**PUBLIC DISCLOSURE COPY**

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)

Do not enter social security numbers on this form as it may be made public.

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

A For the 2017 calendar year, or tax year beginning JUL 1, 2017 and ending JUN 30, 2018

B Check if applicable:

C Name of organization

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

D Employer identification number

***-***0440

E Telephone number

847-709-6318

G Gross receipts $ 12,508,035.

H(a) Is this a group return

Yes X No

H(b) Are all subordinates included?

Yes X No

If "No," attach a list. (see instructions)

J Website:

WWW.CURESMA.ORG

K Form of organization:

X Corporation

Trust

Association

Other ▶

L Year of formation: 1984

M State of legal domicile: IL

Part I Summary

1 Briefly describe the organization’s mission or most significant activities: CURE SMA LEADS THE WAY TO A WORLD WITHOUT SPINAL MUSCULAR ATROPHY, THE NUMBER ONE GENETIC CAUSE

2 Check this box ▶ if the organization discontinued its operations or disposed of more than 25% of its net assets.

3 Number of voting members of the governing body (Part VI, line 1a)

3 20

4 Number of independent voting members of the governing body (Part VI, line 1b)

4 20

5 Total number of individuals employed in calendar year 2017 (Part V, line 2a)

5 42

6 Total number of volunteers (estimate if necessary)

6 6950

7a Total unrelated business revenue from Part VIII, column (C), line 12

7a 0

7b Net unrelated business taxable income from Form 990-T, line 34

7b 0

Revenue

8 Contributions and grants (Part VIII, line 1b)

8

Program service revenue (Part VIII, line 2g)

9 1,381,841. 1,164,295

10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)

10 23,825. 38,580

11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)

11 649,175. 543,412

12 Total revenue - add lines 9 through 11 (must equal Part VIII, column (A), line 12)

12 7,873,276. 11,464,375

Expenses

13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)

13

14 Benefits paid to or for members (Part IX, column (A), line 4)

14 0

15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)

15

16a Professional fundraising fees (Part IX, column (A), line 11e)

16a

16b Total fundraising expenses (Part IX, column (D), line 25) ▶ 1,015,466.

16b

17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)

17

18 Total expenses. Add lines 17-13 (must equal Part IX, column (A), line 25)

18 7,566,017. 9,693,450

19 Revenue less expenses. Subtract line 18 from line 12

19 3,307,259. 1,770,925

Part II Signature Block

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

Sign Here

KENNETH HOBBY, PRESIDENT

Type or print name and title

Paid

SUSAN GREGGO

Preparer’s signature

Preparer’s name

Date

Check if unemployed

PTIN P00595460

Preparer Only

WARADY & DAVIS LLP

Use Only

1717 DEERFIELD RD SUITE 300S

DEERFIELD, IL 60015

Phone no. (847) 267-9600

May the IRS discuss this return with the preparer shown above? (see instructions)

X Yes No

Form 990 (2017)

SEE SCHEDULE O FOR ORGANIZATION MISSION STATEMENT CONTINUATION
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.

Did the organization undertake any significant program services during the year which were not listed on the prior Form 990 or 990-EZ? 

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

Did the organization cease conducting, or make significant changes in how it conducts, any program services? 

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

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.

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.

CURE SMA FOCUSSES 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 16 NEW AND ONGOING BASIC RESEARCH GRANTS, AS WELL AS TWO ONGOING AND TWO NEW DRUG DISCOVERY PROJECTS. WE ALSO FUNDED AND EXECUTED MULTIPLE CLINICAL AND REGULATORY FOCUSED PROJECTS, INCLUDING PROJECTS TO IMPLEMENT NEWBORN SCREENING FOR SMA AT THE STATE LEVEL, TO INCREASE THE NUMBER OF TRAINED SMA CLINICAL TRIALS SITES IN THE US, AND TO UNDERSTAND THE PATIENT EXPERIENCE WITH SMA. CURE SMA ALSO PROVIDES PATIENT AND HEALTHCARE PROVIDER EDUCATION, WITH EXPERTISE DEVELOPED BY MEDICAL EXPERTS AND REVIEWED BY FAMILIES, THESE BOOKLETS COVER TOPICS SUCH AS BREATHING, NUTRITION, PALLIATIVE CARE, GENETICS, ETC.

WE HOSTED OUR 29TH ANNUAL SMA CONFERENCE IN DALLAS, TX, WITH OVER 1771 TOTAL ATTENDEES. OUR ANNUAL CONFERENCE IS AN INVALUABLE RESOURCE FOR THE ENTIRE SMA COMMUNITY, BRIVING 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 RESULTS.
Part IV Checklist of Required Schedules

1. Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)?
   If "Yes," complete Schedule A
   1 X

2. Is the organization required to complete Schedule B, Schedule of Contributors?
   2 X

3. Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I
   3 X

4. Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If "Yes," complete Schedule C, Part II
   4 X

5. Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? If "Yes," complete Schedule C, Part III
   5 X

6. Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? If "Yes," complete Schedule D, Part I
   6 X

7. Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? If "Yes," complete Schedule D, Part II
   7 X

8. Did the organization maintain collections of works of art, historical treasures, or other similar assets? If "Yes," complete Schedule D, Part III
   8 X

9. Did the organization report an amount in Part X, line 21, for escrow or custodial account liability, serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? If "Yes," complete Schedule D, Part IV
   9 X

10. Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? If "Yes," complete Schedule D, Part V
    10 X

11. If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.
    a. Did the organization report an amount for land, buildings, and equipment in Part X, line 10? If "Yes," complete Schedule D, Part VI
       11a X
    b. Did the organization report an amount for investments - other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VII
       11b X
    c. Did the organization report an amount for investments - program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part VIII
       11c X
    d. Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? If "Yes," complete Schedule D, Part IX
       11d X
    e. Did the organization report an amount for other liabilities in Part X, line 25? If "Yes," complete Schedule D, Part X
       11e X
    f. Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? If "Yes," complete Schedule D, Part X
       11f X
    12a Did the organization obtain separate, independent audited financial statements for the tax year? If "Yes," complete Schedule D, Parts XI and XII
       12a X
    b. Was the organization included in consolidated, independent audited financial statements for the tax year? If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional
       12b X

13. Is the organization a school described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E
   13 X

14a Did the organization maintain an office, employees, or agents outside of the United States?
   14a X

14b 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? If "Yes," complete Schedule F, Parts I and IV
   14b X

15. Did the organization report on Part IX, column (A), line 3, more than $5,000 of grants or other assistance to or for foreign organizations? If "Yes," complete Schedule F, Parts I and IV
   15 X

16. Did the organization report on Part IX, column (A), line 3, more than $5,000 of aggregate grants or other assistance to or for foreign individuals? If "Yes," complete Schedule F, Parts II and IV
   16 X

17. Did the organization report a total of more than $15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? If "Yes," complete Schedule G, Part I
   17 X

18. Did the organization report more than $15,000 of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If "Yes," complete Schedule G, Part II
   18 X

19. Did the organization report more than $15,000 of gross income from gaming activities on Part VIII, line 9a? If "Yes," complete Schedule G, Part III
   19 X
**FAMILIES OF SPINAL MUSCULAR ATROPHY**  
DBA CURE SMA  
**-***0440  
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Part IV Checklist of Required Schedules (continued)

<table>
<thead>
<tr>
<th>20a</th>
<th>Did the organization operate one or more hospital facilities? If &quot;Yes,&quot; complete Schedule H</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>20b</td>
<td>If &quot;Yes&quot; to line 20a, did the organization attach a copy of its audited financial statements to this return?</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

21 Did the organization report more than $5,000 of grants or other assistance to any domestic organization or government on Part IX, column (A), line 17? If "Yes," complete Schedule I, Parts I and II  

22 Did the organization report more than $5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III  

23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization’s current and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete Schedule J  

24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than $100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete Schedule K. If "No", go to line 25a  

24b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?  

24c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?  

24d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?  

25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I  

25b 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? If "Yes," complete Schedule L, Part I  

26 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? If "Yes," complete Schedule L, Part II  

27 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? If "Yes," complete Schedule L, Part III  

28 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):  

a A current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV  

b A family member of a current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV  

c 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? If "Yes," complete Schedule L, Part IV  

29 Did the organization receive more than $25,000 in non-cash contributions? If "Yes," complete Schedule M  

30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M  

31 Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I  

32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II  

33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I  

34 Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1  

35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?  

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)? If "Yes," complete Schedule R, Part V, line 2  

36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If "Yes," complete Schedule R, Part V, line 2  

37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI  

38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19?  

