

Form **8879-EO**

# IRS e-file Signature Authorization for an Exempt Organization

OMB No. 1545-1878

For calendar year 2016, or fiscal year beginning JUL 1, 2016, and ending JUN 30, 2017

# 2016

Department of the Treasury  
Internal Revenue Service

▶ **Do not send to the IRS. Keep for your records.**

▶ **Information about Form 8879-EO and its instructions is at [www.irs.gov/form8879eo](http://www.irs.gov/form8879eo).**

Name of exempt organization <b>FAMILIES OF SPINAL MUSCULAR ATROPHY</b>	Employer identification number <b>36-3320440</b>
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Name and title of officer  
**KENNETH HOBBY**  
**PRESIDENT**

### Part I Type of Return and Return Information (Whole Dollars Only)

Check the box for the return for which you are using this Form 8879-EO and enter the applicable amount, if any, from the return. If you check the box on line 1a, 2a, 3a, 4a, or 5a, below, and the amount on that line for the return being filed with this form was blank, then leave line 1b, 2b, 3b, 4b, or 5b, whichever is applicable, blank (do not enter -0-). But, if you entered -0- on the return, then enter -0- on the applicable line below. **Do not** complete more than 1 line in Part I.

1a Form 990 check here ▶ <input checked="" type="checkbox"/>	b Total revenue, if any (Form 990, Part VIII, column (A), line 12) .....	1b <u>7,873,276.</u>
2a Form 990-EZ check here ▶ <input type="checkbox"/>	b Total revenue, if any (Form 990-EZ, line 9) .....	2b _____
3a Form 1120-POL check here ▶ <input type="checkbox"/>	b Total tax (Form 1120-POL, line 22) .....	3b _____
4a Form 990-PF check here ▶ <input type="checkbox"/>	b Tax based on investment income (Form 990-PF, Part VI, line 5) .....	4b _____
5a Form 8868 check here ▶ <input type="checkbox"/>	b Balance Due (Form 8868, line 3c) .....	5b _____

### Part II Declaration and Signature Authorization of Officer

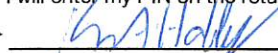
Under penalties of perjury, I declare that I am an officer of the above organization and that I have examined a copy of the organization's 2016 electronic return and accompanying schedules and statements and to the best of my knowledge and belief, they are true, correct, and complete. I further declare that the amount in Part I above is the amount shown on the copy of the organization's electronic return. I consent to allow my intermediate service provider, transmitter, or electronic return originator (ERO) to send the organization's return to the IRS and to receive from the IRS (a) an acknowledgement of receipt or reason for rejection of the transmission, (b) the reason for any delay in processing the return or refund, and (c) the date of any refund. If applicable, I authorize the U.S. Treasury and its designated Financial Agent to initiate an electronic funds withdrawal (direct debit) entry to the financial institution account indicated in the tax preparation software for payment of the organization's federal taxes owed on this return, and the financial institution to debit the entry to this account. To revoke a payment, I must contact the U.S. Treasury Financial Agent at 1-888-353-4537 no later than 2 business days prior to the payment (settlement) date. I also authorize the financial institutions involved in the processing of the electronic payment of taxes to receive confidential information necessary to answer inquiries and resolve issues related to the payment. I have selected a personal identification number (PIN) as my signature for the organization's electronic return and, if applicable, the organization's consent to electronic funds withdrawal.

Officer's PIN: check one box only

I authorize KAUFMAN, ROSSIN & CO., P.A. to enter my PIN 20440  
ERO firm name Enter five numbers, but do not enter all zeros

as my signature on the organization's tax year 2016 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I also authorize the aforementioned ERO to enter my PIN on the return's disclosure consent screen.

As an officer of the organization, I will enter my PIN as my signature on the organization's tax year 2016 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I will enter my PIN on the return's disclosure consent screen.

Officer's signature ▶  Date ▶ NOVEMBER 7, 2017

### Part III Certification and Authentication

ERO's EFIN/PIN. Enter your six-digit electronic filing identification number (EFIN) followed by your five-digit self-selected PIN.

**65071118353**  
do not enter all zeros

I certify that the above numeric entry is my PIN, which is my signature on the 2016 electronically filed return for the organization indicated above. I confirm that I am submitting this return in accordance with the requirements of **Pub. 4163**, Modernized e-File (MeF) Information for Authorized IRS e-file Providers for Business Returns.

ERO's signature ▶ KAUFMAN, ROSSIN & CO., P.A. Date ▶ 11/02/17

**ERO Must Retain This Form - See Instructions**  
**Do Not Submit This Form To the IRS Unless Requested To Do So**

LHA For Paperwork Reduction Act Notice, see instructions.

Form **8879-EO** (2016)

623051 09-26-16

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

**2016**

Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

▶ Do not enter social security numbers on this form as it may be made public.  
▶ Information about Form 990 and its instructions is at [www.irs.gov/form990](http://www.irs.gov/form990).

**A** For the 2016 calendar year, or tax year beginning **JUL 1, 2016** and ending **JUN 30, 2017**

<b>B</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	<b>C</b> Name of organization <b>FAMILIES OF SPINAL MUSCULAR ATROPHY</b> Doing business as <b>CURE SMA</b> Number and street (or P.O. box if mail is not delivered to street address) Room/suite <b>925 BUSSE ROAD</b> City or town, state or province, country, and ZIP or foreign postal code <b>ELK GROVE VILLAGE, IL 60007</b> <b>F</b> Name and address of principal officer: <b>KENNETH HOBBY</b> <b>SAME AS C ABOVE</b>	<b>D</b> Employer identification number <b>36-3320440</b> <b>E</b> Telephone number <b>800-886-1762</b> <b>G</b> Gross receipts \$ <b>8,630,278.</b> <b>H(a)</b> Is this a group return for subordinates? ..... <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No <b>H(b)</b> Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions) <b>H(c)</b> Group exemption number ▶
<b>I</b> 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		
<b>J</b> Website: ▶ <b>WWW.CURESMA.ORG</b>		
<b>K</b> Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other ▶		
<b>L</b> Year of formation: <b>1984</b>		<b>M</b> State of legal domicile: <b>IL</b>

**Part I Summary**

<b>1</b>	Briefly describe the organization's mission or most significant activities: <b>SEE SCHEDULE O</b>	
<b>2</b>	Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.	
<b>3</b>	Number of voting members of the governing body (Part VI, line 1a) .....	<b>3</b> <b>14</b>
<b>4</b>	Number of independent voting members of the governing body (Part VI, line 1b) .....	<b>4</b> <b>14</b>
<b>5</b>	Total number of individuals employed in calendar year 2016 (Part V, line 2a) .....	<b>5</b> <b>32</b>
<b>6</b>	Total number of volunteers (estimate if necessary) .....	<b>6</b> <b>6600</b>
<b>7a</b>	Total unrelated business revenue from Part VIII, column (C), line 12 .....	<b>7a</b> <b>0.</b>
<b>7b</b>	Net unrelated business taxable income from Form 990-T, line 34 .....	<b>7b</b> <b>0.</b>
<b>8</b>	Contributions and grants (Part VIII, line 1h) .....	<b>Prior Year</b> <b>5,149,322.</b> <b>Current Year</b> <b>5,818,435.</b>
<b>9</b>	Program service revenue (Part VIII, line 2g) .....	<b>815,371.</b> <b>1,381,841.</b>
<b>10</b>	Investment income (Part VIII, column (A), lines 3, 4, and 7d) .....	<b>-6,037.</b> <b>23,825.</b>
<b>11</b>	Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) .....	<b>151,130.</b> <b>649,175.</b>
<b>12</b>	Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) .....	<b>6,109,786.</b> <b>7,873,276.</b>
<b>13</b>	Grants and similar amounts paid (Part IX, column (A), lines 1-3) .....	<b>1,219,840.</b> <b>977,500.</b>
<b>14</b>	Benefits paid to or for members (Part IX, column (A), line 4) .....	<b>0.</b> <b>0.</b>
<b>15</b>	Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) .....	<b>1,747,547.</b> <b>2,465,061.</b>
<b>16a</b>	Professional fundraising fees (Part IX, column (A), line 11e) .....	<b>24,159.</b> <b>2,500.</b>
<b>b</b>	Total fundraising expenses (Part IX, column (D), line 25) ▶ <b>1,009,256.</b>	
<b>17</b>	Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) .....	<b>2,875,998.</b> <b>4,120,956.</b>
<b>18</b>	Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) .....	<b>5,867,544.</b> <b>7,566,017.</b>
<b>19</b>	Revenue less expenses. Subtract line 18 from line 12 .....	<b>242,242.</b> <b>307,259.</b>
<b>20</b>	Total assets (Part X, line 16) .....	<b>Beginning of Current Year</b> <b>3,916,800.</b> <b>End of Year</b> <b>4,984,542.</b>
<b>21</b>	Total liabilities (Part X, line 26) .....	<b>1,601,166.</b> <b>2,289,429.</b>
<b>22</b>	Net assets or fund balances. Subtract line 21 from line 20 .....	<b>2,315,634.</b> <b>2,695,113.</b>

