

Form **990**

Return of Organization Exempt From Income Tax
Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

OMB No. 1545-0047

2021

Department of the Treasury
Internal Revenue Service

▶ 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.

Open to Public Inspection

A For the 2021 calendar year, or tax year beginning **JUL 1, 2021** and ending **JUN 30, 2022**

B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> 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 925 BUSSE RD City or town, state or province, country, and ZIP or foreign postal code ELK GROVE VILLAGE, IL 60007 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 \$ 15,738,432. H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. See instructions H(c) Group exemption number ▶
I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () ◀ (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		
J Website: ▶ WWW.CURESMA.ORG		
K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶		
L Year of formation: 1984		M State of legal domicile: IL

Part I Summary

Activities & Governance	1 Briefly describe the organization's mission or most significant activities: CURE SMA LEADS THE WAY TO A WORLD WITHOUT SPINAL MUSCULAR ATROPHY, THE NUMBER ONE GENETIC CAUSE 2 Check this box <input type="checkbox"/> 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 19 4 Number of independent voting members of the governing body (Part VI, line 1b) 4 19 5 Total number of individuals employed in calendar year 2021 (Part V, line 2a) 5 61 6 Total number of volunteers (estimate if necessary) 6 6400 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.																									
Revenue	<table border="1" style="width:100%; border-collapse: collapse;"> <thead> <tr> <th></th> <th align="center">Prior Year</th> <th align="center">Current Year</th> </tr> </thead> <tbody> <tr> <td>8 Contributions and grants (Part VIII, line 1h)</td> <td align="right">8,594,517.</td> <td align="right">9,516,614.</td> </tr> <tr> <td>9 Program service revenue (Part VIII, line 2g)</td> <td align="right">1,627,325.</td> <td align="right">3,528,616.</td> </tr> <tr> <td>10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)</td> <td align="right">83,339.</td> <td align="right">52,111.</td> </tr> <tr> <td>11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)</td> <td align="right">111,132.</td> <td align="right">1,924,878.</td> </tr> <tr> <td>12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)</td> <td align="right">10,416,313.</td> <td align="right">15,022,219.</td> </tr> </tbody> </table>		Prior Year	Current Year	8 Contributions and grants (Part VIII, line 1h)	8,594,517.	9,516,614.	9 Program service revenue (Part VIII, line 2g)	1,627,325.	3,528,616.	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	83,339.	52,111.	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	111,132.	1,924,878.	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	10,416,313.	15,022,219.							
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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 10/12/2022
Paid Preparer Use Only	Print/Type preparer's name KOSTA G. TCHOBANOV	Preparer's signature
	Date 10/18/22	Check <input type="checkbox"/> if self-employed PTIN P01302744
	Firm's name ▶ WARADY & DAVIS LLP	Firm's EIN ▶ 36-2170602
	Firm's address ▶ 1717 DEERFIELD RD SUITE 300S DEERFIELD, IL 60015	Phone no. (847) 267-9600

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

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission: CURE SMA FUNDS AND DIRECTS THE LEADING SMA RESEARCH PROGRAMS TO DEVELOP A TREATMENT AND CURE FOR THE DISEASE. THE SUCCESSFUL RESULTS AND PROGRESS THAT THE ORGANIZATION HAS DELIVERED, FROM BASIC RESEARCH TO DRUG DISCOVERY TO CLINICAL TRIALS TO MULTIPLE APPROVED TREATMENTS,

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 [X] 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 [X] 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 \$ 2,805,278. including grants of \$ 838,944.) (Revenue \$ 27,104.) 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 \$ 5,185,859. including grants of \$ 1,870,773.) (Revenue \$ 342,080.) 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 TEN

ONGOING BASIC RESEARCH GRANTS, AS WELL AS TWO ONGOING DRUG DISCOVERY PROJECTS. WE ALSO FUNDED AND EXECUTED MULTIPLE CLINICAL AND REGULATORY FOCUSED PROJECTS, INCLUDING PROJECTS TO IMPLEMENT AND SUPPORT NEWBORN SCREENING FOR SMA AT THE STATE LEVEL, TO INCREASE THE NUMBER OF TRAINED SMA CLINICAL TRIALS SITES IN THE US, TO DEVELOP NEW OUTCOME MEASURES FOR SMA CLINICAL TRIALS, AND TO COLLECT DATA TO UNDERSTAND THE PATIENT

4c (Code:) (Expenses \$ 3,368,726. including grants of \$ 144,872.) (Revenue \$ 3,298,487.) WE HOSTED THE 2022 ANNUAL SMA CONFERENCE IN ANAHEIM, CA, WITH OVER 2,057 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 CONFERENCE CREATES OPEN COMMUNICATION OF EARLY, UNPUBLISHED SCIENTIFIC DATA, ACCELERATING THE PACE OF RESEARCH. THE MEETING ALSO FURTHERS

4d Other program services (Describe on Schedule O.) (Expenses \$ including grants of \$) (Revenue \$)

4e Total program service expenses 11,359,863.