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

Form 990 (2017)
### 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**

<table>
<thead>
<tr>
<th>Line</th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable</td>
<td>47</td>
<td>X</td>
</tr>
<tr>
<td>1b</td>
<td>Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>1c</td>
<td>Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2a</td>
<td>Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>2b</td>
<td>If at least one is reported on line 2a, did the organization file all required federal employment tax returns?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>3a</td>
<td>Did the organization have unrelated business gross income of $1,000 or more during the year?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3b</td>
<td>If &quot;Yes,&quot; has it filed a Form 990-T for this year? If &quot;No,&quot; to line 3b, provide an explanation in Schedule O</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>4a</td>
<td>At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>4b</td>
<td>If &quot;Yes,&quot; enter the name of the foreign country:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5a</td>
<td>Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>5b</td>
<td>Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>5c</td>
<td>If &quot;Yes,&quot; to line 5a or 5b, did the organization file Form 8886-T?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6a</td>
<td>Does the organization have annual gross receipts that are normally greater than $100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>6b</td>
<td>If &quot;Yes,&quot; did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7a</td>
<td>Did the organization receive a payment in excess of $75 made partly as a contribution and partly for goods and services provided to the payor?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>7b</td>
<td>If &quot;Yes,&quot; did the organization notify the donor of the value of the goods or services provided?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>7c</td>
<td>Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>7d</td>
<td>If &quot;Yes,&quot; indicate the number of Forms 8282 filed during the year</td>
<td>7d</td>
<td></td>
</tr>
<tr>
<td>7e</td>
<td>Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>7f</td>
<td>Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>7g</td>
<td>If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7h</td>
<td>If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1099-C?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Sponsoring organizations maintaining donor advised funds.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9a</td>
<td>Did the sponsoring organization make any taxable distributions under section 4966?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9b</td>
<td>Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Section 501(c)(7) organizations. Enter:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10a</td>
<td>Initiation fees and capital contributions included on Part VIII, line 12</td>
<td>10a</td>
<td></td>
</tr>
<tr>
<td>10b</td>
<td>Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities</td>
<td>10b</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Section 501(c)(12) organizations. Enter:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11a</td>
<td>Gross income from members or shareholders</td>
<td>11a</td>
<td></td>
</tr>
<tr>
<td>11b</td>
<td>Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)</td>
<td>11b</td>
<td></td>
</tr>
<tr>
<td>12a</td>
<td>Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?</td>
<td>12a</td>
<td></td>
</tr>
<tr>
<td>12b</td>
<td>If &quot;Yes,&quot; enter the amount of tax-exempt interest received or accrued during the year</td>
<td>12b</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Section 501(c)(29) qualified nonprofit health insurance issuers.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13a</td>
<td>Is the organization licensed to issue qualified health plans in more than one state?</td>
<td>13a</td>
<td></td>
</tr>
<tr>
<td>13b</td>
<td>Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans</td>
<td>13b</td>
<td></td>
</tr>
<tr>
<td>13c</td>
<td>Enter the amount of reserves on hand</td>
<td>13c</td>
<td></td>
</tr>
<tr>
<td>14a</td>
<td>Did the organization receive any payments for indoor tanning services during the tax year?</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>14b</td>
<td>If &quot;Yes,&quot; has it filed a Form 720 to report these payments? If &quot;No,&quot; provide an explanation in Schedule O</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

Form 990 (2017)
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.

Section A. Governing Body and Management

1a Enter the number of voting members of the governing body at the end of the tax year ......................................................... 1a 20

If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O. 1b 20

2 Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee? .......................................................... 2 X

3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, or trustees, or key employees to a management company or other person? ................. 3 X

4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? ............... 4 X

5 Did the organization become aware during the year of a significant diversion of the organization's assets? ......................... 5 X

6 Did the organization have members or stockholders? ................. 6 X

a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? 7a X

b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? 7b X

8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:

a The governing body? ................................................................. 8a X

b Each committee with authority to act on behalf of the governing body? 8b X

9 Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O ......................................................... 9 X

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

10a Did the organization have local chapters, branches, or affiliates? ................................................................. 10a X

b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? 10b X

11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11a X

b Describe in Schedule O the process, if any, used by the organization to review this Form 990. 11b X

12a Did the organization have a written conflict of interest policy? If "No," go to line 13 12a X

b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? 12b X

12c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done 12c X

13 Did the organization have a written whistleblower policy? ................................................................. 13 X

14 Did the organization have a written document retention and destruction policy? ................................................................. 14 X

15 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision?

a The organization's CEO, Executive Director, or top management official 15a X

b Other officers or key employees of the organization 15b X

If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions). 15b X

16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? 16a X

b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements? 16b X

Section C. Disclosure

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

18 Section 6104 requires an organization to make its Forms 1023 (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. 19 X

20 State the name, address, and telephone number of the person who possesses the organization's books and records: MARLINE PAGAN – 847-709-6318

925 BUSSE RD, ELK GROVE VILLAGE, IL 60007

SEE SCHEDULE O FOR FULL LIST OF STATES

Form 990 (2017)
## Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

**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.

<table>
<thead>
<tr>
<th>(A)</th>
<th>Name and Title</th>
<th>(B) Average hours per week (list any hours for related organizations below line)</th>
<th>(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)</th>
<th>(D) Reportable compensation from the organization (W-2/1099-MISC)</th>
<th>(E) Reportable compensation from related organizations (W-2/1099-MISC)</th>
<th>(F) Estimated amount of other compensation from the organization and related organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>RICHARD M. RUBENSTEIN</td>
<td>15.00</td>
<td>X X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(2)</td>
<td>KELLY COLE</td>
<td>6.00</td>
<td>X X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(3)</td>
<td>BRAD NUNEMAKER</td>
<td>6.00</td>
<td>X X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(4)</td>
<td>COREY BRAASTAD</td>
<td>2.00</td>
<td>X X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(5)</td>
<td>MATT EVANS</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(6)</td>
<td>NICK FARRELL</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(7)</td>
<td>JACLYN GREENWOOD</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(8)</td>
<td>ANNIE KENNEDY</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(9)</td>
<td>EDMUND LEE</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(10)</td>
<td>ROB LOCKWOOD</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(11)</td>
<td>GILLIAN MULLINS</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(12)</td>
<td>DOUGLAS KERR</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(13)</td>
<td>MELISSA MILINOVICH</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(14)</td>
<td>THOMAS MURRAY</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(15)</td>
<td>SPENCER PERLMAN</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(16)</td>
<td>SHANNON SHRINE</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
<tr>
<td>(17)</td>
<td>BRYAN SNYDER</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
</tr>
</tbody>
</table>
**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees**

<table>
<thead>
<tr>
<th>Name and title</th>
<th>Position</th>
<th>Average hours per week</th>
<th>Individual trustee or director</th>
<th>Institutional trustee</th>
<th>Officer</th>
<th>Highest compensated employee</th>
<th>Key employee</th>
<th>Total from continuation sheets to Part VII, Section A</th>
</tr>
</thead>
<tbody>
<tr>
<td>(18) DANYELLE SUN DIRECTOR</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(19) PETER STATILE DIRECTOR</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(20) GREG ZERZAN DIRECTOR</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(21) DOUGLAS ERVIN DIRECTOR (THROUGH JUNE 2017)</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(22) STEVE RAGLAND DIRECTOR (THROUGH JUNE 2017)</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(23) JOHN PORTER DIRECTOR (THROUGH JUNE 2017)</td>
<td>2.00</td>
<td>X</td>
<td>0.</td>
<td>0.</td>
<td>0.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(24) KENNETH HOBBY PRESIDENT</td>
<td>70.00</td>
<td>X</td>
<td>184,965.</td>
<td>0.</td>
<td>32,044.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(25) JILL JARECKI CHIEF SCIENTIFIC OFFICER</td>
<td>60.00</td>
<td>X</td>
<td>185,457.</td>
<td>0.</td>
<td>7,714.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(26) MARLINE PAGAN VICE PRESIDENT, FINANCE &amp; OPERATIONS</td>
<td>60.00</td>
<td>X</td>
<td>103,191.</td>
<td>0.</td>
<td>11,906.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1b Sub-total: 473,613. |
1c Total from continuation sheets to Part VII, Section A: 224,496. |
1d Total (add lines 1b and 1c): 698,109. |

2 Total number of individuals (including but not limited to those listed above) who received more than $100,000 of reportable compensation from the organization: 5 |

3 Did the organization list any former officer, director, or trustee, key employee, or highest compensated employee on line 1a? If "Yes," complete Schedule J for such individual: Yes |

4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than $150,000? If "Yes," complete Schedule J for such individual: No |

5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person: No |

**Section B. Independent Contractors**

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

<table>
<thead>
<tr>
<th>Name and business address</th>
<th>Description of services</th>
<th>Compensation</th>
</tr>
</thead>
<tbody>
<tr>
<td>NONE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NONE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NONE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NONE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NONE</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2 Total number of independent contractors (including but not limited to those listed above) who received more than $100,000 of compensation from the organization: 0 |
<table>
<thead>
<tr>
<th>(A) Name and title</th>
<th>(B) Average hours per week</th>
<th>(C) Position</th>
<th>(D) Reportable compensation from the organization (W-2/1099-MISC)</th>
<th>(E) Reportable compensation from related organizations (W-2/1099-MISC)</th>
<th>(F) Estimated amount of other compensation from the organization and related organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>COLLEEN MCCARTHY O’TOOLE</td>
<td>60.00</td>
<td>X</td>
<td>113,477.</td>
<td>0.</td>
<td>20,846.</td>
</tr>
<tr>
<td>DIRECTOR OF CLINICAL AFFAIRS</td>
<td>45.00</td>
<td>X</td>
<td>111,019.</td>
<td>0.</td>
<td>12,700.</td>
</tr>
</tbody>
</table>

Total to Part VII, Section A, line 1c ................................................................................................................. 224,496. 33,546.
## Part VIII Statement of Revenue