**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.

<b>Sign Here</b>	Signature of officer <b>KENNETH HOBBY, PRESIDENT</b> Type or print name and title	Date _____			
<b>Paid Preparer Use Only</b>	Print/Type preparer's name <b>JANET FIFER</b>	Preparer's signature <b>JANET FIFER</b>	Date <b>11/08/17</b>	Check if self-employed <input type="checkbox"/>	PTIN <b>P01225772</b>
	Firm's name ▶ <b>KAUFMAN, ROSSIN &amp; CO., P.A.</b>	Firm's EIN ▶ <b>59-1818353</b>			
	Firm's address ▶ <b>2699 S. BAYSHORE DRIVE</b> <b>MIAMI, FL 33133</b>	Phone no. <b>305-858-5600</b>			

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, PROVIDE REAL HOPE FOR FAMILIES

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 \$ 949,094. including grants of \$ ) (Revenue \$ ) INDIVIDUALS WITH SMA NEED SPECIALIZED CARE AND EQUIPMENT, WHICH CAN PUT ENORMOUS EMOTIONAL, 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.

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 \$ 3,099,625. including grants of \$ 977,500. ) (Revenue \$ 320,298. ) 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 15 NEW AND ONGOING BASIC RESEARCH GRANTS, AS WELL AS 4 ONGOING DRUG DISCOVERY PROJECTS. WE ALSO FUNDED AND EXECUTED MULTIPLE CLINICAL AND REGULATORY FOCUSED PROJECTS, INCLUDING NOMINATING SMA FOR INCLUSION ON THE FEDERAL UNIFORM RECOMMENDED SCREENING PANEL AND HOLDING A EXTERNALLY-LED PATIENT FOCUSED DRUG DEVELOPMENT MEETING WITH THE FDA. CURE SMA ALSO PROVIDES PATIENT AND CLINICAL CARE EDUCATION, WITH EXPERTISE FROM ITS MEDICAL ADVISORY COUNCIL. IT ALSO IS

4c (Code: ) (Expenses \$ 2,171,808. including grants of \$ ) (Revenue \$ 1,061,543. ) WE HOSTED OUR 28TH ANNUAL SMA CONFERENCE IN ORLANDO, FL, WITH OVER 2,073 TOTAL ATTENDEES. OUR ANNUAL CONFERENCE IS AN INVALUABLE RESOURCE FOR THE ENTIRE SMA COMMUNITY, BRINGING TOGETHER RESEARCHERS, CLINICIANS, AND FAMILIES TO NETWORK, LEARN, AND COLLABORATE. THE CONFERENCE IS THE LARGEST IN THE WORLD FOCUSED SPECIFICALLY ON SMA, AND IT ATTRACTS THE TOP SCIENTISTS AND COMPANIES IN THE FIELD.

THE FAMILY CONFERENCE INCLUDES A VARIETY OF WORKSHOPS, KEYNOTE SESSIONS WITH LEADING RESEARCHERS, A FAMILY-FRIENDLY RESEARCH POSTER SESSION, AND MORE-PLUS FUN EVENTS LIKE OUR DANCE PARTY, MEET-AND-GREET, PAJAMA PARTY AND MOVIE NIGHT, AND TEEN AND ADULT SOCIAL ACTIVITIES. THE RESEARCHER CONFERENCE CREATES OPEN COMMUNICATION OF EARLY, UNPUBLISHED

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

4e Total program service expenses 6,220,527.

**Part IV Checklist of Required Schedules**

	Yes	No
<b>1</b> 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	
<b>2</b> Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ? .....	X	
<b>3</b> 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
<b>4 Section 501(c)(3) organizations.</b> 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	
<b>5</b> 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 Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III</i> .....		X
<b>6</b> 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
<b>7</b> 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
<b>8</b> 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
<b>9</b> 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
<b>10</b> Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i> .....	X	
<b>11</b> 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.		
<b>a</b> 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>b</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
<b>c</b> 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
<b>d</b> 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
<b>e</b> Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i> .....		X
<b>f</b> 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	
<b>12a</b> 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>b</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
<b>13</b> Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i> .....		X
<b>14a</b> Did the organization maintain an office, employees, or agents outside of the United States? .....		X
<b>b</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
<b>15</b> 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	
<b>16</b> 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
<b>17</b> 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> .....	X	
<b>18</b> 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	
<b>19</b> 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

**Part IV Checklist of Required Schedules** (continued)

	Yes	No
<b>20a</b> Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i> .....		X
<b>b</b> If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? .....		
<b>21</b> 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	
<b>22</b> 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
<b>23</b> 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	
<b>24a</b> 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>b</b> Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? .....		
<b>c</b> Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? .....		
<b>d</b> Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? .....		
<b>25a</b> <b>Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations.</b> 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>b</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
<b>26</b> Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If "Yes," complete Schedule L, Part II</i> .....		X
<b>27</b> Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i> .....		X
<b>28</b> Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
<b>a</b> A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>b</b> A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>c</b> An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? <i>If "Yes," complete Schedule L, Part IV</i> .....		X
<b>29</b> Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i> .....	X	
<b>30</b> 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
<b>31</b> Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i> .....		X
<b>32</b> 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
<b>33</b> 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
<b>34</b> 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
<b>35a</b> Did the organization have a controlled entity within the meaning of section 512(b)(13)? .....		X
<b>b</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> .....		
<b>36</b> <b>Section 501(c)(3) organizations.</b> 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
<b>37</b> 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
<b>38</b> Did the organization complete Schedule O and provide explanations in 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

Input box for Schedule O

Table with columns for question number, description, and Yes/No checkboxes. Includes rows for backup withholding, employee reporting, unrelated business income, foreign accounts, prohibited transactions, and charitable contributions.

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 in Schedule O. See instructions.

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

Section A. Governing Body and Management

Table with 3 columns: Question, Yes, No. Rows include: 1a Enter the number of voting members of the governing body at the end of the tax year; 1b Enter the number of voting members included in line 1a, above, who are independent; 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?; 3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, or trustees, or key employees to a management company or other person?; 4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?; 5 Did the organization become aware during the year of a significant diversion of the organization's assets?; 6 Did the organization have members or stockholders?; 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?; 7b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?; 8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: a The governing body? b Each committee with authority to act on behalf of the governing body?; 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 in Schedule O.