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

Form 990 (2021)

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>	X	
2 Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? See instructions	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>	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>	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>	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>	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>	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>	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>		X
14a Did the organization maintain an office, employees, or agents outside of the United States?		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>	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>	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.</i> See instructions		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>	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>		X
b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		
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>	X	

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

Form 990 (2021)

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>	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>	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>		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
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?		
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
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>		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>		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>		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>		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>		X
b A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>		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>		X
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	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>		X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		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>		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>		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>		X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		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>		
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>		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>		X
38 Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19?	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		
b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable		
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?		

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

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		61
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note: If the sum of lines 1a and 2a is greater than 250, you may be required to e-file. See instructions.	X	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		X
b	If "Yes," has it filed a Form 990-T for this year? If "No" to line 3b, provide an explanation on Schedule O		
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)?		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?		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		
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?		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
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?	X	
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?	X	
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		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?		X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		X
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
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?		
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the sponsoring organization make any taxable distributions under section 4966?		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		
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?		
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.		
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?		X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation on Schedule O		
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.		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.		X
17	Section 501(c)(21) organizations. Did the trust, any disqualified person, or mine operator 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.		

FAMILIES OF SPINAL MUSCULAR ATROPHY

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	1a	19		
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	1b	19		
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?	10a		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?	10b		X	
11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	11a		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	12a		X	
b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?	12b		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	12c		X	
13 Did the organization have a written whistleblower policy?	13		X	
14 Did the organization have a written document retention and destruction policy?	14		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	15a		X	
b Other officers or key employees of the organization	15b		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?	16a			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?	16b			

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**
925 BUSSE RD, ELK GROVE VILLAGE, IL 60007

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

Form 990 (2021)

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, 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				312,639.	0.	17,387.
(2) MARY SCHROTH CHIEF MEDICAL OFFICER	60.00				X			259,537.	0.	17,781.
(3) MARLINE PAGAN VICE PRESIDENT, FINANCE	60.00				X			168,795.	0.	23,733.
(4) JILL JARECKI CHIEF SCIENTIFIC OFFICER	60.00				X			169,943.	0.	8,670.
(5) COLLEEN MCCARTHY O'TOOLE VICE PRESIDENT, FAMILY SUPPORT	60.00					X		149,198.	0.	23,654.
(6) PAMELA SWENK CHIEF OF STAFF OFFICER	60.00					X		149,272.	0.	18,294.
(7) ERIN OGANESIAN VP, DEVELOPMENT	50.00					X		135,108.	0.	17,077.
(8) MAYNARD FRIESZ VICE PRESIDENT, POLICY & A	50.00					X		115,409.	0.	16,173.
(9) AMBER EWERT SNYDER SR. DIRECTOR DATABASE MGMT	45.00					X		102,227.	0.	9,717.
(10) ALLYSON HENKEL DIRECTOR	2.00	X						0.	0.	0.
(11) AMY MEDINA DIRECTOR	2.00	X						0.	0.	0.
(12) ANNIE KENNEDY DIRECTOR	2.00	X						0.	0.	0.
(13) BRAD NUNEMAKER TREASURER	2.00	X		X				0.	0.	0.
(14) BRIAN SNYDER DIRECTOR	2.00	X						0.	0.	0.
(15) COREY BRAASTAD DIRECTOR	2.00	X						0.	0.	0.
(16) EDMUND LEE DIRECTOR	2.00	X						0.	0.	0.
(17) GILLIAN MULLINS SECRETARY	2.00	X		X				0.	0.	0.

**FAMILIES OF SPINAL MUSCULAR ATROPHY
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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) JACLYN GREENWOOD DIRECTOR	2.00	X					0.	0.	0.	
(19) KELLY COLE DIRECTOR	2.00	X					0.	0.	0.	
(20) KELLY JANKOWSKI DIRECTOR	2.00	X					0.	0.	0.	
(21) MATT EVANS DIRECTOR (THROUGH 3/15/22)	4.00	X					0.	0.	0.	
(22) NICK FARRELL BOARD CHAIR	15.00	X		X			0.	0.	0.	
(23) PETER STATILE DIRECTOR	2.00	X					0.	0.	0.	
(24) ROB LOCKWOOD DIRECTOR	2.00	X					0.	0.	0.	
(25) ROBERT GRAHAM DIRECTOR	2.00	X					0.	0.	0.	
(26) SHANNON SHRYNE DIRECTOR	2.00	X					0.	0.	0.	
1b Subtotal							1,562,128.	0.	152,486.	
c Total from continuation sheets to Part VII, Section A							0.	0.	0.	
d Total (add lines 1b and 1c)							1,562,128.	0.	152,486.	

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 9

	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>	3	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>	4	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>	5	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
DRINKER BIDDLE AND REATH LLP, ONE LOGAN SQUARE, SUITE 2000, PHILADELPHIA, PA 19103	LEGAL	196,119.