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

<table>
<thead>
<tr>
<th>Contributions, Gifts, Grants and Other Similar Amounts</th>
<th>(A) Total revenue</th>
<th>(B) Related or exempt function revenue</th>
<th>(C) Unrelated business revenue</th>
<th>(D) Revenue excluded from tax under sections 512-514</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a Federated campaigns</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1b Membership dues</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1c Fundraising events</td>
<td></td>
<td>3,142,100.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1d Related organizations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1e Government grants (contributions)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1f All other contributions, gifts, grants, and similar amounts not included above</td>
<td></td>
<td>7,662,812.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>g Noncash contributions included in lines 1a-1f $</td>
<td></td>
<td>234,192.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>h Total. Add lines 1a-1f</td>
<td></td>
<td>10,804,912.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Program Service Revenue

<table>
<thead>
<tr>
<th>Business Code</th>
<th>Total revenue</th>
<th>Related or exempt function revenue</th>
<th>Unrelated business revenue</th>
<th>Revenue excluded from tax under sections 512-514</th>
</tr>
</thead>
<tbody>
<tr>
<td>2a ANNUAL CONFERENCE</td>
<td>900099</td>
<td>1,159,409.</td>
<td>1,159,409.</td>
<td></td>
</tr>
<tr>
<td>2b INDUSTRY SPONSORED RESEARCH</td>
<td>900099</td>
<td>4,886.</td>
<td>4,886.</td>
<td></td>
</tr>
</tbody>
</table>

### Other Revenue

<table>
<thead>
<tr>
<th>Business Code</th>
<th>Total revenue</th>
<th>Related or exempt function revenue</th>
<th>Unrelated business revenue</th>
<th>Revenue excluded from tax under sections 512-514</th>
</tr>
</thead>
<tbody>
<tr>
<td>8a Gross income from fundraising events (not including $ 3,142,100. of contributions reported on line 1c). See Part IV, line 18</td>
<td></td>
<td>158,737.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8b Less: direct expenses</td>
<td></td>
<td>829,363.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8c Net income or (loss) from fundraising events</td>
<td></td>
<td>-670,626.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Miscellaneous Revenue

<table>
<thead>
<tr>
<th>Business Code</th>
<th>Total revenue</th>
<th>Related or exempt function revenue</th>
<th>Unrelated business revenue</th>
<th>Revenue excluded from tax under sections 512-514</th>
</tr>
</thead>
<tbody>
<tr>
<td>11a STORE MERCHANDISE</td>
<td>900099</td>
<td>15,895.</td>
<td>15,895.</td>
<td></td>
</tr>
<tr>
<td>11b</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11c</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11d</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11e Total. Add lines 11a-11d</td>
<td></td>
<td>15,895.</td>
<td></td>
<td>-520,727.</td>
</tr>
<tr>
<td>12 Total revenue. See instructions.</td>
<td></td>
<td>11,464,375.</td>
<td>1,180,190.</td>
<td>0.</td>
</tr>
</tbody>
</table>
### 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.**

<table>
<thead>
<tr>
<th>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</th>
<th>(A)</th>
<th>(B)</th>
<th>(C)</th>
<th>(D)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21</td>
<td>2,364,627</td>
<td>2,364,627</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Grants and other assistance to domestic individuals. See Part IV, line 22</td>
<td>43,802</td>
<td>43,802</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16</td>
<td>175,000</td>
<td>175,000</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Benefits paid to or for members</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Compensation of current officers, directors, trustees, and key employees</td>
<td>468,876</td>
<td>387,555</td>
<td>44,595</td>
</tr>
<tr>
<td>6</td>
<td>Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Other salaries and wages</td>
<td>2,373,978</td>
<td>1,606,637</td>
<td>223,967</td>
</tr>
<tr>
<td>8</td>
<td>Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)</td>
<td>67,890</td>
<td>52,207</td>
<td>3,556</td>
</tr>
<tr>
<td>9</td>
<td>Other employee benefits</td>
<td>156,967</td>
<td>100,693</td>
<td>15,939</td>
</tr>
<tr>
<td>10</td>
<td>Payroll taxes</td>
<td>210,960</td>
<td>147,651</td>
<td>19,809</td>
</tr>
<tr>
<td>11</td>
<td>Fees for services (non-employees):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a</td>
<td>Management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td>Legal</td>
<td>36,394</td>
<td>36,394</td>
<td></td>
</tr>
<tr>
<td>c</td>
<td>Accounting</td>
<td>45,847</td>
<td>45,847</td>
<td></td>
</tr>
<tr>
<td>d</td>
<td>Lobbying</td>
<td>55,893</td>
<td>39,125</td>
<td>3,913</td>
</tr>
<tr>
<td>e</td>
<td>Professional fundraising services. See Part IV, line 17</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f</td>
<td>Investment management fees</td>
<td>7,937</td>
<td>7,937</td>
<td></td>
</tr>
<tr>
<td>g</td>
<td>Other. (If line 11g amount exceeds 10% of line 25, column (A) amount, list line 11g expenses on Sch O.)</td>
<td>424,018</td>
<td>406,901</td>
<td>3,687</td>
</tr>
<tr>
<td>12</td>
<td>Advertising and promotion</td>
<td>196,258</td>
<td>155,859</td>
<td>12,568</td>
</tr>
<tr>
<td>13</td>
<td>Office expenses</td>
<td>306,605</td>
<td>257,492</td>
<td>10,535</td>
</tr>
<tr>
<td>14</td>
<td>Information technology</td>
<td>102,017</td>
<td>86,704</td>
<td>4,126</td>
</tr>
<tr>
<td>15</td>
<td>Royalties</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Occupancy</td>
<td>210,008</td>
<td>147,010</td>
<td>14,692</td>
</tr>
<tr>
<td>17</td>
<td>Travel</td>
<td>290,262</td>
<td>145,202</td>
<td>99,180</td>
</tr>
<tr>
<td>18</td>
<td>Payments of travel or entertainment expenses for any federal, state, or local public officials</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Conferences, conventions, and meetings</td>
<td>1,530,579</td>
<td>1,512,446</td>
<td>1,927</td>
</tr>
<tr>
<td>20</td>
<td>Interest</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Payments to affiliates</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Depreciation, depletion, and amortization</td>
<td>191,964</td>
<td>177,388</td>
<td>2,915</td>
</tr>
<tr>
<td>23</td>
<td>Insurance</td>
<td>21,136</td>
<td>11,332</td>
<td>6,466</td>
</tr>
<tr>
<td>24</td>
<td>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.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a</td>
<td>WEBSITE</td>
<td>182,308</td>
<td>139,813</td>
<td>8,599</td>
</tr>
<tr>
<td>b</td>
<td>BANK CHARGES, CREDIT CA</td>
<td>86,148</td>
<td></td>
<td>43,357</td>
</tr>
<tr>
<td>c</td>
<td>BAD DEBT EXPENSE</td>
<td>47,030</td>
<td></td>
<td>47,030</td>
</tr>
<tr>
<td>d</td>
<td>ANNUAL CAMPAIGN</td>
<td>39,861</td>
<td>13,763</td>
<td></td>
</tr>
<tr>
<td>e</td>
<td>Other all other expenses</td>
<td>57,085</td>
<td>29,562</td>
<td>20,166</td>
</tr>
<tr>
<td>25</td>
<td>Total functional expenses. Add lines 1 through 24e</td>
<td>9,693,450</td>
<td>8,000,769</td>
<td>677,215</td>
</tr>
<tr>
<td>26</td>
<td>Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### FAMILIES OF SPINAL MUSCULAR ATROPHY

**DBA CURE SMA**

**Form 990 (2017)**

**Page 11**

#### Part X | Balance Sheet

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

<table>
<thead>
<tr>
<th></th>
<th>(A) Beginning of year</th>
<th>(B) End of year</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Cash - non-interest-bearing</td>
<td>2,251,340</td>
</tr>
<tr>
<td>2</td>
<td>Savings and temporary cash investments</td>
<td>875,061</td>
</tr>
<tr>
<td>3</td>
<td>Pledges and grants receivable, net</td>
<td>209,652</td>
</tr>
<tr>
<td>4</td>
<td>Accounts receivable, net</td>
<td>327,032</td>
</tr>
<tr>
<td>5</td>
<td>Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>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</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Notes and loans receivable, net</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Inventories for sale or use</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Prepaid expenses and deferred charges</td>
<td>49,845</td>
</tr>
<tr>
<td>10a</td>
<td>Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D</td>
<td>291,035</td>
</tr>
<tr>
<td>10b</td>
<td>Less: accumulated depreciation</td>
<td>116,880</td>
</tr>
<tr>
<td>11</td>
<td>Investments - publicly traded securities</td>
<td>1,032,313</td>
</tr>
<tr>
<td>12</td>
<td>Investments - other securities. See Part IV, line 11</td>
<td>547</td>
</tr>
<tr>
<td>13</td>
<td>Investments - program-related. See Part IV, line 11</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Intangible assets</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Other assets. See Part IV, line 11</td>
<td>22,795</td>
</tr>
<tr>
<td>16</td>
<td>Total assets. Add lines 1 through 15 (must equal line 34)</td>
<td>4,984,542</td>
</tr>
<tr>
<td>17</td>
<td>Accounts payable and accrued expenses</td>
<td>1,299,429</td>
</tr>
<tr>
<td>18</td>
<td>Grants payable</td>
<td>990,000</td>
</tr>
<tr>
<td>19</td>
<td>Deferred revenue</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Tax-exempt bond liabilities</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Escrow or custodial account liability. Complete Part IV of Schedule D</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>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</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Secured mortgages and notes payable to unrelated third parties</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Unsecured notes and loans payable to unrelated third parties</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>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</td>
<td>0</td>
</tr>
<tr>
<td>26</td>
<td>Total liabilities. Add lines 17 through 25</td>
<td>2,289,429</td>
</tr>
<tr>
<td>27</td>
<td>Organizations that follow SFAS 117 (ASC 958), check here</td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Unrestricted net assets</td>
<td>1,212,123</td>
</tr>
<tr>
<td>29</td>
<td>Temporarily restricted net assets</td>
<td>484,392</td>
</tr>
<tr>
<td>30</td>
<td>Permanently restricted net assets</td>
<td>998,598</td>
</tr>
<tr>
<td>31</td>
<td>Capital stock or trust principal, or current funds</td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>Paid-in or capital surplus, or land, building, or equipment fund</td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>Retained earnings, endowment, accumulated income, or other funds</td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>Total net assets or fund balances</td>
<td>2,695,113</td>
</tr>
<tr>
<td>35</td>
<td>Total liabilities and net assets/fund balances</td>
<td>4,984,542</td>
</tr>
</tbody>
</table>