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

Table with 3 columns: Question, Yes, No. Rows include: 10a Did the organization have local chapters, branches, or affiliates?; 10b 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?; 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?; 11b Describe in 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; 12b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts?; 12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done; 13 Did the organization have a written whistleblower policy?; 14 Did the organization have a written document retention and destruction policy?; 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?; 15a The organization's CEO, Executive Director, or top management official; 15b Other officers or key employees of the organization; 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?; 16b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements?

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed AL, AZ, CA, CO, CT, FL, IA, IL, KS, LA, NJ, NY
18 Section 6104 requires an organization to make its Forms 1023 (or 1024 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. [X] Own website [ ] Another's website [X] Upon request [ ] Other (explain in Schedule O)
19 Describe in 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: KENNETH HOBBY - 800-886-1762 925 BUSSE ROAD, ELK GROVE VILLAGE, IL 60007

**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 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 and/or Box 7 of Form 1099-MISC) 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.

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

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)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) RICHARD RUBENSTEIN BOARD CHAIR	15.00	X		X				0.	0.	0.
(2) KELLY COLE SECRETARY	6.00	X		X				0.	0.	0.
(3) BRAD NUNEMAKER TREASURER	6.00	X		X				0.	0.	0.
(4) DOUGLAS KERR DIRECTOR	2.00	X						0.	0.	0.
(5) COREY BRAASTAD DIRECTOR	2.00	X						0.	0.	0.
(6) DOUGLAS ERWIN DIRECTOR	2.00	X						0.	0.	0.
(7) THOMAS MURRAY DIRECTOR	2.00	X						0.	0.	0.
(8) MELISSA MILINOVICH DIRECTOR	2.00	X						0.	0.	0.
(9) STEVE RAGLAND DIRECTOR	2.00	X						0.	0.	0.
(10) SHANNON SHRYNE DIRECTOR	2.00	X						0.	0.	0.
(11) GREG ZERZAN DIRECTOR	2.00	X						0.	0.	0.
(12) ANNIE KENNEDY DIRECTOR	2.00	X						0.	0.	0.
(13) SPENCER PERLMAN DIRECTOR	2.00	X						0.	0.	0.
(14) JOHN PORTER DIRECTOR	2.00	X						0.	0.	0.
(15) ROBERT LOCKWOOD DIRECTOR	2.00	X						0.	0.	0.
(16) KENNETH HOBBY PRESIDENT	70.00			X				182,099.	0.	14,664.
(17) JILL JARECKI RESEARCH DIRECTOR	50.00				X			171,689.	0.	628.





**Part VIII Statement of Revenue**

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

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512 - 514	
<b>Contributions, Gifts, Grants and Other Similar Amounts</b>	<b>1 a</b> Federated campaigns .....	<b>1a</b>					
	<b>b</b> Membership dues .....	<b>1b</b>					
	<b>c</b> Fundraising events .....	<b>1c</b>	3,134,377.				
	<b>d</b> Related organizations .....	<b>1d</b>					
	<b>e</b> Government grants (contributions) .....	<b>1e</b>					
	<b>f</b> All other contributions, gifts, grants, and similar amounts not included above .....	<b>1f</b>	2,684,058.				
	<b>g</b> Noncash contributions included in lines 1a-1f: \$ .....		371,235.				
	<b>h Total.</b> Add lines 1a-1f .....		5,818,435.				
	<b>Program Service Revenue</b>	<b>2 a</b> ANNUAL CONFERENCE .....	<b>Business Code</b> 900099	1,061,543.	1,061,543.		
<b>b</b> INDUSTRY COLLABORATION .....		900099	320,298.	320,298.			
<b>c</b> .....							
<b>d</b> .....							
<b>e</b> .....							
<b>f</b> All other program service revenue .....							
<b>g Total.</b> Add lines 2a-2f .....			1,381,841.				
<b>Other Revenue</b>	<b>3</b> Investment income (including dividends, interest, and other similar amounts) .....		20,834.			20,834.	
	<b>4</b> Income from investment of tax-exempt bond proceeds .....						
	<b>5</b> Royalties .....						
	<b>6 a</b> Gross rents .....	(i) Real					
		(ii) Personal					
		<b>b</b> Less: rental expenses .....					
		<b>c</b> Rental income or (loss) .....					
	<b>d</b> Net rental income or (loss) .....						
	<b>7 a</b> Gross amount from sales of assets other than inventory .....	(i) Securities		240,055.			
		(ii) Other					
		<b>b</b> Less: cost or other basis and sales expenses .....		237,064.			
		<b>c</b> Gain or (loss) .....		2,991.			
	<b>d</b> Net gain or (loss) .....		2,991.			2,991.	
	<b>8 a</b> Gross income from fundraising events (not including \$ 3,134,377. of contributions reported on line 1c). See Part IV, line 18 .....	<b>a</b>	502,807.				
		<b>b</b> Less: direct expenses .....	<b>b</b>	496,065.			
<b>c</b> Net income or (loss) from fundraising events .....			6,742.			6,742.	
<b>9 a</b> Gross income from gaming activities. See Part IV, line 19 .....	<b>a</b>						
	<b>b</b> Less: direct expenses .....	<b>b</b>					
	<b>c</b> Net income or (loss) from gaming activities .....						
<b>10 a</b> Gross sales of inventory, less returns and allowances .....	<b>a</b>	15,773.					
	<b>b</b> Less: cost of goods sold .....	<b>b</b>	23,873.				
	<b>c</b> Net income or (loss) from sales of inventory .....		-8,100.	-8,100.			
Miscellaneous Revenue		<b>Business Code</b>					
<b>11 a</b> SEE SCHEDULE O .....		900099	585,000.	585,000.			
	<b>b</b> OUTLICENSING .....		900099	65,533.	65,533.		
		<b>c</b> .....					
		<b>d</b> All other revenue .....					
		<b>e Total.</b> Add lines 11a-11d .....		650,533.			
<b>12 Total revenue.</b> See instructions. ....		7,873,276.	2,024,274.	0.	30,567.		

**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	592,500.	592,500.		
2 Grants and other assistance to domestic individuals. See Part IV, line 22				
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16	385,000.	385,000.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	218,855.	151,010.	37,205.	30,640.
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	1,917,325.	1,364,890.	104,497.	447,938.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	28,129.	21,192.	1,325.	5,612.
9 Other employee benefits	129,286.	91,064.	6,468.	31,754.
10 Payroll taxes	171,466.	120,036.	12,459.	38,971.
11 Fees for services (non-employees):				
a Management				
b Legal	101,399.	80,751.		20,648.
c Accounting	38,588.		38,588.	
d Lobbying	123,086.	123,086.		
e Professional fundraising services. See Part IV, line 17	2,500.			2,500.
f Investment management fees	6,701.		6,701.	
g Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O.)	18,209.	2,625.	8,573.	7,011.
12 Advertising and promotion	136,227.	95,919.	9,414.	30,894.
13 Office expenses	431,754.	328,586.	18,977.	84,191.
14 Information technology	114,713.	86,035.	5,736.	22,942.
15 Royalties				
16 Occupancy	149,047.	104,482.	10,377.	34,188.
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	1,377,797.	1,221,871.	70,009.	85,917.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	148,136.	131,097.	3,408.	13,631.
23 Insurance	17,982.	12,587.	1,259.	4,136.
24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a <b>FUNDRAISING EVENTS</b>	737,310.	605,880.	46.	131,384.
b <b>SMA RESEARCH EXPENSES</b>	570,709.	570,709.		
c <b>PATIENT SERVICES</b>	120,000.	120,000.		
d <b>MISCELLANEOUS</b>	29,298.	11,207.	1,192.	16,899.
e All other expenses				
25 <b>Total functional expenses.</b> Add lines 1 through 24e	7,566,017.	6,220,527.	336,234.	1,009,256.
26 <b>Joint costs.</b> Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.				