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 1

SEE PART VII, SECTION A CONTINUATION SHEETS

Form **990** (2021)

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

Part VIII Statement of Revenue

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

			(A)	(B)	(C)	(D)	
			Total revenue	Related or exempt function revenue	Unrelated business revenue	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	1,064,037.				
	d Related organizations	1d					
	e Government grants (contributions)	1e	2,083,597.				
	f All other contributions, gifts, grants, and similar amounts not included above	1f	6,368,980.				
	g Noncash contributions included in lines 1a-1f	1g	\$ 77,968.				
	h Total. Add lines 1a-1f			9,516,614.			
	Program Service Revenue	2 a ANNUAL CONFERENCE	Business Code	900099	2,678,616.	2,678,616.	
b SUMMIT OF STRENGTH SYMPOSIUMS			900099	500,000.	500,000.		
c INDUSTRY SPONSORED RESEARCH			900099	350,000.	350,000.		
d							
e							
f All other program service revenue							
g Total. Add lines 2a-2f				3,528,616.			
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			50,353.		50,353.	
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
	6 a Gross rents	6a	(i) Real				
			(ii) Personal				
	b Less: rental expenses	6b					
	c Rental income or (loss)	6c					
	d Net rental income or (loss)						
	7 a Gross amount from sales of assets other than inventory	7a	(i) Securities	402,474.			
			(ii) Other				
	b Less: cost or other basis and sales expenses	7b		400,716.			
c Gain or (loss)	7c		1,758.				
d Net gain or (loss)			1,758.		1,758.		
8 a Gross income from fundraising events (not including \$ 1,064,037. of contributions reported on line 1c). See Part IV, line 18	8a		2,101,320.				
b Less: direct expenses	8b		315,497.				
c Net income or (loss) from fundraising events			1,785,823.		1,785,823.		
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	11 a MISCELLANEOUS	Business Code	900099	129,205.	129,205.		
	b STORE MERCHANDISE		900099	29,650.	29,650.		
	c LOSS ON DISPOSAL OF INTANGIBLES		900099	-19,800.	-19,800.		
	d All other revenue						
	e Total. Add lines 11a-11d			139,055.			
12 Total revenue. See instructions			15,022,219.	3,667,671.	0.	1,837,934.	

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

Form 990 (2021)

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	2,268,795.	2,268,795.		
2 Grants and other assistance to domestic individuals. See Part IV, line 22	144,872.	144,872.		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	440,922.	440,922.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	915,445.	606,923.	114,752.	193,770.
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	3,331,182.	1,954,302.	332,982.	1,043,898.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	88,950.	50,266.	9,213.	29,471.
9 Other employee benefits	284,659.	169,891.	28,178.	86,590.
10 Payroll taxes	286,981.	172,762.	30,133.	84,086.
11 Fees for services (nonemployees):				
a Management				
b Legal	8,956.		8,956.	
c Accounting	33,335.		33,335.	
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees	11,739.		11,739.	
g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Sch O.)	717,656.	629,300.	11,173.	77,183.
12 Advertising and promotion	285,839.	223,749.	20,137.	41,953.
13 Office expenses	541,976.	469,980.	17,122.	54,874.
14 Information technology	426,243.	298,370.	29,837.	98,036.
15 Royalties				
16 Occupancy	214,441.	149,529.	25,669.	39,243.
17 Travel	226,907.	136,598.	23,825.	66,484.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	3,134,741.	3,116,776.	17,965.	
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	347,456.	338,031.	1,885.	7,540.
23 Insurance	48,516.	23,969.	12,881.	11,666.
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 WEBSITE	140,459.	105,344.	7,023.	28,092.
b BANK CHARGES, CREDIT CA	105,787.		65,197.	40,590.
c STAFF DEVELOPMENT/TRAIN	41,192.	28,835.	2,883.	9,474.
d MISCELLANEOUS	34,710.	4,457.	30,253.	
e All other expenses	101,518.	26,192.	69,232.	6,094.
25 Total functional expenses. Add lines 1 through 24e	14,183,277.	11,359,863.	904,370.	1,919,044.
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 <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

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

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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	6,815,576.	1	5,444,777.
	2 Savings and temporary cash investments		2	
	3 Pledges and grants receivable, net	1,138,834.	3	3,845,469.
	4 Accounts receivable, net		4	122,677.
	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	230,474.	9	93,219.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	1,174,647.		
	b Less: accumulated depreciation	886,367.		
	11 Investments - publicly traded securities	383,292.	10c	288,280.
	12 Investments - other securities. See Part IV, line 11	1,478,490.	11	1,411,074.
	13 Investments - program-related. See Part IV, line 11		12	
	14 Intangible assets	150,246.	13	85,619.
	15 Other assets. See Part IV, line 11	15,402.	14	6,344.
16 Total assets. Add lines 1 through 15 (must equal line 33)	10,212,314.	15	11,297,459.	
Liabilities	17 Accounts payable and accrued expenses	549,354.	16	11,297,459.
	18 Grants payable	549,354.	17	2,001,020.
	19 Deferred revenue	2,064,687.	18	2,045,472.
	20 Tax-exempt bond liabilities	13,000.	19	0.
	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	959,467.	23	0.
	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	6,514.	24	20,247.
	26 Total liabilities. Add lines 17 through 25	3,593,022.	25	4,066,739.
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.			
	27 Net assets without donor restrictions	1,805,369.	26	3,294,012.
	28 Net assets with donor restrictions	4,813,923.	27	3,936,708.
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> 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	6,619,292.	31	7,230,720.
33 Total liabilities and net assets/fund balances	10,212,314.	32	11,297,459.	