---

Form 990 (2017)
### Part XI Reconciliation of Net Assets

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

<table>
<thead>
<tr>
<th>Line</th>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Total revenue (must equal Part VIII, column (A), line 12)</td>
<td>11,464,375</td>
</tr>
<tr>
<td>2</td>
<td>Total expenses (must equal Part IX, column (A), line 25)</td>
<td>9,693,450</td>
</tr>
<tr>
<td>3</td>
<td>Revenue less expenses. Subtract line 2 from line 1</td>
<td>1,770,925</td>
</tr>
<tr>
<td>4</td>
<td>Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))</td>
<td>2,695,113</td>
</tr>
<tr>
<td>5</td>
<td>Net unrealized gains (losses) on investments</td>
<td>35,817</td>
</tr>
<tr>
<td>6</td>
<td>Donated services and use of facilities</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Investment expenses</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Prior period adjustments</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Other changes in net assets or fund balances (explain in Schedule O)</td>
<td>454,067</td>
</tr>
<tr>
<td>10</td>
<td>Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))</td>
<td>4,955,922</td>
</tr>
</tbody>
</table>

### Part XII Financial Statements and Reporting

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

<table>
<thead>
<tr>
<th>Line</th>
<th>Description</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Accounting method used to prepare the Form 990: [ ] Cash  [X] Accrual  [ ] Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>If the organization changed its method of accounting from a prior year or checked &quot;Other,&quot; explain in Schedule O.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2a</td>
<td>Were the organization's financial statements compiled or reviewed by an independent accountant?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>If &quot;Yes,&quot; 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:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>[ ] Separate basis  [ ] Consolidated basis  [ ] Both consolidated and separate basis</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>[X] Were the organization's financial statements audited by an independent accountant?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>If &quot;Yes,&quot; check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>[X] Separate basis  [ ] Consolidated basis  [ ] Both consolidated and separate basis</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>[ ] If &quot;Yes&quot; 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?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3a</td>
<td>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?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>[X] If &quot;Yes,&quot; 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</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Form 990 (2017)
**Schedule A (Form 990 or 990-EZ)**

**Public Charity Status and Public Support**

Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

Attach to Form 990 or Form 990-EZ.

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

![Image of text](https://example.com/image.png)

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

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

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

<table>
<thead>
<tr>
<th>(i) Name of supported organization</th>
<th>(ii) EIN</th>
<th>(iii) Type of organization (described on lines 1-10 above (see instructions))</th>
<th>(iv) Is the organization listed in your governing document?</th>
<th>(v) Amount of monetary support (see instructions)</th>
<th>(vi) Amount of other support (see instructions)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total

LHA For Paperwork Reduction Act Notice, see the instructions for Form 990 or 990-EZ. 732021  10-06-17 Schedule A (Form 990 or 990-EZ) 2017

11201214 758396 00012990000  2017.05010 FAMILIES OF SPINAL MUSCULAR 00012991
<table>
<thead>
<tr>
<th>Calendar year (or fiscal year beginning in)</th>
<th>(a) 2013</th>
<th>(b) 2014</th>
<th>(c) 2015</th>
<th>(d) 2016</th>
<th>(e) 2017</th>
<th>(f) Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Gifts, grants, contributions, and membership fees received. (Do not include any &quot;unusual grants.&quot;)</td>
<td>4,639,671</td>
<td>4,716,073</td>
<td>5,374,986</td>
<td>5,818,435</td>
<td>10,804,912</td>
<td>31,354,077</td>
</tr>
<tr>
<td>2 Tax revenues levied for the organization’s benefit and either paid to or expended on its behalf</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 The value of services or facilities furnished by a governmental unit to the organization without charge</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Total. Add lines 1 through 3</td>
<td>4,639,671</td>
<td>4,716,073</td>
<td>5,374,986</td>
<td>5,818,435</td>
<td>10,804,912</td>
<td>31,354,077</td>
</tr>
<tr>
<td>5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5,952,938</td>
<td></td>
</tr>
<tr>
<td>6 Public support. Subtract line 5 from line 4.</td>
<td></td>
<td></td>
<td></td>
<td>25,401,139</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Section B. Total Support

<table>
<thead>
<tr>
<th>Calendar year (or fiscal year beginning in)</th>
<th>(a) 2013</th>
<th>(b) 2014</th>
<th>(c) 2015</th>
<th>(d) 2016</th>
<th>(e) 2017</th>
<th>(f) Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 Amounts from line 4</td>
<td>4,639,671</td>
<td>4,716,073</td>
<td>5,374,986</td>
<td>5,818,435</td>
<td>10,804,912</td>
<td>31,354,077</td>
</tr>
<tr>
<td>8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources</td>
<td>3,330</td>
<td>21,373</td>
<td>19,250</td>
<td>86,367</td>
<td>138,587</td>
<td>268,907</td>
</tr>
<tr>
<td>9 Net income from unrelated business activities, whether or not the business is regularly carried on</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)</td>
<td></td>
<td></td>
<td></td>
<td>585,000</td>
<td>15,895</td>
<td>600,895</td>
</tr>
<tr>
<td>11 Total support. Add lines 7 through 10</td>
<td></td>
<td></td>
<td></td>
<td>32,223,879</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Gross receipts from related activities, etc. (see instructions)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 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</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Section C. Computation of Public Support Percentage

<table>
<thead>
<tr>
<th>Line</th>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>Public support percentage for 2017 (line 6, column (f) divided by line 11, column (f))</td>
<td>78.83%</td>
</tr>
<tr>
<td>15</td>
<td>Public support percentage from 2016 Schedule A, Part II, line 14</td>
<td>82.74%</td>
</tr>
</tbody>
</table>

### Private Foundation

- **33 1/3% support test - 2017**: If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization.
- **33 1/3% support test - 2016**: If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization.
- **10% - facts-and-circumstances test - 2017**: If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization.
- **10% - facts-and-circumstances test - 2016**: If the organization did not check a box on line 13, 16a, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization.
- **Private foundation**: If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions.
### 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

<table>
<thead>
<tr>
<th>Calendar year (or fiscal year beginning in)</th>
<th>(a) 2013</th>
<th>(b) 2014</th>
<th>(c) 2015</th>
<th>(d) 2016</th>
<th>(e) 2017</th>
<th>(f) Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Gifts, grants, contributions, and membership fees received. (Do not include any &quot;unusual grants.&quot;)</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>3 Gross receipts from activities that are not an unrelated trade or business under section 513</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>5 The value of services or facilities furnished by a governmental unit to the organization without charge</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>7a Amounts included on lines 1, 2, and 3 received from disqualified persons</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>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</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>c Add lines 7a and 7b</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>8 Public support. (Subtract line 7c from line 6)</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
</tbody>
</table>

#### Section B. Total Support

<table>
<thead>
<tr>
<th>Calendar year (or fiscal year beginning in)</th>
<th>(a) 2013</th>
<th>(b) 2014</th>
<th>(c) 2015</th>
<th>(d) 2016</th>
<th>(e) 2017</th>
<th>(f) Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>13 Total support. (Add lines 9, 10c, 11, and 12)</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
<tr>
<td>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</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
<td>..........</td>
</tr>
</tbody>
</table>

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

| Public support percentage for 2017 (line 8, column (f) divided by line 13, column (f)) | 15 % |
| Public support percentage from 2016 Schedule A, Part III, line 15 | 16 % |

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

| Investment income percentage for 2017 (line 10c, column (f) divided by line 13, column (f)) | 17 % |
| Investment income percentage from 2016 Schedule A, Part III, line 17 | 18 % |

**a 33 1/3% support tests - 2017.** 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 - 2016.** 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

---

11201214 758396 00012990000 2017.05010 FAMILIES OF SPINAL MUSCULAR 00012991
### 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

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10b</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Part IV Supporting Organizations (continued)

#### Section B. Type I Supporting Organizations

1. 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.

2. Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.

#### Section C. Type II Supporting Organizations

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

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

1. Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided?

2. Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).

3. By reason of the relationship described 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

1. Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).
   - a. The organization satisfied the Activities Test. Complete line 2 below.
   - b. The organization is the parent of each of its supported organizations. Complete line 3 below.
   - c. The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see instructions).

2. Activities Test. Answer (a) and (b) below.
   - a. Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.
   - b. Did the activities described 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.

3. Parent of Supported Organizations. Answer (a) and (b) below.
   - a. Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? Provide details in Part VI.
   - b. Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.
### Section A - Adjusted Net Income

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

### Section B - Minimum Asset Amount

<table>
<thead>
<tr>
<th>Item</th>
<th>(A) Prior Year</th>
<th>(B) Current Year (optional)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Aggregate fair market value of all non-exempt-use assets (see</td>
<td></td>
<td></td>
</tr>
<tr>
<td>instructions for short tax year or assets held for part of year):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Average monthly value of securities</td>
<td>1a</td>
<td></td>
</tr>
<tr>
<td>b. Average monthly cash balances</td>
<td>1b</td>
<td></td>
</tr>
<tr>
<td>c. Fair market value of other non-exempt-use assets</td>
<td>1c</td>
<td></td>
</tr>
<tr>
<td>d. <strong>Total</strong> (add lines 1a, 1b, and 1c)</td>
<td>1d</td>
<td></td>
</tr>
<tr>
<td>e. <strong>Discount</strong> claimed for blockage or other factors (explain in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>detail in Part VI):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Acquisition indebtedness applicable to non-exempt-use assets</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>3. Subtract line 2 from line 1d</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>4. Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>greater amount, see instructions)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Net value of non-exempt-use assets (subtract line 4 from line 3)</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>6. <strong>Multiply line 5 by .035</strong></td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>7. Recoveries of prior-year distributions</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>8. Minimum Asset Amount (add line 7 to line 6)</td>
<td>8</td>
<td></td>
</tr>
</tbody>
</table>

### Section C - Distributable Amount

<table>
<thead>
<tr>
<th>Item</th>
<th>Current Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Adjusted net income for prior year (from Section A, line 8,</td>
<td>1</td>
</tr>
<tr>
<td>Column A)</td>
<td></td>
</tr>
<tr>
<td>2. Enter 85% of line 1</td>
<td>2</td>
</tr>
<tr>
<td>3. Minimum asset amount for prior year (from Section B, line 8,</td>
<td>3</td>
</tr>
<tr>
<td>Column A)</td>
<td></td>
</tr>
<tr>
<td>4. Enter greater of line 2 or line 3</td>
<td>4</td>
</tr>
<tr>
<td>5. Income tax imposed in prior year</td>
<td>5</td>
</tr>
<tr>
<td>6. **Distributable Amount. Subtract line 5 from line 4, unless</td>
<td>6</td>
</tr>
<tr>
<td>subject to emergency temporary reduction (see instructions)</td>
<td></td>
</tr>
</tbody>
</table>

### Notes
- Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).
### Part VI

1. **Total annual distributions.** Add lines 1 through 6.
   - Excess Distributions
   - Underdistributions Pre-2017
   - Distributable Amount for 2017

2. **Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI).** See instructions.

3. **Distributable amount for 2017 from Section C, line 6**

4. **Line 8 amount divided by line 9 amount**

### Section E - Distribution Allocations (see instructions)

<table>
<thead>
<tr>
<th>Line</th>
<th>Description</th>
<th>(i) Excess Distributions</th>
<th>(ii) Underdistributions Pre-2017</th>
<th>(iii) Distributable Amount for 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Distributable amount for 2017 from Section C, line 6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Underdistributions, if any, for years prior to 2017 (reasonable cause required - explain in Part VI). See instructions.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Excess distributions carryover, if any, to 2017</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a</td>
<td>From 2013</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td>From 2014</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c</td>
<td>From 2015</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d</td>
<td>From 2016</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e</td>
<td>Total of lines 3a through e</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g</td>
<td>Applied to underdistributions of prior years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h</td>
<td>Applied to 2017 distributable amount</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i</td>
<td>Carryover from 2012 not applied (see instructions)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j</td>
<td>Remainder. Subtract lines 3g, 3h, and 3i from 3f.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Distributions for 2017 from Section D, line 7: $</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a</td>
<td>Applied to underdistributions of prior years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td>Applied to 2017 distributable amount</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c</td>
<td>Remainder. Subtract lines 4a and 4b from 4.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Remaining underdistributions for years prior to 2017, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Remaining underdistributions for 2017. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td><strong>Excess distributions carryover to 2018.</strong> Add lines 3j and 4c.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Breakdown of line 7:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a</td>
<td>Excess from 2013</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td>Excess from 2014</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c</td>
<td>Excess from 2015</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d</td>
<td>Excess from 2016</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e</td>
<td>Excess from 2017</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
** Schedule B **

*Form 990, 990-EZ, or 990-PF*

** 2017 **

<table>
<thead>
<tr>
<th>Name of the organization</th>
<th>Employer identification number</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAMILIES OF SPINAL MUSCULAR ATROPHY</td>
<td>**-***0440</td>
</tr>
</tbody>
</table>

** Organization type (check one): **

- **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) (2017)
### Part I Contributors

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

<table>
<thead>
<tr>
<th>(a) No.</th>
<th>(b) Name, address, and ZIP + 4</th>
<th>(c) Total contributions</th>
<th>(d) Type of contribution</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>$2,575,155</td>
<td>Person [X] Payroll [ ] Noncash [ ]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Complete Part II for noncash contributions.)</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>$2,419,213</td>
<td>Person [X] Payroll [ ] Noncash [ ]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Complete Part II for noncash contributions.)</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>$676,000</td>
<td>Person [X] Payroll [ ] Noncash [ ]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Complete Part II for noncash contributions.)</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td>$364,823</td>
<td>Person [X] Payroll [ ] Noncash [ ]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Complete Part II for noncash contributions.)</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>$686,010</td>
<td>Person [X] Payroll [ ] Noncash [ ]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Complete Part II for noncash contributions.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Part II Noncash Property

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

<table>
<thead>
<tr>
<th>No. from Part I</th>
<th>Description of noncash property given</th>
<th>FMV (or estimate)</th>
<th>Date received</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td><strong>$</strong></td>
<td></td>
</tr>
</tbody>
</table>

1. Description of noncash property given
2. **$**
3. Date received
4. Description of noncash property given
5. **$**
6. Date received
7. Description of noncash property given
8. **$**
9. Date received
10. Description of noncash property given
11. **$**
12. Date received
13. Description of noncash property given
14. **$**
15. Date received
16. Description of noncash property given
17. **$**
18. Date received
19. Description of noncash property given
20. **$**
21. Date received
### 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.]

<table>
<thead>
<tr>
<th>No. from Part I</th>
<th>Purpose of gift</th>
<th>Use of gift</th>
<th>Description of how gift is held</th>
<th>Transfer of gift</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Transferee's name, address, and ZIP + 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Use duplicate copies of Part III if additional space is needed.
# Political Campaign and Lobbying Activities

For Organizations Exempt From Income Tax Under section 501(c) and section 527

*Complete if the organization is described below.*  
*Attach to Form 990 or Form 990-EZ.*  
*Go to www.irs.gov/Form990 for instructions and the latest information.*

## 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 [ ]
4. a) Was a correction made?
   - [ ]
   - 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).

<table>
<thead>
<tr>
<th>(a) Name</th>
<th>(b) Address</th>
<th>(c) EIN</th>
<th>(d) Amount paid from filing organization’s funds. If none, enter 0.</th>
<th>(e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter 0.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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<tr>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Limits on Lobbying Expenditures</th>
<th>(a) Filing organization's totals</th>
<th>(b) Affiliated group totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a Total lobbying expenditures to influence public opinion (grass roots lobbying)</td>
<td>![Formula](<a href="https://latex.codecogs.com/png.latex?20%5C%25%5Ctext%7B%5C">https://latex.codecogs.com/png.latex?20\%\text{\</a> of\ \ the\ \ amount\ \ on\ \ line\ 1e.})</td>
<td>![Formula](<a href="https://latex.codecogs.com/png.latex?20%5C%25%5Ctext%7B%5C">https://latex.codecogs.com/png.latex?20\%\text{\</a> of\ \ the\ \ amount\ \ on\ \ line\ 1e.})</td>
</tr>
<tr>
<td>b Total lobbying expenditures to influence a legislative body (direct lobbying)</td>
<td>![Formula](<a href="https://latex.codecogs.com/png.latex?$100,000%5C">https://latex.codecogs.com/png.latex?$100,000\</a> \text{\ plus\ \ 15%\ \ of\ \ the\ \ excess\ \ over\ $500,000.}$)</td>
<td>![Formula](<a href="https://latex.codecogs.com/png.latex?$100,000%5C">https://latex.codecogs.com/png.latex?$100,000\</a> \text{\ plus\ \ 15%\ \ of\ \ the\ \ excess\ \ over\ $500,000.}$)</td>
</tr>
<tr>
<td>c Total lobbying expenditures (add lines 1a and 1b)</td>
<td>![Formula](<a href="https://latex.codecogs.com/png.latex?$175,000%5C">https://latex.codecogs.com/png.latex?$175,000\</a> \text{\ plus\ \ 10%\ \ of\ \ the\ \ excess\ \ over\ $1,000,000.}$)</td>
<td>![Formula](<a href="https://latex.codecogs.com/png.latex?$175,000%5C">https://latex.codecogs.com/png.latex?$175,000\</a> \text{\ plus\ \ 10%\ \ of\ \ the\ \ excess\ \ over\ $1,000,000.}$)</td>
</tr>
<tr>
<td>d Other exempt purpose expenditures</td>
<td>![Formula](<a href="https://latex.codecogs.com/png.latex?$225,000%5C">https://latex.codecogs.com/png.latex?$225,000\</a> \text{\ plus\ \ 5%\ \ of\ \ the\ \ excess\ \ over\ $1,500,000.}$)</td>
<td>![Formula](<a href="https://latex.codecogs.com/png.latex?$225,000%5C">https://latex.codecogs.com/png.latex?$225,000\</a> \text{\ plus\ \ 5%\ \ of\ \ the\ \ excess\ \ over\ $1,500,000.}$)</td>
</tr>
<tr>
<td>e Total exempt purpose expenditures (add lines 1c and 1d)</td>
<td><img src="https://latex.codecogs.com/png.latex?$1,000,000.$" alt="Formula" /></td>
<td><img src="https://latex.codecogs.com/png.latex?$1,000,000.$" alt="Formula" /></td>
</tr>
</tbody>
</table>