Check here  if following SOP 98-2 (ASC 958-720)

**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
<b>Assets</b>	<b>1</b> Cash - non-interest-bearing .....	1,961,915.	<b>1</b>	2,251,340.
	<b>2</b> Savings and temporary cash investments .....	696,160.	<b>2</b>	875,061.
	<b>3</b> Pledges and grants receivable, net .....	76,550.	<b>3</b>	209,652.
	<b>4</b> Accounts receivable, net .....	89,780.	<b>4</b>	327,032.
	<b>5</b> Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L .....		<b>5</b>	
	<b>6</b> Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing employers and sponsoring organizations of section 501(c)(9) voluntary employees' beneficiary organizations (see instr). Complete Part II of Sch L .....		<b>6</b>	
	<b>7</b> Notes and loans receivable, net .....		<b>7</b>	
	<b>8</b> Inventories for sale or use .....		<b>8</b>	
	<b>9</b> Prepaid expenses and deferred charges .....	16,413.	<b>9</b>	49,845.
	<b>10a</b> Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D .....	<b>10a</b> 381,064.		
	<b>b</b> Less: accumulated depreciation .....	<b>10b</b> 165,107.	215,630.	<b>10c</b> 215,957.
	<b>11</b> Investments - publicly traded securities .....	854,008.	<b>11</b>	1,032,313.
	<b>12</b> Investments - other securities. See Part IV, line 11 .....	547.	<b>12</b>	547.
	<b>13</b> Investments - program-related. See Part IV, line 11 .....		<b>13</b>	
	<b>14</b> Intangible assets .....		<b>14</b>	
	<b>15</b> Other assets. See Part IV, line 11 .....	5,797.	<b>15</b>	22,795.
<b>16 Total assets.</b> Add lines 1 through 15 (must equal line 34) .....	3,916,800.	<b>16</b>	4,984,542.	
<b>Liabilities</b>	<b>17</b> Accounts payable and accrued expenses .....	622,416.	<b>17</b>	1,299,429.
	<b>18</b> Grants payable .....	978,750.	<b>18</b>	990,000.
	<b>19</b> Deferred revenue .....		<b>19</b>	
	<b>20</b> Tax-exempt bond liabilities .....		<b>20</b>	
	<b>21</b> Escrow or custodial account liability. Complete Part IV of Schedule D .....		<b>21</b>	
	<b>22</b> Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L .....		<b>22</b>	
	<b>23</b> Secured mortgages and notes payable to unrelated third parties .....		<b>23</b>	
	<b>24</b> Unsecured notes and loans payable to unrelated third parties .....		<b>24</b>	
	<b>25</b> 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 .....		<b>25</b>	
	<b>26 Total liabilities.</b> Add lines 17 through 25 .....	1,601,166.	<b>26</b>	2,289,429.
<b>Net Assets or Fund Balances</b>	<b>Organizations that follow SFAS 117 (ASC 958), check here</b> <input checked="" type="checkbox"/> <b>and complete lines 27 through 29, and lines 33 and 34.</b>			
	<b>27</b> Unrestricted net assets .....	1,186,315.	<b>27</b>	1,212,123.
	<b>28</b> Temporarily restricted net assets .....	305,881.	<b>28</b>	484,392.
	<b>29</b> Permanently restricted net assets .....	823,438.	<b>29</b>	998,598.
	<b>Organizations that do not follow SFAS 117 (ASC 958), check here</b> <input type="checkbox"/> <b>and complete lines 30 through 34.</b>			
	<b>30</b> Capital stock or trust principal, or current funds .....		<b>30</b>	
	<b>31</b> Paid-in or capital surplus, or land, building, or equipment fund .....		<b>31</b>	
	<b>32</b> Retained earnings, endowment, accumulated income, or other funds .....		<b>32</b>	
<b>33</b> Total net assets or fund balances .....	2,315,634.	<b>33</b>	2,695,113.	
<b>34</b> Total liabilities and net assets/fund balances .....	3,916,800.	<b>34</b>	4,984,542.	

**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	7,873,276.
2	Total expenses (must equal Part IX, column (A), line 25)	2	7,566,017.
3	Revenue less expenses. Subtract line 2 from line 1	3	307,259.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	2,315,634.
5	Net unrealized gains (losses) on investments	5	72,220.
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 in Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	2,695,113.

**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 in Schedule O.		
2a Were the organization's financial statements compiled or reviewed by an independent accountant?		X
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		
b Were the organization's financial statements audited by an independent accountant?	X	
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		
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?	X	
If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.		
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		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 in Schedule O and describe any steps taken to undergo such audits		



**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) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....	4,596,877.	4,639,671.	4,716,073.	5,374,986.	6,321,242.	25,648,849.
<b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....						
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge ...						
<b>4 Total.</b> Add lines 1 through 3 .....	4,596,877.	4,639,671.	4,716,073.	5,374,986.	6,321,242.	25,648,849.
<b>5</b> 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) .....						319,381.
<b>6 Public support.</b> Subtract line 5 from line 4.						25,329,468.

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ▶	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
<b>7</b> Amounts from line 4 .....	4,596,877.	4,639,671.	4,716,073.	5,374,986.	6,321,242.	25,648,849.
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources ...	2,391.	3,330.	21,373.	19,250.	20,834.	67,178.
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on ...						
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....	589,565.	556,430.	605,696.	1,111,599.	2,032,374.	4,895,664.
<b>11 Total support.</b> Add lines 7 through 10						30,611,691.
<b>12</b> Gross receipts from related activities, etc. (see instructions) .....					12	1,205,020.
<b>13 First five years.</b> 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 <b>stop here</b> .....						<input type="checkbox"/>

**Section C. Computation of Public Support Percentage**

<b>14</b> Public support percentage for 2016 (line 6, column (f) divided by line 11, column (f)) .....	<b>14</b>	82.74 %
<b>15</b> Public support percentage from 2015 Schedule A, Part II, line 14 .....	<b>15</b>	87.80 %
<b>16a 33 1/3% support test - 2016.</b> If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization .....		<input checked="" type="checkbox"/>
<b>b 33 1/3% support test - 2015.</b> 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 <b>stop here.</b> The organization qualifies as a publicly supported organization .....		<input type="checkbox"/>
<b>17a 10% -facts-and-circumstances test - 2016.</b> 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 <b>stop here.</b> 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>b 10% -facts-and-circumstances test - 2015.</b> 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 <b>stop here.</b> 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>18 Private foundation.</b> 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"/>

**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) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") .....						
<b>2</b> 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 .....						
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513 .....						
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf .....						
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge .....						
<b>6 Total.</b> Add lines 1 through 5 .....						
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons .....						
<b>b</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 .....						
<b>c</b> Add lines 7a and 7b .....						
<b>8 Public support.</b> (Subtract line 7c from line 6.)						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ►	(a) 2012	(b) 2013	(c) 2014	(d) 2015	(e) 2016	(f) Total
<b>9</b> Amounts from line 6 .....						
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources .....						
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 .....						
<b>c</b> Add lines 10a and 10b .....						
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on .....						
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) .....						
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.)						

**14 First five 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**

<b>15</b> Public support percentage for 2016 (line 8, column (f) divided by line 13, column (f)) .....	<b>15</b>	%
<b>16</b> Public support percentage from 2015 Schedule A, Part III, line 15 .....	<b>16</b>	%

**Section D. Computation of Investment Income Percentage**

<b>17</b> Investment income percentage for 2016 (line 10c, column (f) divided by line 13, column (f)) .....	<b>17</b>	%
<b>18</b> Investment income percentage from 2015 Schedule A, Part III, line 17 .....	<b>18</b>	%

**19a 33 1/3% support tests - 2016.** 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 - 2015.** 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 12a of Part I, complete Sections A and B. If you checked 12b of Part I, complete Sections A and C. If you checked 12c of Part I, complete Sections A, D, and E. If you checked 12d of Part I, complete Sections A and D, and complete Part V.)