Form 990 (2021)

**FAMILIES OF SPINAL MUSCULAR ATROPHY
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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	15,022,219.
2	Total expenses (must equal Part IX, column (A), line 25)	2	14,183,277.
3	Revenue less expenses. Subtract line 2 from line 1	3	838,942.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	6,619,292.
5	Net unrealized gains (losses) on investments	5	-227,514.
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	7,230,720.

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: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> 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: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	2a	X
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: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	2b	X
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.	2c	X
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? _____	3a	X
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 _____	3b	

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	10,804,912.	9,307,212.	8,139,396.	7,340,383.	9,516,614.	45,108,517.
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	10,804,912.	9,307,212.	8,139,396.	7,340,383.	9,516,614.	45,108,517.
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)						21,356,199.
6 Public support. Subtract line 5 from line 4.						23,752,318.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(f) Total
7 Amounts from line 4	10,804,912.	9,307,212.	8,139,396.	7,340,383.	9,516,614.	45,108,517.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources ...	138,587.	45,169.	39,285.	29,302.	50,353.	302,696.
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.)	15,895.	45,183.	31,591.	33,326.	139,055.	265,050.
11 Total support. Add lines 7 through 10						45,676,263.
12 Gross receipts from related activities, etc. (see instructions)					12	19,672,576.
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						<input type="checkbox"/>

Section C. Computation of Public Support Percentage

14 Public support percentage for 2021 (line 6, column (f), divided by line 11, column (f)).....	14	52.00 %
15 Public support percentage from 2020 Schedule A, Part II, line 14	15	55.79 %
16a 33 1/3% support test - 2021. 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		<input checked="" type="checkbox"/>
b 33 1/3% support test - 2020. 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		<input type="checkbox"/>
17a 10% -facts-and-circumstances test - 2021. 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		<input type="checkbox"/>
b 10% -facts-and-circumstances test - 2020. 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		<input type="checkbox"/>
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		<input type="checkbox"/>

**FAMILIES OF SPINAL MUSCULAR ATROPHY
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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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(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) 2017	(b) 2018	(c) 2019	(d) 2020	(e) 2021	(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 2021 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2020 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2021 (line 10c, column (f), divided by line 13, column (f))	17	%
18 Investment income percentage from 2020 Schedule A, Part III, line 17	18	%

19a 33 1/3% support tests - 2021. 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 - 2020. 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 in line 12 on 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>		

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 .		
11a		
11b		
11c		

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.		
1		
2		

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).		
1		

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.		
1		
2		
3		

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 <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.			
b <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.			
c <input type="checkbox"/> 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.		Yes	No
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.			
2a			
2b			
3a			
3b			

FAMILIES OF SPINAL MUSCULAR ATROPHY

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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 (explain in detail in Part VI):		
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	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).		

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

Schedule A (Form 990) 2021

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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 (<i>describe in Part VI</i>). 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 2021 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-2021	(iii) Distributable Amount for 2021
1 Distributable amount for 2021 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2021 (reasonable cause required - <i>explain in Part VI</i>). See instructions.			
3 Excess distributions carryover, if any, to 2021			
a From 2016			
b From 2017			
c From 2018			
d From 2019			
e From 2020			
f Total of lines 3a through 3e			
g Applied to underdistributions of prior years			
h Applied to 2021 distributable amount			
i Carryover from 2016 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2021 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2021 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2021, 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 2021. 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 2022. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2017			
b Excess from 2018			
c Excess from 2019			
d Excess from 2020			
e Excess from 2021			

Schedule A (Form 990) 2021

FAMILIES OF SPINAL MUSCULAR ATROPHY

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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.)

Multiple horizontal lines for supplemental information.

SCHEDULE C
(Form 990)

Political Campaign and Lobbying Activities

OMB No. 1545-0047

2021

Department of the Treasury
Internal Revenue Service

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.**

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 B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and 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	36-3320440
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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 employer identification number (EIN) 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) 2021

FAMILIES OF SPINAL MUSCULAR ATROPHY

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 border="1"> <thead> <tr> <th>If the amount on line 1e, column (a) or (b) is:</th> <th>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:	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:	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?		<input type="checkbox"/> Yes	<input type="checkbox"/> 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) 2018	(b) 2019	(c) 2020	(d) 2021	(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					

FAMILIES OF SPINAL MUSCULAR ATROPHY

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		184,994.
j Total. Add lines 1c through 1i			184,994.
2a Did the activities in line 1 cause the organization to be not 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 expenditure 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 ONE STAFF MEMBER THAT SPECIALIZES IN LOBBYING AND GOVERNMENT RELATIONS AND THIS STAFF MEMBER'S COMPENSATION INCLUDING TAXES AND BENEFITS, TOTALED \$157,442.72 FOR THE FISCAL YEAR ENDED JUNE 30, 2022.

OUR TEAM WORKS WITH PUBLIC POLICY EXPERTS AND ADVOCATES IN WASHINGTON AND

Part IV Supplemental Information *(continued)*

IN THE STATE CAPITAL TO KEEP ABREAST OF DEVELOPMENTS IMPACTING THE SMA
COMMUNITY.

Multiple horizontal lines for supplemental information.

SCHEDULE D (Form 990)

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

2021

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.

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate value of contributions, grants, and end of year, and questions about donor property and grant fund usage.