f Lobbying nontaxable amount. Enter the amount from the following table in both columns.

<table>
<thead>
<tr>
<th>The lobbying nontaxable amount is:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not over $500,000</td>
</tr>
<tr>
<td>Over $500,000 but not over $1,000,000</td>
</tr>
<tr>
<td>Over $1,000,000 but not over $1,500,000</td>
</tr>
<tr>
<td>Over $1,500,000 but not over $17,000,000</td>
</tr>
<tr>
<td>Over $17,000,000</td>
</tr>
</tbody>
</table>

| g Grassroots nontaxable amount (enter 25% of line 1f) | ![Formula](https://latex.codecogs.com/png.latex?20\%\text{\ of\ \ the\ \ amount\ \ on\ \ line\ 1e.}) |
| h Subtract line 1g from line 1a. If zero or less, enter 0- | ![Formula](https://latex.codecogs.com/png.latex?20\%\text{\ of\ \ the\ \ amount\ \ on\ \ line\ 1e.}) |
| i Subtract line 1f from line 1c. If zero or less, enter 0- | ![Formula](https://latex.codecogs.com/png.latex?20\%\text{\ of\ \ the\ \ amount\ \ on\ \ line\ 1e.}) |
| j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year? | ![Formula](https://latex.codecogs.com/png.latex?20\%\text{\ of\ \ the\ \ amount\ \ on\ \ line\ 1e.}) |

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.)

<table>
<thead>
<tr>
<th>Lobbying Expenditures During 4-Year Averaging Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calendar year (or fiscal year beginning in)</td>
</tr>
<tr>
<td>2a Lobbying nontaxable amount</td>
</tr>
<tr>
<td>b Lobbying ceiling amount (150% of line 2a, column(e))</td>
</tr>
<tr>
<td>c Total lobbying expenditures</td>
</tr>
<tr>
<td>d Grassroots nontaxable amount</td>
</tr>
<tr>
<td>e Grassroots ceiling amount (150% of line 2d, column (e))</td>
</tr>
<tr>
<td>f Grassroots lobbying expenditures</td>
</tr>
</tbody>
</table>

Schedule C (Form 990 or 990-EZ) 2017

FAMILIES OF SPINAL MUSCULAR ATROPHY

DBA CURE SMA

**-***0440

Page 2

11201214 758396 00012990000 2017.05010 FAMILIES OF SPINAL MUSCULAR 00012991
FAMILIES OF SPINAL MUSCULAR ATROPHY

Schedule C (Form 990 or 990-EZ) 2017  DBA CURE SMA

**--***0440  Page 3

### Part II-B
Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5788 (election under section 501(h)).

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

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(a)</td>
<td>(b)</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

1. During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:

   a. Volunteers? 
   b. Paid staff or management (include compensation in expenses reported on lines 1c through 1i)? 
   c. Media advertisements? 
   d. Mailings to members, legislators, or the public? 
   e. Publications, or published or broadcast statements? 
   f. Grants to other organizations for lobbying purposes? 
   g. Direct contact with legislators, their staffs, government officials, or a legislative body? 
   h. Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means? 
   i. Other activities? 

   j. Total, Add lines 1c through 1i

2a. Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?

   b. If "Yes," enter the amount of any tax incurred under section 4912

   c. If "Yes," enter the amount of any tax incurred by organization managers under section 4912

   d. If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?

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

1. Were substantially all (90% or more) dues received nondeductible by members?
2. Did the organization make only in-house lobbying expenditures of $2,000 or less?
3. Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year?

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

1. Dues, assessments and similar amounts from members
2. Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid).
   a. Current year
   b. Carryover from last year
   c. Total

3. Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues

4. If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditure next year?

5. Taxable amount of lobbying and political expenditures (see instructions)

### Part IV
Supplemental Information

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

**PART II-B, LINE 1**

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

---

732043 11-09-17
112051214 758396 00012990000 2017.05010 FAMILIES OF SPINAL MUSCULAR 00012991
LOBBING AND GOVERNMENT RELATIONS AND THIS STAFF MEMBER'S COMPENSATION INCLUDING TAXES AND BENEFITS TOTALED $104,958 FOR FISCAL YEAR ENDED JUNE 30, 2018.

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

1  Total number at end of year .................................................................  

2  Aggregate value of contributions to (during year)  

3  Aggregate value of grants from (during year)  

4  Aggregate value at end of year  

5  Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization’s property, subject to the organization’s exclusive legal control? ☐ Yes ☐ No  

6  Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? ☐ Yes ☐ No

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

1  Purpose(s) of conservation easements held by the organization (check all that apply).  

☐ Preservation of land for public use (e.g., recreation or education) ☐ Preservation of a historically important land area  

☐ Protection of natural habitat ☐ Preservation of a certified historic structure  

☐ Preservation of open space  

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

2a  Total number of conservation easements ...............................................  

2b  Total acreage restricted by conservation easements  

2c  Number of conservation easements on a certified historic structure included in (a)  

2d  Number of conservation easements included in (c) acquired after 7/25/06, and not on a historic structure listed in the National Register  

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

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

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

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

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

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

Part III  Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered “Yes” on Form 990, Part IV, line 8.

1a  If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items.  

b  If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:  

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

(ii) Assets included in Form 990, Part X  

2  If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items:  

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

b  Assets included in Form 990, Part X
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

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:

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>1c</td>
</tr>
<tr>
<td>1d</td>
</tr>
<tr>
<td>1e</td>
</tr>
<tr>
<td>1f</td>
</tr>
</tbody>
</table>

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.

1a Beginning of year balance

   b. Contributions

   c. Net investment earnings, gains, and losses

   d. Grants or scholarships

   e. Other expenditures for facilities and programs

   f. Administrative expenses

   g. End of year balance

<table>
<thead>
<tr>
<th>(a) Current year</th>
<th>(b) Prior year</th>
<th>(c) Two years back</th>
<th>(d) Three years back</th>
<th>(e) Four years back</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,032,313.</td>
<td>854,008.</td>
<td>741,466.</td>
<td>620,515.</td>
<td>436,946.</td>
</tr>
<tr>
<td>48,571.</td>
<td>116,736.</td>
<td>112,008.</td>
<td>109,608.</td>
<td>181,698.</td>
</tr>
<tr>
<td>58,042.</td>
<td>87,854.</td>
<td>534.</td>
<td>11,343.</td>
<td>1,871.</td>
</tr>
<tr>
<td>28,064.</td>
<td>26,285.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:
   a. Board designated or quasi-endowment 3.13%
   b. Permanent endowment 96.87%
   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:
   (i) unrelated organizations
   (ii) related organizations

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

   3b

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.

<table>
<thead>
<tr>
<th>Description of property</th>
<th>(a) Cost or other basis (investment)</th>
<th>(b) Cost or other basis (other)</th>
<th>(c) Accumulated depreciation</th>
<th>(d) Book value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a Land</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1b Buildings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1c Leasehold improvements</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1d Equipment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1e Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total, Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10c.)

   | 174,155. |

31
### 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.

<table>
<thead>
<tr>
<th>(a) Description of security or category (including name of security)</th>
<th>(b) Book value</th>
<th>(c) Method of valuation: Cost or end-of-year market value</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Financial derivatives</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) Closely-held equity interests</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3) Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(A)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(B)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(C)</td>
<td></td>
<td></td>
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<tr>
<td>(D)</td>
<td></td>
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<tr>
<td>(E)</td>
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<td>(F)</td>
<td></td>
<td></td>
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<tr>
<td>(G)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(H)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total. (Col. (b) must equal Form 990, Part X, col. (B) line 12.)

### Part VIII Investments - Program Related.
Complete if the organization answered "Yes" on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

<table>
<thead>
<tr>
<th>(a) Description of investment</th>
<th>(b) Book value</th>
<th>(c) Method of valuation: Cost or end-of-year market value</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(6)</td>
<td></td>
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<td>(7)</td>
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<td>(8)</td>
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<tr>
<td>(9)</td>
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<td></td>
</tr>
</tbody>
</table>

Total. (Col. (b) must equal Form 990, Part X, col. (B) line 13.)