**Section A. All Supporting Organizations**

	Yes	No
<b>1</b> 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>		
<b>2</b> 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>		
<b>3a</b> Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer (b) and (c) below.</i>		
<b>b</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>		
<b>c</b> 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>		
<b>4a</b> Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked 12a or 12b in Part I, answer (b) and (c) below.</i>		
<b>b</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>		
<b>c</b> 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>		
<b>5a</b> Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer (b) and (c) 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>b Type I or Type II only.</b> Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
<b>c Substitutions only.</b> Was the substitution the result of an event beyond the organization's control?		
<b>6</b> 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>		
<b>7</b> Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (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 or 990-EZ).</i>		
<b>8</b> Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7? <i>If "Yes," complete Part I of Schedule L (Form 990 or 990-EZ).</i>		
<b>9a</b> 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>b</b> Did one or more disqualified persons (as defined in 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>		
<b>c</b> Did a disqualified person (as defined in 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>		
<b>10a</b> 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 10b below.</i>		
<b>b</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
<b>11</b> Has the organization accepted a gift or contribution from any of the following persons?		
<b>a</b> A person who directly or indirectly controls, either alone or together with persons described in (b) and (c) below, the governing body of a supported organization?		
<b>b</b> A family member of a person described in (a) above?		
<b>c</b> A 35% controlled entity of a person described in (a) or (b) above? If "Yes" to a, b, or c, provide detail in Part VI.		

**Section B. Type I Supporting Organizations**

	Yes	No
<b>1</b> Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's 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 directors or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.		
<b>2</b> Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.		

**Section C. Type II Supporting Organizations**

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

**Section D. All Type III Supporting Organizations**

	Yes	No
<b>1</b> 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?		
<b>2</b> 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).		
<b>3</b> By reason of the relationship described in (2), did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.		

**Section E. Type III Functionally Integrated Supporting Organizations**

<b>1</b> Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).		
<b>a</b> <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
<b>b</b> <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
<b>c</b> <input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).		
<b>2</b> Activities Test. Answer (a) and (b) below.		
<b>a</b> 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.	Yes	No
<b>b</b> Did the activities described in (a) 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.		
<b>3</b> Parent of Supported Organizations. Answer (a) and (b) below.		
<b>a</b> 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? Provide details in Part VI.		
<b>b</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.		

**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.

<b>Section A - Adjusted Net Income</b>		(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	<b>Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4)	8	

<b>Section B - Minimum Asset Amount</b>		(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	<b>Total</b> (add lines 1a, 1b, and 1c)	1d	
e	<b>Discount</b> claimed for blockage or other factors (explain in detail in <b>Part VI</b> ):		
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 1-1/2% 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 .035	6	
7	Recoveries of prior-year distributions	7	
8	<b>Minimum Asset Amount</b> (add line 7 to line 6)	8	

<b>Section C - Distributable Amount</b>			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1	
2	Enter 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	<b>Distributable Amount.</b> 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).		

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

Section D - Distributions	Current Year
<b>1</b> Amounts paid to supported organizations to accomplish exempt purposes	
<b>2</b> Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
<b>3</b> Administrative expenses paid to accomplish exempt purposes of supported organizations	
<b>4</b> Amounts paid to acquire exempt-use assets	
<b>5</b> Qualified set-aside amounts (prior IRS approval required)	
<b>6</b> Other distributions (describe in <b>Part VI</b> ). See instructions	
<b>7 Total annual distributions.</b> Add lines 1 through 6	
<b>8</b> Distributions to attentive supported organizations to which the organization is responsive (provide details in <b>Part VI</b> ). See instructions	
<b>9</b> Distributable amount for 2016 from Section C, line 6	
<b>10</b> Line 8 amount divided by Line 9 amount	

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2016	(iii) Distributable Amount for 2016
<b>1</b> Distributable amount for 2016 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2016 (reasonable cause required- explain in Part VI). See instructions			
<b>3</b> Excess distributions carryover, if any, to 2016:			
<b>a</b>			
<b>b</b>			
<b>c</b> From 2013			
<b>d</b> From 2014			
<b>e</b> From 2015			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2016 distributable amount			
<b>i</b> Carryover from 2011 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
<b>4</b> Distributions for 2016 from Section D, line 7: \$			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2016 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from 4			
<b>5</b> Remaining underdistributions for years prior to 2016, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions			
<b>6</b> Remaining underdistributions for 2016. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions			
<b>7 Excess distributions carryover to 2017.</b> Add lines 3j and 4c			
<b>8</b> Breakdown of line 7:			
<b>a</b>			
<b>b</b> Excess from 2013			
<b>c</b> Excess from 2014			
<b>d</b> Excess from 2015			
<b>e</b> Excess from 2016			

Schedule A (Form 990 or 990-EZ) 2016



**Schedule B**

(Form 990, 990-EZ, or 990-PF)

Department of the Treasury  
Internal Revenue Service

**Schedule of Contributors**

▶ Attach to Form 990, Form 990-EZ, or Form 990-PF.  
▶ Information about Schedule B (Form 990, 990-EZ, or 990-PF) and its instructions is at [www.irs.gov/form990](http://www.irs.gov/form990).

OMB No. 1545-0047

**2016**

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number

36-3320440

Organization type (check one):

Filers of:

Section:

Form 990 or 990-EZ

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

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

527 political organization

Form 990-PF

501(c)(3) exempt private foundation

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

501(c)(3) taxable private foundation

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

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

**General Rule**

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

**Special Rules**

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

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

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

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

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990, 990-EZ, or 990-PF. Schedule B (Form 990, 990-EZ, or 990-PF) (2016)

<b>Name of organization</b>  <b>FAMILIES OF SPINAL MUSCULAR ATROPHY</b>	<b>Employer identification number</b>  <b>36-3320440</b>
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**Part I Contributors** (See instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	_____ _____ _____	\$ 165,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2	_____ _____ _____	\$ 100,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3	_____ _____ _____	\$ 756,615.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
4	_____ _____ _____	\$ 413,758.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization  <b>FAMILIES OF SPINAL MUSCULAR ATROPHY</b>	Employer identification number  <b>36-3320440</b>
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**Part II Noncash Property** (See instructions). Use duplicate copies of Part II if additional space is needed.

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



Name of organization <b>FAMILIES OF SPINAL MUSCULAR ATROPHY</b>	Employer identification number <b>36-3320440</b>
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**Part III** Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of exclusively religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this info. once.) ▶ \$ \_\_\_\_\_  
Use duplicate copies of Part III if additional space is needed.

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

**SCHEDULE C**  
**(Form 990 or 990-EZ)**

**Political Campaign and Lobbying Activities**

OMB No. 1545-0047

**2016**

Open to Public Inspection

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.
- ▶ Information about Schedule C (Form 990 or 990-EZ) and its instructions is at [www.irs.gov/form990](http://www.irs.gov/form990).

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 <b>FAMILIES OF SPINAL MUSCULAR ATROPHY</b>	Employer identification number <b>36-3320440</b>
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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 or 990-EZ) 2016

**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.

<b>Limits on Lobbying Expenditures</b> (The term "expenditures" means amounts paid or incurred.)	(a) Filing organization's totals	(b) Affiliated group totals												
<b>1a</b> Total lobbying expenditures to influence public opinion (grass roots lobbying) .....														
<b>b</b> Total lobbying expenditures to influence a legislative body (direct lobbying) .....														
<b>c</b> Total lobbying expenditures (add lines 1a and 1b) .....														
<b>d</b> Other exempt purpose expenditures .....														
<b>e</b> Total exempt purpose expenditures (add lines 1c and 1d) .....														
<b>f</b> Lobbying nontaxable amount. Enter the amount from the following table in both columns.														
<table border="1" style="width:100%; border-collapse: collapse;"> <thead> <tr> <th style="width:35%;">If the amount on line 1e, column (a) or (b) is:</th> <th style="width:65%;">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.													
<b>g</b> Grassroots nontaxable amount (enter 25% of line 1f) .....														
<b>h</b> Subtract line 1g from line 1a. If zero or less, enter -0- .....														
<b>i</b> Subtract line 1f from line 1c. If zero or less, enter -0- .....														
<b>j</b> 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.)