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

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include purpose of easements, number of easements, acreage, and monitoring expenses.

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.

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include reporting requirements for art and historical treasures.

FAMILIES OF SPINAL MUSCULAR ATROPHY

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
 - b Scholarly research
 - c Preservation for future generations
 - d Loan or exchange program
 - e Other _____
- 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 |
|---------------------------------|--------|
| c Beginning balance | 1c |
| d Additions during the year | 1d |
| e Distributions during the year | 1e |
| f Ending balance | 1f |
- 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 on 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	1,471,634.	1,277,887.	1,201,609.	1,110,862.	1,032,313.
b Contributions	137,735.	5,475.	66,864.	63,994.	48,571.
c Net investment earnings, gains, and losses	-198,295.	265,384.	42,101.	53,541.	58,042.
d Grants or scholarships					
e Other expenditures for facilities and programs		41,181.	32,687.	26,788.	28,064.
f Administrative expenses		35,931.			
g End of year balance	1,411,074.	1,471,634.	1,277,887.	1,201,609.	1,110,862.

- 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 100.0000 %
 - c Term endowment _____ %
- 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:
- | | Yes | No |
|---|--------------------------|-------------------------------------|
| (i) Unrelated organizations | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| (ii) Related organizations | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R? <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
- 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		1,113,261.	851,612.	261,649.
e Other		61,386.	34,755.	26,631.
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)				288,280.

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule D (Form 990) 2021

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, col. (B) line 12.) ▶		

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, col. (B) line 13.) ▶		

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, col. (B) line 15.) ▶	

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) DEFERRED RENT	20,247.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	20,247.

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) 2021

FAMILIES OF SPINAL MUSCULAR ATROPHY

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	14,794,916.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	-227,514.	
b	Donated services and use of facilities	2b	11,950.	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d	2e	-215,564.	
3	Subtract line 2e from line 1		3	15,010,480.
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	11,739.	
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c	11,739.	
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.)		5	15,022,219.

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	14,183,488.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	11,950.	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d		
e	Add lines 2a through 2d	2e	11,950.	
3	Subtract line 2e from line 1		3	14,171,538.
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	11,739.	
b	Other (Describe in Part XIII.)	4b		
c	Add lines 4a and 4b	4c	11,739.	
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.)		5	14,183,277.

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 PROVING SCHOLARSHIPS WHICH WILL ENABLE CURE SMA TO WAIVE REGISTRATIONS FEES FOR ANY FAMILIES OF PATIENTS NEWLY DIAGNOSED WITH SMA TO ATTEND THE ANNUAL SMA CONFERENCE.

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

Part XIII Supplemental Information (continued)

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.

**SCHEDULE F
(Form 990)**

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

2021

Open to Public
Inspection

Name of the organization FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA	Employer identification number 36-3320440
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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	440,922.
3 a Subtotal	0	0			440,922.
b Total from continuation sheets to Part I	0	0			0.
c Totals (add lines 3a and 3b)	0	0			440,922.

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 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 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 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 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 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 Instructions for Form 5713; don't file with Form 990)* Yes No

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.

FAMILIES OF SPINAL MUSCULAR ATROPHY

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	(b) Event #2	(c) Other events	(d) Total events (add col. (a) through col. (c))	
		WALK FOR GRAHAM (event type)	MUSCLES FOR MCKENNA EOH (event type)	108 (total number)		
Revenue	1	Gross receipts	167,919.	115,330.	2,882,108.	3,165,357.
	2	Less: Contributions	163,695.	99,370.	800,972.	1,064,037.
	3	Gross income (line 1 minus line 2)	4,224.	15,960.	2,081,136.	2,101,320.
Direct Expenses	4	Cash prizes				
	5	Noncash prizes				
	6	Rent/facility costs				
	7	Food and beverages		23,650.	68,105.	91,755.
	8	Entertainment	2,750.	5,000.	13,976.	21,726.
	9	Other direct expenses	17,990.	3,342.	180,684.	202,016.
	10	Direct expense summary. Add lines 4 through 9 in column (d)				315,497.
11	Net income summary. Subtract line 10 from line 3, column (d)				1,785,823.	

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	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> 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: _____

**SCHEDULE I
(Form 990)**

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 the latest information.

OMB No. 1545-0047

2021

**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
GILLETTE CHILDREN'S SPECIALTY HEALTHCARE - 200 UNIVERSITY DRIVE, AVENUE E - ST PAUL, MN 55101	36-3379150	501(C)(3)	19,600.	0.			CARE CENTER NETWORK
UNIVERSITY OF UTAH 201 PRESIDENT CIRCLE, ROOM 406 SALT LAKE CITY, UT 84112	87-6000525	501(C)(3)	48,000.	0.			CARE CENTER NETWORK
AR CHILDREN'S RESEARCH INSTITUTE 13 CHILDREN'S WAY, SLOT 842 LITTLE ROCK, AR 72202	71-0694931	501(C)(3)	32,900.	0.			CARE CENTER NETWORK
YALE UNIVERSITY P.O. BOX 1873 NEW HAVEN, CT 06508	06-0646973	501(C)(3)	5,400.	0.			CARE CENTER NETWORK
UNIVERSITY OF ROCHESTER 601 ELMWOOD AVENUE, BOX 673 ROCHESTER, NY 14624	16-0743209	501(C)(3)	37,900.	0.			CARE CENTER NETWORK
CHILDREN'S NATIONAL MEDICAL CENTER 111 MICHIGAN AVE, NW, SUITE 5400 WASHINGTON, DC 20010	52-1654453	501(C)(3)	22,800.	0.			CARE CENTER NETWORK

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ▶ 29.
- 3** Enter total number of other organizations listed in the line 1 table ▶ 2.

