAM SERVICES \$ _____ ; (III) THE AMOUNT ALLOCATED TO MANAGEMENT AND GENERAL \$ _____ ; AND (IV) THE AMOUNT ALLOCATED TO FUNDRAISING \$ _____.			
7. DID THE ORGANIZATION EXPEND ITS RESTRICTED FUNDS FOR PURPOSES OTHER THAN RESTRICTED PURPOSES?	7.		X
8. HAS THE ORGANIZATION EVER BEEN REFUSED REGISTRATION OR HAD ITS REGISTRATION OR TAX EXEMPTION SUSPENDED OR REVOKED BY ANY GOVERNMENTAL AGENCY?	8.		X
9. DID THE ORGANIZATION LEARN OR BECOME AWARE OF ANY KICKBACK, BRIBE OR ANY THEFT, DEFALCATION, MISAPPROPRIATION, COMMINGLING OR MISUSE OF ORGANIZATIONAL FUNDS IN THE CURRENT OR PREVIOUS FISCAL YEARS?	9.		X
10. LIST THE NAME AND ADDRESS OF THE FINANCIAL INSTITUTIONS WHERE THE ORGANIZATION MAINTAINS ITS THREE LARGEST ACCOUNTS: FIFTH THIRD BANK, PO BOX 630900, CINCINNATI, OH 45263-0900 JP MORGAN CHASE BANK, N.A., PO BOX 182051, COLUMBUS, OH 43218			
11. NAME AND TELEPHONE NUMBER OF CONTACT PERSON: MARLINE PAGAN - 847-709-6318			

• ALL ATTACHMENTS MUST ACCOMPANY THIS REPORT - SEE INSTRUCTIONS •

UNDER PENALTY OF PERJURY, I (WE) THE UNDERSIGNED DECLARE AND CERTIFY THAT I (WE) HAVE EXAMINED THIS ANNUAL REPORT AND THE ATTACHED DOCUMENTS, INCLUDING ALL THE SCHEDULES AND STATEMENTS, AND THE FACTS THEREIN STATED ARE TRUE AND COMPLETE AND FILED WITH THE ILLINOIS ATTORNEY GENERAL FOR THE PURPOSE OF HAVING THE PEOPLE OF THE STATE OF ILLINOIS RELY THEREUPON. I HEREBY FURTHER AUTHORIZE AND AGREE TO SUBMIT MYSELF AND THE REGISTRANT HEREBY TO THE JURISDICTION OF THE STATE OF ILLINOIS.

BE SURE TO INCLUDE ALL FEES DUE:

- 1.) REPORTS ARE DUE WITHIN SIX MONTHS OF YOUR FISCAL YEAR END.
- 2.) FOR FEES DUE, SEE INSTRUCTIONS.
- 3.) REPORTS THAT ARE LATE OR INCOMPLETE ARE SUBJECT TO A \$100.00 PENALTY.

KENNETH HOBBY

PRESIDENT OR OTHER AUTHORIZED OFFICER OR TRUSTEE (PRINT NAME)	SIGNATURE	DATE
---	-----------	------

BRADLEY A. NUNEMAKER

CHIEF FISCAL OFFICER OR TRUSTEE (PRINT NAME)	SIGNATURE	DATE
--	-----------	------

KOSTA G. TCHOBANOV

PREPARER (PRINT NAME)	SIGNATURE	DATE
-----------------------	-----------	------