<b>Lobbying Expenditures During 4-Year Averaging Period</b>					
Calendar year (or fiscal year beginning in)	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) Total
<b>2a</b> Lobbying nontaxable amount					
<b>b</b> Lobbying ceiling amount (150% of line 2a, column(e))					
<b>c</b> Total lobbying expenditures					
<b>d</b> Grassroots nontaxable amount					
<b>e</b> Grassroots ceiling amount (150% of line 2d, column (e))					
<b>f</b> Grassroots lobbying expenditures					

**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)).**

	(a)		(b)
	Yes	No	Amount
<i>For each "Yes," response on lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.</i>			
<b>1</b> 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:			
<b>a</b> Volunteers? .....		X	
<b>b</b> Paid staff or management (include compensation in expenses reported on lines 1c through 1i)? ..		X	
<b>c</b> Media advertisements? .....		X	
<b>d</b> Mailings to members, legislators, or the public? .....		X	
<b>e</b> Publications, or published or broadcast statements? .....		X	
<b>f</b> Grants to other organizations for lobbying purposes? .....		X	
<b>g</b> Direct contact with legislators, their staffs, government officials, or a legislative body? .....		X	
<b>h</b> Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means? .....		X	
<b>i</b> Other activities? .....	X		123,086.
<b>j</b> Total. Add lines 1c through 1i .....			123,086.
<b>2a</b> Did the activities in line 1 cause the organization to be not described in section 501(c)(3)? .....		X	
<b>b</b> If "Yes," enter the amount of any tax incurred under section 4912 .....			
<b>c</b> If "Yes," enter the amount of any tax incurred by organization managers under section 4912 .....			
<b>d</b> 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
<b>1</b> Were substantially all (90% or more) dues received nondeductible by members? .....	1	
<b>2</b> Did the organization make only in-house lobbying expenditures of \$2,000 or less? .....	2	
<b>3</b> 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."**

<b>1</b> Dues, assessments and similar amounts from members .....	1	
<b>2</b> Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).		
<b>a</b> Current year .....	2a	
<b>b</b> Carryover from last year .....	2b	
<b>c</b> Total .....	2c	
<b>3</b> Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues .....	3	
<b>4</b> 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	
<b>5</b> 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, LOBBYING ACTIVITIES:**

THE ORGANIZATION PAID DRINKER BIDDLE & REATH LLP, A LAW FIRM PROVIDING PROFESSIONAL LOBBYING SERVICES, FEES TO LOBBY FOR LEGISLATION THAT WOULD BENEFIT THE ORGANIZATION'S MISSION AND TO KEEP THE ORGANIZATION'S MANAGEMENT INFORMED ABOUT LEGISLATION THAT MAY AFFECT THE ORGANIZATION'S MISSION.

**Part IV** Supplemental Information (continued)

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

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.

Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2016

Open to Public Inspection

Name of the organization: FAMILIES OF SPINAL MUSCULAR ATROPHY; 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 two yes/no 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, total number and acreage, number of easements on historic structures, and monitoring details.

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.

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**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 are a 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 programs
- 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	854,008.	741,466.	620,515.	436,946.	220,438.
b Contributions	116,736.	112,008.	109,608.	181,698.	214,976.
c Net investment earnings, gains, and losses	87,854.	534.	11,343.	1,871.	1,532.
d Grants or scholarships					
e Other expenditures for facilities and programs	26,285.				
f Administrative expenses					
g End of year balance	1,032,313.	854,008.	741,466.	620,515.	436,946.

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

- a Board designated or quasi-endowment  \_\_\_\_\_ %
- b Permanent endowment  \_\_\_\_\_ %
- c Temporarily restricted 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		X
(ii) related organizations		X
b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?		

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

**Part VI Land, Buildings, and Equipment.**

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

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment		381,064.	165,107.	215,957.
e Other				
<b>Total.</b> Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)				215,957.

**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)		
<b>Total.</b> (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)		
<b>Total.</b> (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)	
<b>Total.</b> (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)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
<b>Total.</b> (Column (b) must equal Form 990, Part X, col. (B) line 25.) ▶	

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 FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII



**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.

<b>1</b>	Total revenue, gains, and other support per audited financial statements	<b>1</b>	8,458,733.
<b>2</b>	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
<b>a</b>	Net unrealized gains (losses) on investments	<b>2a</b>	72,220.
<b>b</b>	Donated services and use of facilities	<b>2b</b>	
<b>c</b>	Recoveries of prior year grants	<b>2c</b>	
<b>d</b>	Other (Describe in Part XIII.)	<b>2d</b>	519,938.
<b>e</b>	Add lines <b>2a</b> through <b>2d</b>	<b>2e</b>	592,158.
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b>	<b>3</b>	7,866,575.
<b>4</b>	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b	<b>4a</b>	6,701.
<b>b</b>	Other (Describe in Part XIII.)	<b>4b</b>	
<b>c</b>	Add lines <b>4a</b> and <b>4b</b>	<b>4c</b>	6,701.
<b>5</b>	Total revenue. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 12.)	<b>5</b>	7,873,276.

**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.

<b>1</b>	Total expenses and losses per audited financial statements	<b>1</b>	8,079,254.
<b>2</b>	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
<b>a</b>	Donated services and use of facilities	<b>2a</b>	
<b>b</b>	Prior year adjustments	<b>2b</b>	
<b>c</b>	Other losses	<b>2c</b>	
<b>d</b>	Other (Describe in Part XIII.)	<b>2d</b>	519,938.
<b>e</b>	Add lines <b>2a</b> through <b>2d</b>	<b>2e</b>	519,938.
<b>3</b>	Subtract line <b>2e</b> from line <b>1</b>	<b>3</b>	7,559,316.
<b>4</b>	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
<b>a</b>	Investment expenses not included on Form 990, Part VIII, line 7b	<b>4a</b>	6,701.
<b>b</b>	Other (Describe in Part XIII.)	<b>4b</b>	
<b>c</b>	Add lines <b>4a</b> and <b>4b</b>	<b>4c</b>	6,701.
<b>5</b>	Total expenses. Add lines <b>3</b> and <b>4c</b> . (This must equal Form 990, Part I, line 18.)	<b>5</b>	7,566,017.

**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 X, LINE 2:**

THE ORGANIZATION ASSESSES ITS TAX POSITION IN ACCORDANCE WITH "ACCOUNTING FOR UNCERTAINTY IN INCOME TAXES" AS PRESCRIBED BY THE ACCOUNTING STANDARDS CODIFICATION, WHICH PROVIDES GUIDANCE FOR FINANCIAL STATEMENT RECOGNITION AND MEASUREMENT OF UNCERTAIN TAX POSITIONS TAKEN OR EXPECTED TO BE TAKEN IN A TAX RETURN FOR OPEN TAX YEARS (GENERALLY A PERIOD OF THREE YEARS FROM THE LATER OF EACH RETURN'S DUE DATE OR THE DATE FILED) THAT REMAIN SUBJECT TO EXAMINATION BY THE ORGANIZATION'S MAJOR TAX JURISDICTIONS.

THE ORGANIZATION BELIEVES THAT IT DOES NOT HAVE ANY SIGNIFICANT UNCERTAIN TAX POSITIONS REQUIRING RECOGNITION OR MEASUREMENT.