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

Schedule I (Form 990) 2021

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule I (Form 990)

DBA CURE SMA

36-3320440

Page 1

Part II Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments (Schedule I (Form 990), Part II.)

(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 non-cash assistance	(h) Purpose of grant or assistance
ADVOCATE HEALTH & HOSPITAL CORP 3075 HIGHLAND PARKWAY, SUITE 600 DOWNERS GROVE, IL 60515	36-2169147	501(C)(3)	17,200.	0.			CARE CENTER NETWORK
UNIVERSITY OF ALABAMA OF BIRMINGHAM - 1720 2ND AVENUE SOUTH - AB1170 - BIRMINGHAM, AL 35294	63-6005396	501(C)(3)	31,700.	0.			CARE CENTER NETWORK
PHOENIX CHILDREN'S HOSPITAL 1919 E THOMAS ROAD PHOENIX, AZ 85016	86-0422559	501(C)(3)	43,250.	0.			CARE CENTER NETWORK
CONNECTICUT CHILDREN'S MEDICAL CENTER - 282 WASHINGTON STREET - HARTFORD, CT 06106	06-0646755	501(C)(3)	17,000.	0.			CARE CENTER NETWORK
TRUSTEES OF COLUMBIA UNIVERSITY - NYC - 154 HAVEN AVENUE - NEW YORK, NY 10032	13-5598093	501(C)(3)	61,250.	0.			CARE CENTER NETWORK
BOSTON CHILDREN'S HOSPITAL 300 LONGWOOD AVENUE BOSTON, MA 02115	04-2774441	501(C)(3)	87,467.	0.			CARE CENTER NETWORK
DUKE UNIVERSITY 2200 WEST MAIN ST, SUITE 300 DURHAM, NC 27705	56-0532129	501(C)(3)	44,100.	0.			CARE CENTER NETWORK
SEATTLE CHILDREN'S HOSPITAL 4800 SAND POINT WAY NE SEATTLE, WA 98105	91-0564748	501(C)(3)	58,600.	0.			CARE CENTER NETWORK
UNIVERSITY OF TEXAS 1935 MEDICAL DISTRICT DRIVE DALLAS, TX 75207	74-6000203	501(C)(3)	53,300.	0.			CARE CENTER NETWORK

Schedule I (Form 990)

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule I (Form 990)

DBA CURE SMA

36-3320440

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Part II Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments (Schedule I (Form 990), Part II.)

(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 non-cash assistance	(h) Purpose of grant or assistance
TRUSTEES OF COLUMBIA UNIVERSITY - NYC - 154 HAVEN AVENUE - NEW YORK, NY 10032	13-5598093	501(C)(3)	250,000.	0.			RESEARCH - CLINICAL TRIALS
CHILDREN'S HOSPITAL OF PHILADELPHIA - 34TH STREET CIVIC CENTER RD - PHILADELPHIA, PA 19104	52-1654453	501(C)(3)	135,145.	0.			PNCR NETWORK
UNIVERSITY OF ROCHESTER 601 ELMWOOD AVENUE, BOX 673 ROCHESTER, NY 14624	16-0743209	501(C)(3)	150,000.	0.			PNCR NETWORK
BOSTON CHILDREN'S HOSPITAL 300 LONGWOOD AVENUE BOSTON, MA 02115	04-2774441	501(C)(3)	411,657.	0.			PNCR NETWORK
TRUSTEES OF COLUMBIA UNIVERSITY - NYC - 154 HAVEN AVENUE - NEW YORK, NY 10032	13-5598093	501(C)(3)	108,049.	0.			PNCR NETWORK
LELAND STANFORD JUNIOR UNIVERITY 450 SERRA MALL STANFORD, CA 94305	94-1156365	501(C)(3)	375,000.	0.			PNCR NETWORK
STANFORD UNIVERSITY 420 MONTGOMERY ST SAN FRANCISCO, CA 94104	94-1156365	501(C)(3)	49,000.	0.			CARE CENTER NETWORK
THE UNIVERSITY OF CALIFORNIA 10889 WILSHIRE BOULEVARD LOS ANGELES, CA 90095	95-6006143	IRC 115 (1)	30,000.	0.			CARE CENTER NETWORK
CHILDREN'S HEALTHCARE OF ATLANTA 1575 NORTHEAST EXPRESSWAY ATLANTA, GA 30329	58-2367819	501(C)(3)	30,000.	0.			CARE CENTER NETWORK

Schedule I (Form 990)

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule I (Form 990)

DBA CURE SMA

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Page 1

Part II Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments (Schedule I (Form 990), Part II.)