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

<table>
<thead>
<tr>
<th>(a) Description</th>
<th>(b) Book value</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td></td>
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<td>(2)</td>
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<tr>
<td>(3)</td>
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<td>(4)</td>
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<td>(8)</td>
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<td>(9)</td>
<td></td>
</tr>
</tbody>
</table>

Total. (Column (b) must equal Form 990, Part X, col. (B) line 15.)

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

1. | (a) Description of liability | (b) Book value |
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Federal income taxes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) DEFERRED RENT</td>
<td>24,093</td>
<td></td>
</tr>
<tr>
<td>(3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(4)</td>
<td></td>
<td></td>
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<tr>
<td>(5)</td>
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<td>(6)</td>
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<td>(8)</td>
<td></td>
<td></td>
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<tr>
<td>(9)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total. (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 [X]
Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.

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

1. Total revenue, gains, and other support per audited financial statements

2. Amounts included on line 1 but not on Form 990, Part VIII, line 12:
   a. Net unrealized gains (losses) on investments
   b. Donated services and use of facilities
   c. Recoveries of prior year grants
   d. Other (Describe in Part XIII.)
   e. Add lines 2a through 2d

3. Subtract line 2e from line 1

4. Amounts included on Form 990, Part VIII, line 12, but not on line 1:
   a. Investment expenses not included on Form 990, Part VIII, line 7b
   b. Other (Describe in Part XIII.)
   c. Add lines 4a and 4b

5. Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12)

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

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

1. Total expenses and losses per audited financial statements

2. Amounts included on line 1 but not on Form 990, Part IX, line 25:
   a. Donated services and use of facilities
   b. Prior year adjustments
   c. Other losses
   d. Other (Describe in Part XIII.)
   e. Add lines 2a through 2d

3. Subtract line 2e from line 1

4. Amounts included on Form 990, Part IX, line 25, but not on line 1:
   a. Investment expenses not included on Form 990, Part VIII, line 7b
   b. Other (Describe in Part XIII.)
   c. Add lines 4a and 4b

5. Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18)

Part XIII Supplemental Information.

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

PART V, LINE 4:

THE ENDOWMENT FUND IS INTENDED FOR THE PURPOSE OF PROVIDING SCHOLARSHIPS WHICH WILL ENABLE CURE SMA TO WAIVE REGISTRATIONS FEES FOR ANY FAMILIES OF PATIENTS NEWLY DIAGNOSED WITH SMA TO ATTEND THE ANNUAL SMA CONFERENCE.

PART X, LINE 2:

THE ORGANIZATION FOLLOWS THE GUIDANCE IN THE FASB CODIFICATION TOPIC RELATED TO UNCERTAINTY IN INCOME TAXES WHICH PRESCRIBES A COMPREHENSIVE MODEL FOR RECOGNIZING, MEASURING, PRESENTING AND DISCLOSING IN THE FINANCIAL STATEMENTS UNCERTAIN TAX POSITIONS THAT THE ORGANIZATION HAS TAKEN OR EXPECTS TO TAKE IN ITS TAX RETURNS. UNDER THE GUIDANCE, THE ORGANIZATION MAY RECOGNIZE THE TAX BENEFIT FROM AN UNCERTAIN TAX POSITION...
ONLY IF IT IS "MORE LIKELY THAN NOT" THAT IT IS SUSTAINABLE, BASED ON ITS TECHNICAL MERITS. THE TAX BENEFITS RECOGNIZED IN THE FINANCIAL STATEMENTS FROM SUCH A POSITION SHOULD BE MEASURED BASED ON THE LARGEST BENEFIT THAT HAS A GREATER THAN 50% LIKELIHOOD OF BEING REALIZED UPON ULTIMATE SETTLEMENT WITH A TAXING AUTHORITY HAVING FULL KNOWLEDGE OF ALL RELEVANT INFORMATION. THE ORGANIZATION BELIEVES THAT IT HAS APPROPRIATE SUPPORT FOR THE POSITIONS TAKEN ON ITS RETURNS.
<table>
<thead>
<tr>
<th>(a) Region</th>
<th>(b) Number of offices in the region</th>
<th>(c) Number of employees, agents, and independent contractors in the region</th>
<th>(d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region)</th>
<th>(e) If activity listed in (d) is a program service, describe specific type of service(s) in the region</th>
<th>(f) Total expenditures for and investments in the region</th>
</tr>
</thead>
<tbody>
<tr>
<td>EUROPE (INCLUDING ICELAND &amp; GREENLAND)</td>
<td>0</td>
<td>0</td>
<td>REGION GRANTS TO RECIPIENTS IN THE REGION GRANTS</td>
<td>150,000.</td>
<td></td>
</tr>
<tr>
<td>NORTH AMERICA</td>
<td>0</td>
<td>0</td>
<td>REGION GRANTS TO RECIPIENTS IN THE REGION GRANTS</td>
<td>25,000.</td>
<td></td>
</tr>
</tbody>
</table>

3 a Sub-total .............. 0 0 0 0 0 175,000.
3 b Total from continuation sheets to Part I .............. 0 0 0 0 0 0.
3 c Totals (add lines 3a and 3b) ...................... 0 0 0 0 0 175,000.

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

Schedule F (Form 990) 2017
**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.

<table>
<thead>
<tr>
<th></th>
<th>(a) Name of organization</th>
<th>(b) IRS code section and EIN (if applicable)</th>
<th>(c) Region</th>
<th>(d) Purpose of grant</th>
<th>(e) Amount of cash grant</th>
<th>(f) Manner of cash disbursement</th>
<th>(g) Amount of noncash assistance</th>
<th>(h) Description of noncash assistance</th>
<th>(i) Method of valuation (book, FMV, appraisal, other)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>FAMILIES OF SPINAL MUSCULAR ATROPHY</strong> DBA CURE SMA **-***0440</td>
<td></td>
<td>EUROPE (INCLUDING ICELAND &amp; GREENLAND)</td>
<td>RESEARCH</td>
<td>150,000</td>
<td>WIRE TRANSFER</td>
<td>0</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>NORTH AMERICA</td>
<td>RESEARCH</td>
<td>25,000</td>
<td>WIRE TRANSFER</td>
<td>0</td>
<td></td>
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</tr>
</tbody>
</table>

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. 
3 Enter total number of other organizations or entities.
### Part III: Grants and Other Assistance to Individuals Outside the United States

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

Part III can be duplicated if additional space is needed.

<table>
<thead>
<tr>
<th>(a) Type of grant or assistance</th>
<th>(b) Region</th>
<th>(c) Number of recipients</th>
<th>(d) Amount of cash grant</th>
<th>(e) Manner of cash disbursement</th>
<th>(f) Amount of noncash assistance</th>
<th>(g) Description of noncash assistance</th>
<th>(h) Method of valuation (book, FMV, appraisal, other)</th>
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<td>Description</td>
<td>Answer</td>
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</tr>
</tbody>
</table>
| 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  
虿 No |
| 2 | Did the organization have an interest in a foreign trust during the tax year? If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; don't file with Form 990) | ☐ Yes  
虿 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  
虿 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  
虿 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  
虿 No |
| 6 | Did the organization have any operations in or related to any boycotting countries during the tax year? If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see Instructions for Form 5713; don't file with Form 990) | ☐ Yes  
虿 No |
FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA  **-***0440

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, GRANTEES 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)

**Supplemental Information Regarding Fundraising or Gaming Activities**

Complete if the organization answered "Yes" on Form 990, Part IV, line 17, 18, or 19, or if the organization entered more than $15,000 on Form 990-EZ, line 6a. 

Attach to Form 990 or Form 990-EZ. Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest instructions.

**Name of the organization**

FAMILIES OF SPINAL MUSCULAR ATROPHY

**DBA CURE SMA**

**Employer identification number**

**[** 0440**]**

**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. 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?

   a. [ ] 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

<table>
<thead>
<tr>
<th>(i) Name and address of individual or entity (fundraiser)</th>
<th>(ii) Activity</th>
<th>(iii) Did fundraiser have custody or control of contributions?</th>
<th>(iv) Gross receipts from activity</th>
<th>(v) Amount paid to (or retained by) fundraiser listed in col. (i)</th>
<th>(vi) Amount paid to (or retained by) organization</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
</tbody>
</table>

**Total**

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.

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

LHA  For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.  
Schedule G (Form 990 or 990-EZ) 2017

732081 09-13-17

11201214 758396 00012990000 2017.05010 FAMILIES OF SPINAL MUSCULAR 00012991
### 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.