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

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of noncash assistance	(h) Description of noncash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		EUROPE (INCLUDING ICELAND & GREENLAND) - ALBANIA, ANDORRA,	RESEARCH	30,000.	WIRE TRANSFER	0.		
		EUROPE (INCLUDING ICELAND & GREENLAND)	RESEARCH	70,000.	WIRE TRANSFER	0.		
		EUROPE (INCLUDING ICELAND & GREENLAND)	RESEARCH	70,000.	WIRE TRANSFER	0.		
		EAST ASIA AND THE PACIFIC	RESEARCH	75,000.	WIRE TRANSFER	0.		
		SOUTH AMERICA	RESEARCH	140,000.	WIRE TRANSFER	0.		

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter ..... **5**

3 Enter total number of other organizations or entities ..... **5**



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; do not 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; do not 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.

**SCHEDULE G**  
**(Form 990 or 990-EZ)**

Department of the Treasury  
Internal Revenue Service

**Supplemental Information Regarding Fundraising or Gaming Activities**  
Complete if the organization answered "Yes" on Form 990, Part IV, line 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.  
▶ Attach to Form 990 or Form 990-EZ.  
▶ Information about Schedule G (Form 990 or 990-EZ) and its instructions is at [www.irs.gov/form990](http://www.irs.gov/form990).

OMB No. 1545-0047

**2016**

Open to Public Inspection

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

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

- 1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.
- a  Mail solicitations
  - b  Internet and email solicitations
  - c  Phone solicitations
  - d  In-person solicitations
  - e  Solicitation of non-government grants
  - f  Solicitation of government grants
  - g  Special fundraising events
- 2 a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees, or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services?  Yes  No
- b If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
EPIPHANY PRODUCTIONS, INC. - 104 HUME AVE, ALEXANDRIA, VA	SPECIAL EVENTS ASSISTANCE		X	279,500.	24,868.	254,632.
EPIPHANY PRODUCTIONS, INC. - 104 HUME AVE, ALEXANDRIA, VA	FUND RAISING CONSULTATIONS		X	0.	2,500.	-2,500.
<b>Total</b>				279,500.	27,368.	252,132.

- 3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.
- AL, AK, AZ, AR, CA, CO, CT, DE, FL, GA, HI, ID, IL, IN, IA, KS, KY, LA, ME, MD, MA, MI, MN, MS, MO, MT, NE, NV, NH, NJ, NM, NY, NC, ND, OH, OK, OR, PA, RI, SC, SD, TN, TX, UT, VT, VA, WA, WV, WI, WY, DC



**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	
		CONGRESSIONAL DINNER (event type)	GALA OF HOPE (event type)	120 (total number)	(add col. (a) through col. (c))	
Revenue	1	Gross receipts	279,500.	349,078.	3,008,606.	3,637,184.
	2	Less: Contributions	148,680.	57,100.	2,928,597.	3,134,377.
	3	Gross income (line 1 minus line 2)	130,820.	291,978.	80,009.	502,807.
Direct Expenses	4	Cash prizes				
	5	Noncash prizes				
	6	Rent/facility costs				
	7	Food and beverages	31,804.	20,178.		51,982.
	8	Entertainment		62,270.		62,270.
	9	Other direct expenses	32,140.	17,697.	331,972.	381,809.
	10	Direct expense summary. Add lines 4 through 9 in column (d)				496,061.
11	Net income summary. Subtract line 10 from line 3, column (d)				6,746.	

**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: \_\_\_\_\_

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

Name ▶ \_\_\_\_\_

Address ▶ \_\_\_\_\_

- 15a Does the organization have a contract with a third party from whom the organization receives gaming revenue?  Yes  No
- b If "Yes," enter the amount of gaming revenue received by the organization ▶ \$ \_\_\_\_\_ and the amount of gaming revenue retained by the third party ▶ \$ \_\_\_\_\_
- c If "Yes," enter name and address of the third party:

Name ▶ \_\_\_\_\_

Address ▶ \_\_\_\_\_

16 Gaming manager information:

Name ▶ \_\_\_\_\_

Gaming manager compensation ▶ \$ \_\_\_\_\_

Description of services provided ▶ \_\_\_\_\_

\_\_\_\_\_

Director/officer       Employee       Independent contractor

17 Mandatory distributions:

- a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license?  Yes  No
- b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year ▶ \$ \_\_\_\_\_

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

**SCHEDULE G, PART I, LINE 2B, LIST OF TEN HIGHEST PAID FUNDRAISERS:**

(I) NAME OF FUNDRAISER: EPIPHANY PRODUCTIONS, INC.

(I) ADDRESS OF FUNDRAISER: 104 HUME AVE, ALEXANDRIA, VA 22301

(I) NAME OF FUNDRAISER: EPIPHANY PRODUCTIONS, INC.

(I) ADDRESS OF FUNDRAISER: 104 HUME AVE, ALEXANDRIA, VA 22301

**Part IV** Supplemental Information (continued)

EPIPHANY PRODUCTIONS, INC WAS PAID TO PROVIDE FUND RAISING AND CONSULTING SERVICES AND ADVICE AND TO ASSIST WITH THE PLANNING AND CONDUCTING OF THE CONGRESSIONAL DINNER. THE FUNDRAISER DOES NOT TAKE POSSESSION OF ANY FUNDS BUT INVOICES THE ORGANIZATION FOR THE EXPENSES. THE FINANCIAL AGREEMENT INCLUDES 10% OF GROSS RECEIPTS FOR THE ASSISTANCE OF THE SPECIFIC SPECIAL EVENT. THESE AMOUNTS ARE INCLUDED ON PART 1 LINE 2B (1).

THE FUNDRAISER ALSO PROVIDES GENERAL ADVICE ON FUNDRAISING ISSUES. EXPENSES FOR THESE SERVICES ARE INCLUDED ON PART 1, LINE 2B(2)

**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.

▶ Information about Schedule I (Form 990) and its instructions is at [www.irs.gov/form990](http://www.irs.gov/form990).

OMB No. 1545-0047

**2016**

Open to Public  
Inspection

Name of the organization **FAMILIES OF SPINAL MUSCULAR ATROPHY** 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 non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of noncash assistance	(h) Purpose of grant or assistance
TRUSTEES OF COLUMBIA UNIVERSITY IN N.Y. - 615 WEST 131ST STREET, MAIL CODE 8749 - NEW YORK, NY 10027	13-5598093	501(C)(3)	50,000.	0.			RESEARCH GRANT - PATIENT CARE
JOHNS HOPKINS UNIVERSITY 1101 E. 33RD STREET, STE C020 BALTIMORE, MD 21218	52-1317896	501(C)(3)	37,500.	0.			RESEARCH GRANT - DRUG DISCOVERY
OHIO STATE UNIVERSITY 901 WOODY HAYES DRIVE 2050 COLUMBUS, OH 43210	31-6025986	501(C)(3)	215,000.	0.			RESEARCH - BASIC
LURIE CHILDREN'S HOSPITAL PO BOX 269 CHICAGO, IL 60690	36-2170833	501(C)(3)	215,000.	0.			RESEARCH - BASIC
CURATORS OF THE UNIVERISTY OF MISSOURI - 118 UNIVERSITY HALL - COLUMBIA, MO 65211-3020	26-6440629	501(C)(3)	75,000.	0.			RESEARCH - BASIC

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table ▶ 5.

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

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

Schedule I (Form 990) (2016)

**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

**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.

**Part IV** Supplemental Information

RECIPIENTS SHALL ALSO SUBMIT TO THE ORGANIZATION A COMPREHENSIVE FINAL REPORT WITHIN NINETY (90) DAYS OF TERMINATION OF THE RESEARCH PROJECT.