(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 non-cash assistance	(h) Purpose of grant or assistance
NORTHWESTERN UNIVERSITY 750 N LAKESHORE DRIVE CHICAGO, IL 60611	36-2167817	501(C)(3)	30,000.	0.			CARE CENTER NETWORK
THE WASHINGTON UNIVERSITY ONE BROOKINGS DRIVE ST. LOUIS, MO 63130	43-0653611	501(C)(3)	30,000.	0.			CARE CENTER NETWORK
UNIVERSITY OF NEW MEXICO 1 UNIVERSITY OF NEW MEXICO DRIVE ALBUQUERQUE, NM 87131	85-6000642	IRC 115 (1)	30,000.	0.			CARE CENTER NETWORK
THE OHIO STATE UNIVERSITY WEXNER MEDICAL CENTER - 1960 KENNY ROAD - COLUMBUS, OH 43210	31-6025986	501(C)(3)	30,000.	0.			CARE CENTER NETWORK
BAYLOR COLLEGE OF MEDICINE ONE BAYLOR PLAZA HOUSTON, TX 77030	74-1613878	501(C)(3)	30,000.	0.			CARE CENTER NETWORK

Schedule I (Form 990)

FAMILIES OF SPINAL MUSCULAR ATROPHY

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	226	66,349.	0.	FMV	CARE PACKAGES FOR FAMILIES WITH RECENTLY DIAGNOSED CHILDREN
ADULT CARE PACKAGES	525	75,412.	0.	FMV	CARE PACKAGES FOR TEENS AND ADULTS INDEPENDENCE PACKAGES
EQUIPMENT	10	3,111.	0.	FMV	NON RETURNABLE BACKPACK CARRIER DEVICE, TRICYCLE, ETC.

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

Part IV Supplemental Information

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.

Multiple horizontal lines for supplemental information.

**SCHEDULE J
(Form 990)**

Compensation Information

OMB No. 1545-0047

2021

Open to Public Inspection

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.

Department of the Treasury
Internal Revenue Service

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

Part I Questions Regarding Compensation

	Yes	No
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. <input type="checkbox"/> First-class or charter travel <input type="checkbox"/> Travel for companions <input type="checkbox"/> Tax indemnification and gross-up payments <input type="checkbox"/> Discretionary spending account <input type="checkbox"/> Housing allowance or residence for personal use <input type="checkbox"/> Payments for business use of personal residence <input type="checkbox"/> Health or social club dues or initiation fees <input type="checkbox"/> 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	1b	
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?	2	
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. <input checked="" type="checkbox"/> Compensation committee <input type="checkbox"/> Independent compensation consultant <input type="checkbox"/> Form 990 of other organizations <input type="checkbox"/> Written employment contract <input checked="" type="checkbox"/> Compensation survey or study <input checked="" type="checkbox"/> 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?	4a	X
b Participate in or receive payment from a supplemental nonqualified retirement plan?	4b	X
c Participate in or receive payment from an equity-based compensation arrangement?	4c	X
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?	5a	X
b Any related organization?	5b	X
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?	6a	X
b Any related organization?	6b	X
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	7	X
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	8	X
9 If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?	9	

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

Schedule J (Form 990) 2021

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

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)	312,639.	0.	0.	11,215.	6,172.	330,026.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(2) MARY SCHROTH CHIEF MEDICAL OFFICER	(i)	247,037.	12,500.	0.	10,444.	7,337.	277,318.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(3) MARLINE PAGAN VICE PRESIDENT, FINANCE	(i)	161,045.	7,750.	0.	6,339.	17,394.	192,528.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(4) JILL JARECKI CHIEF SCIENTIFIC OFFICER	(i)	158,943.	11,000.	0.	7,136.	1,534.	178,613.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(5) COLLEEN MCCARTHY O'TOOLE VICE PRESIDENT, FAMILY SUPPORT	(i)	141,698.	7,500.	0.	6,300.	17,354.	172,852.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(6) PAMELA SWENK CHIEF OF STAFF OFFICER	(i)	149,272.	0.	0.	5,846.	12,448.	167,566.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(7) ERIN OGANESIAN VP, DEVELOPMENT	(i)	128,358.	6,750.	0.	5,670.	11,407.	152,185.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							

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)**

Noncash Contributions

OMB No. 1545-0047

2021

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

- ▶ Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.
- ▶ Attach to Form 990.
- ▶ Go to www.irs.gov/Form990 for instructions and the latest information.

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	5	9,510.	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 ▶ (SUPPLIES)	X	2	57,796.	FAIR MARKET VALUE
26 Other ▶ (EQUIPMENT)	X	5	10,402.	FAIR MARKET VALUE
27 Other ▶ (EVENT ADMISSI)	X	1	260.	FAIR MARKET VALUE
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**

	Yes	No
30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least three years from the date of the initial contribution, and which isn't required to be used for exempt purposes for the entire holding period?		X
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?	X	
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?	X	
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.		

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

Schedule M (Form 990) 2021

FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule M (Form 990) 2021

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, LINE 32B:

THE ORGANIZATION USES TD AMERITRADE TO RECEIVE AND SELL DONATED STOCK.

**SCHEDULE O
(Form 990)**

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 the latest information.

OMB No. 1545-0047

2021

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:

OF DEATH FOR INFANTS. CURE SMA FUNDS AND DIRECTS COMPREHENSIVE RESEARCH THAT DRIVES BREAKTHROUGHS IN TREATMENT AND CARE AND PROVIDES FAMILIES THE SUPPORT THEY NEED FOR TODAY.

FORM 990, PART III, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:

PROVIDE REAL IMPACT AND HOPE FOR FAMILIES AND PATIENTS IMPACTED BY THE DISEASE. THE CHARITY HAS INVESTED OVER \$70 MILLION IN RESEARCH AND HAS BEEN INVOLVED IN FUNDING HALF OF ALL THE ONGOING NOVEL DRUG PROGRAMS FOR SMA. CURE SMA IS A NONPROFIT 501(C)(3) ORGANIZATION, WITH 34 CHAPTERS AND 115,000 MEMBERS AND SUPPORTERS THROUGHOUT THE UNITED STATES, AND IS DEDICATED TO CREATING A TREATMENT AND CURE BY FUNDING AND ADVANCING A COMPREHENSIVE RESEARCH PROGRAM, SUPPORTING SMA FAMILIES THROUGH NETWORKING, INFORMATION AND SERVICES, IMPROVING CARE FOR ALL SMA PATIENTS, EDUCATING HEALTHCARE PROFESSIONALS AND THE PUBLIC ABOUT SMA, ENLISTING GOVERNMENT SUPPORT FOR SMA, EMBRACING ALL TOUCHED BY SMA IN A CARING COMMUNITY.

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

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

CURE SMA WORKS DIRECTLY WITH CLINICIANS, HEALTH CARE PROVIDERS, AND CAREGIVERS TO ENSURE THAT PATIENTS HAVE ACCESS TO THE BEST POSSIBLE CARE.

FORM 990, PART III, LINE 4B, PROGRAM SERVICE ACCOMPLISHMENTS: EXPERIENCE WITH SMA.

CURRENTLY, THERE ARE THREE APPROVED DRUGS FOR SMA, WITH ANOTHER SEVERAL DOZEN DRUG PROGRAMS IN DEVELOPMENT, INCLUDING SEVEN CLINICAL TRIALS. CURE SMA HAS FUNDED HALF OF ALL THE ONGOING DRUG PROGRAMS IN SMA.

CURE SMA HAS EXPANDED FOCUS TO SUPPORT CLINICAL CARE. THE CURE SMA CARE CENTER NETWORK KICKED OFF IN 2018. IN 2022, THE SMA CARE CENTER NETWORK EXPANDED BY 5 ADDITIONAL CENTERS FOR A TOTAL OF 24 CENTERS WHO RECEIVED GRANT FUNDING. THESE CENTERS PROVIDE PATIENT CONSENTED ELECTRONIC MEDICAL RECORD DATA TO THE CURE SMA CLINICAL DATA REGISTRY. THE GOAL OF THE SMA CARE CENTER NETWORK AND CLINICAL DATA REGISTRY IS TO IMPROVE CLINICAL CARE FOR INDIVIDUALS WITH SMA BY ESTABLISHING AN EVIDENCE-BASED STANDARD OF CARE THAT WILL BE AVAILABLE AND DISTRIBUTED NATIONALLY. THE CLINICAL DATA REGISTRY HAS PROGRESSIVELY GROWN, AND

Name of the organization	FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA	Employer identification number	36-3320440
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MORE THAN 750 PATIENTS ARE ENROLLED. ADDITIONAL DATA ELEMENTS HAVE BEEN ADDED TO INCLUDE PROVIDER NAME AND SPECIALTY FOR EACH CLINICAL ENCOUNTER. CURE SMA COLLABORATES WITH STATE PUBLIC HEALTH LABS AND LEGISLATURES TO ADVOCATE FOR SMA NEWBORN SCREENING IMPLEMENTATION THROUGHOUT THE US. CURRENTLY 47 STATES SCREEN NEWBORNS FOR SMA FACILITATING EARLY PRESYMPTOMATIC TREATMENT. THIS REPRESENTS 97% OF ALL INFANTS BORN IN THE US. CURE SMA CO-CREATED FOUR NEW HEALTHCARE PROVIDER ENDURING CONTINUING MEDICAL EDUCATION PROGRAMS IN ADDITION TO THE IN-PERSON CURE SMA CLINICAL CARE SESSION OFFERED IN JUNE 2022. RESOURCES WERE ALSO DEVOTED TO MAINTAINING WEBSITE LISTINGS OF CARE CENTERS, SMA NEWBORN SCREENING REFERRAL CENTERS AND TREATMENT CENTERS THAT PROVIDE FDA-APPROVED SMA TREATMENTS.

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

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.

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

Name of the organization FAMILIES OF SPINAL MUSCULAR ATROPHY DBA CURE SMA	Employer identification number 36-3320440
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DIRECTORS APPROVES THE RELEASE OF DOCUMENTS.

FORM 990, PART XII, LINE 2C

THE ORGANIZATION HAS A FINANCE/AUDIT COMMITTEE THAT REVIEWS THE AUDIT AND 990. A REQUEST FOR PROPOSALS WAS ISSUED IN A PRIOR YEAR AND NEW AUDITORS WERE SELECTED.