FOR THE PURPOSE OF IDENTIFYING PATENTABLE INVENTIONS NOT COVERED BY PRE EXISTING PATENTS, RECIPIENTS SHALL SUBMIT A COPY OF ALL PROPOSED PUBLICATIONS, PAPERS, AND ANY OTHER WRITTEN DISCLOSURE OF SUCH DATA OR INFORMATION TO THE ORGANIZATION AT LEAST THIRTY (30) DAYS PRIOR TO SUBMISSION FOR PUBLICATION OR DISCLOSURE TO A THIRD PARTY.

SCHEDULE I, PART II

CERTAIN GRANT PAYMENTS ARE MADE TO GRANTEES BASED ON RESEARCH MILESTONES BEING MET. THESE AMOUNTS ARE NOT INCLUDED IN THE GRANTS PAYABLE. AS OF THE END OF THE CURRENT YEAR, FUTURE AMOUNTS OF THESE PAYMENTS ARE ESTIMATED TO BE \$341,500.

**SCHEDULE J  
(Form 990)**

**Compensation Information**

OMB No. 1545-0047

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

**2016**

▶ Complete if the organization answered "Yes" on Form 990, Part IV, line 23.

▶ Attach to Form 990.

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Department of the Treasury  
Internal Revenue Service

▶ Information about Schedule J (Form 990) and its instructions is at [www.irs.gov/form990](http://www.irs.gov/form990).

Name of the organization

**FAMILIES OF SPINAL MUSCULAR ATROPHY**

Employer identification number

**36-3320440**

**Part I Questions Regarding Compensation**

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

- |  |   |
|--|---|
| <input type="checkbox"/> First-class or charter travel             | <input type="checkbox"/> Housing allowance or residence for personal use    |
| <input type="checkbox"/> Travel for companions                     | <input type="checkbox"/> Payments for business use of personal residence    |
| <input type="checkbox"/> Tax indemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees      |
| <input type="checkbox"/> Discretionary spending account            | <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 .....

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

**3** Indicate which, if any, of the following the filing 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 type="checkbox"/> Compensation committee              | <input type="checkbox"/> Written employment contract                                |
| <input type="checkbox"/> Independent compensation consultant | <input type="checkbox"/> Compensation survey or study                               |
| <input type="checkbox"/> Form 990 of other organizations     | <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? .....
- b** Participate in, or receive payment from, a supplemental nonqualified retirement plan? .....
- c** Participate in, or receive payment from, an equity-based compensation arrangement? .....
- If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

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

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

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

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

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

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

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

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

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

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

Schedule J (Form 990) 2016

**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 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)	182,099.	0.	0.	0.	14,664.	196,763.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
(2) JILL JARECKI RESEARCH DIRECTOR	(i)	171,689.	0.	0.	0.	628.	172,317.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							
	(i)							
	(ii)							





**SCHEDULE M  
(Form 990)**

**Noncash Contributions**

OMB No. 1545-0047

**2016**

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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.
- ▶ Information about Schedule M (Form 990) and its instructions is at [www.irs.gov/form990](http://www.irs.gov/form990).

Name of the organization **FAMILIES OF SPINAL MUSCULAR ATROPHY** 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				
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 ▶ ( SEE PART II )	X	90	371,235	RETAIL VALUE
26 Other ▶ ( )				
27 Other ▶ ( )				
28 Other ▶ ( )				

29 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, 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) (2016)

**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 33:

.

PAGE 1, LINE 25: THE AMOUNT ON LINE 25 INCLUDES DONATED RENTAL EQUIPMENT AND FOOD FOR SPECIAL EVENTS, DONATED EQUIPMENT, AND OTHER ITEMS.

**SCHEDULE O**  
**(Form 990 or 990-EZ)**

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 990-EZ.

▶ Information about Schedule O (Form 990 or 990-EZ) and its instructions is at [www.irs.gov/form990](http://www.irs.gov/form990).

OMB No. 1545-0047

**2016**

Open to Public  
Inspection

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number

36-3320440

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

CURE SMA LEADS THE WAY TO A WORLD WITHOUT SPINAL MUSCULAR ATROPHY, THE  
NUMBER ONE GENETIC CAUSE 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:

AND PATIENTS IMPACTED BY THE DISEASE. THE CHARITY HAS INVESTED OVER  
\$60 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

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

Schedule O (Form 990 or 990-EZ) (2016)

Name of the organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

Employer identification number

36-3320440

INFORMATION FOR PARENTS, AND USEFUL ITEMS SUGGESTED BY OTHER SMA PARENTS BASED ON THEIR OWN EXPERIENCES.

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

CURE SMA WORKS DIRECTLY WITH CLINICIANS, MEDICAL DOCTORS, SPECIALISTS, AND SKILLED CAREGIVERS TO ENSURE THAT PATIENTS HAVE ACCESS TO THE BEST POSSIBLE CARE.

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

IN THE BEGINNING STAGES OF LAUNCHING A MULTI-CENTER CLINICAL DATA REGISTRY WITHIN AN ACCREDITED CARE CENTER NETWORK. WITH THE FIRST FDA-APPROVED THERAPY COMING IN DECEMBER 2016, THE TEAM DEVOTED RESOURCES TO COMPILING A LIST OF ACCESS CENTERS FOR PATIENTS.

CURRENTLY, THERE IS ONE APPROVED DRUG FOR SMA, WITH ANOTHER 19 DRUG PROGRAMS IN DEVELOPMENT, INCLUDING FIVE IN CLINICAL TRIALS. CURE SMA HAS FUNDED HALF OF ALL THE ONGOING DRUG PROGRAMS IN SMA, INCLUDING FUNDING SIX DRUG PROGRAMS THIS YEAR.

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

SCIENTIFIC DATA, ACCELERATING THE PACE OF RESEARCH. THE MEETING ALSO FURTHERS RESEARCH BY BUILDING PRODUCTIVE COLLABORATIONS-INCLUDING CROSS-DISCIPLINARY DIALOGUE, PARTNERSHIPS, INTEGRATION OF NEW RESEARCHERS AND DRUG COMPANIES, AND EDUCATIONAL OPPORTUNITIES FOR

Name of the organization <b>FAMILIES OF SPINAL MUSCULAR ATROPHY</b>	Employer identification number <b>36-3320440</b>
--	---

JUNIOR RESEARCHERS.

THE MOST POWERFUL ACTIVITIES OF THE CONFERENCE HAPPEN WHEN THE FAMILY AND RESEARCHER CONFERENCES COME TOGETHER. FAMILIES HAVE DIRECT ACCESS TO THE LATEST INFORMATION ABOUT RESEARCH, AND RESEARCHERS HAVE AN OPPORTUNITY TO BUILD PERSONAL CONNECTIONS WITH THE PATIENTS WHO WILL BENEFIT FROM THEIR WORK.

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

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

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

MEMBERS OF THE BOARD OF DIRECTORS ARE REQUIRED TO SIGN AN ANNUAL STATEMENT DISCLOSING ANY POSSIBLE CONFLICTS OF INTEREST.

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

PRESIDENT'S 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:

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

AL, AZ, CA, CO, CT, FL, IA, IL, KS, LA, NJ, NY, OH, TN, TX, WA, AK, VA, NC, SC, UT, AR, KY, ME, WV  
 GA, DE, HI, ID, IN, MD, MT, ND, NE, NV, NH, OK, SD, VT, WI, WY, NM, MN, MS, MA, MI, MO, OR, RI, PA,  
 DC

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

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

FORM 990, PAGE 9, PART VIII, LINE 11A

INCOME FROM NON-RECURRING LICENSING AGREEMENT

FORM 990, PAGE 12, PART XII, QUESTION 2C:

NO CHANGES WERE MADE TO THE AUDIT OVERSIGHT PROCESS FOR THE CURRENT  
 YEAR.