<table>
<thead>
<tr>
<th>Revenue</th>
<th>(a) Event #1</th>
<th>(b) Event #2</th>
<th>(c) Other events</th>
</tr>
</thead>
<tbody>
<tr>
<td>Event</td>
<td>(event type)</td>
<td>(event type)</td>
<td>(total number)</td>
</tr>
<tr>
<td>1 Gross receipts</td>
<td>195,250</td>
<td>123,986</td>
<td>2,981,601</td>
</tr>
<tr>
<td>2 Less: Contributions</td>
<td>169,970</td>
<td>103,536</td>
<td>2,868,594</td>
</tr>
<tr>
<td>3 Gross income (line 1 minus line 2)</td>
<td>25,280</td>
<td>20,450</td>
<td>113,007</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Direct Expenses</th>
<th>(a) Bingo</th>
<th>(b) Pull tabs/instant bingo/progressive bingo</th>
<th>(c) Other gaming</th>
<th>(d) Total events (add col. (a) through col. (c))</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 Cash prizes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Noncash prizes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Rent/facility costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Food and beverages</td>
<td>19,701</td>
<td>11,267</td>
<td>30,968</td>
<td></td>
</tr>
<tr>
<td>8 Entertainment</td>
<td></td>
<td>15,800</td>
<td></td>
<td>15,800</td>
</tr>
<tr>
<td>9 Other direct expenses</td>
<td>60,320</td>
<td>10,550</td>
<td>711,725</td>
<td>782,595</td>
</tr>
<tr>
<td>10 Direct expense summary. Add lines 4 through 9 in column (d)</td>
<td></td>
<td></td>
<td></td>
<td>829,363</td>
</tr>
<tr>
<td>11 Net income summary. Subtract line 10 from line 3, column (d)</td>
<td></td>
<td></td>
<td></td>
<td>-670,626</td>
</tr>
</tbody>
</table>

### 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.

<table>
<thead>
<tr>
<th>Revenue</th>
<th>(a) Bingo</th>
<th>(b) Pull tabs/instant bingo/progressive bingo</th>
<th>(c) Other gaming</th>
<th>(d) Total gaming (add col. (a) through col. (c))</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Gross revenue</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Cash prizes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Noncash prizes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Rent/facility costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Other direct expenses</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Direct Expenses</th>
<th>(a) Bingo</th>
<th>(b) Pull tabs/instant bingo/progressive bingo</th>
<th>(c) Other gaming</th>
<th>(d) Total gaming (add col. (a) through col. (c))</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 Volunteer labor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Direct expense summary. Add lines 2 through 5 in column (d)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Net gaming income summary. Subtract line 7 from line 1, column (d)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

a Is the organization licensed to conduct gaming activities in each of these states? 

   Yes [ ] No [ ]

b If "No," explain:

10a Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year? 

   Yes [ ] No [ ]

b If "Yes," explain:

---

Schedule G (Form 990 or 990-EZ) 2017
Schedule G (Form 990 or 990-EZ) 2017

Page 3

Does the organization conduct gaming activities with nonmembers? ☐ Yes ☐ No

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

Indicate the percentage of gaming activity conducted in:

a The organization's facility %

b An outside facility %

Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name

Address

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 $.

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

Name

Address

Gaming manager information:

Name

Gaming manager compensation $.

Description of services provided

☐ Director/Officer ☐ Employee ☐ Independent contractor

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.
### 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.

<table>
<thead>
<tr>
<th>Name and address of organization or government</th>
<th>EIN</th>
<th>IRC section (if applicable)</th>
<th>Amount of cash grant</th>
<th>Amount of non-cash assistance</th>
<th>Method of valuation (book, FMV, appraisal, other)</th>
<th>Description of noncash assistance</th>
<th>Purpose of grant or assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>MEDICAL COLLEGE OF WISCONSIN, INC. 8701 WATERTOWN PLANK ROAD MILWAUKEE, WI 53226</td>
<td>**-***6261</td>
<td>501(C)(3)</td>
<td>150,000.</td>
<td>0.</td>
<td>RESEARCH - BASIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NORTHWESTERN UNIVERSITY 750 N LAKE SHORE DR. RUBLOFF 7TH FL CHICAGO, IL 60611</td>
<td>**-***7817</td>
<td>501(C)(3)</td>
<td>75,000.</td>
<td>0.</td>
<td>RESEARCH - BASIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TRUSTEES OF COLUMBIA UNIVERSITY OF NYC - P.O. BOX 29789, GENERAL POST OFFICE - NEW YORK, NY 10087</td>
<td>**-***8093</td>
<td>501(C)(3)</td>
<td>229,000.</td>
<td>0.</td>
<td>RESEARCH - BASIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>JOHN HOPKINS UNIVERSITY 12529 COLLECTIONS CENTER DRIVE CHICAGO, IL 60693</td>
<td>**-***5110</td>
<td>501(C)(3)</td>
<td>187,500.</td>
<td>0.</td>
<td>RESEARCH - BASIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OHIO STATE UNIVERSITY 1960 KENNY ROAD COLUMBUS, OH 43210</td>
<td>**-***5986</td>
<td>501(C)(3)</td>
<td>150,000.</td>
<td>0.</td>
<td>RESEARCH - BASIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MA GENERAL HOSPITAL-RESEARCH P.O. BOX 414876 BOSTON, MA 02241</td>
<td>**-***7983</td>
<td>501(C)(3)</td>
<td>150,000.</td>
<td>0.</td>
<td>RESEARCH - BASIC</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

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

25.

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990.
<table>
<thead>
<tr>
<th>(a) Name and address of organization or government</th>
<th>(b) EIN</th>
<th>(c) IRC section if applicable</th>
<th>(d) Amount of cash grant</th>
<th>(e) Amount of non-cash assistance</th>
<th>(f) Method of valuation (book, FMV, appraisal, other)</th>
<th>(g) Description of non-cash assistance</th>
<th>(h) Purpose of grant or assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNIVERSITY OF ROCHESTER/DEPT. OF NEUROLOGY - 601 ELMWOOD AVE, BOX 673 - ROCHESTER, NY 14624</td>
<td>**...**3209</td>
<td>501(C)(3)</td>
<td>150,000.</td>
<td>0.</td>
<td>RESEARCH - BASIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RTI INTERNATIONAL</td>
<td>**...**6338</td>
<td>501(C)(3)</td>
<td>47,940.</td>
<td>0.</td>
<td>RESEARCH - NEWBORN</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MI DEPT. OF HEALTH &amp; HUMAN SERVICES - P.O. BOX 30437 - LANSING, MI 48909</td>
<td>**...**0134</td>
<td>501(C)(3)</td>
<td>213,940.</td>
<td>0.</td>
<td>SCREENING</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BOARD OF REGENTS OF THE UNIVERSITY OF WI-MADISON - DRAWER 538 - MILWAUKEE, WI 53278</td>
<td>**...**6492</td>
<td>501(C)(3)</td>
<td>211,247.</td>
<td>0.</td>
<td>SCREENING</td>
<td></td>
<td></td>
</tr>
<tr>
<td>UNIVERSITY OF UTAH</td>
<td>**...**0525</td>
<td>501(C)(3)</td>
<td>150,000.</td>
<td>0.</td>
<td>SCREENING</td>
<td></td>
<td></td>
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<tr>
<td>C H NEUROLOGY FOUNDATION, INC.</td>
<td>**...**8594</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHILDREN'S HOSPITAL OF PHILADELPHIA - P.O. BOX 8500 - PHILADELPHIA, PA 19178</td>
<td>**...**2166</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OHIO STATE UNIVERSITY</td>
<td>**...**5986</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>JOHN HOPKINS UNIVERSITY</td>
<td>**...**5110</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(a) Name and address of organization or government</td>
<td>(b) EIN</td>
<td>(c) IRC section if applicable</td>
<td>(d) Amount of cash grant</td>
<td>(e) Amount of non-cash assistance</td>
<td>(f) Method of valuation (book, FMV, appraisal, other)</td>
<td>(g) Description of non-cash assistance</td>
<td>(h) Purpose of grant or assistance</td>
</tr>
<tr>
<td>---</td>
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<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>WASHINGTON UNIVERSITY SCHOOL OF MEDICINE - 700 ROSEDALE AVENUE - ST. LOUIS, MO 63112</td>
<td>**...**3611</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NEMOURS CHILDRENS HOSPITAL/NEMOURS FOUNDATION - 10140 CENTURION PARKWAY NORTH - JACKSONVILLE, FL 32256</td>
<td>**...**4433</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>COLUMBIA UNIVERSITY P.O. BOX 29789, GENERAL POST OFFICE NEW YORK, NY 10087</td>
<td>**...**8093</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LUCILE PACKARD FOUNDATION FOR CHILDREN'S HEALTH - 400 HAMILTON AVENUE, SUITE 340 - PALO ALTO, CA 94301</td>
<td>**...**8090</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GILLETTE CHILDREN’S SPECIALTY HEALTHCARE - 200 UNIVERSITY AVENUE EAST - ST. PAUL, MN 55101</td>
<td>**...**9150</td>
<td>501(C)(3)</td>
<td>25,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHILDREN’S HOSPITAL OF COLORADO BOX 285, 13123 E. 16TH AVE AURORA, CO 80045</td>
<td>**...**6760</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>REGENTS OF THE UNIVERSITY OF CALIFORNIA - 401 HILGARD AVENUE - LOS ANGELES, CA 90095</td>
<td>**...**6143</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>UNIVERSITY OF TEXAS P.O. BOX 841765 DALLAS, TX 75284</td>
<td>**...**2868</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>UNIVERSITY OF UT HEALTH BUTTERFIELD FUND - 175 N. MEDICAL DRIVE EAST - SALT LAKE CITY, UT 84132</td>
<td>**...**7384</td>
<td>501(C)(3)</td>
<td>50,000.</td>
<td>0.</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(a) Name and address of organization or government</td>
<td>(b) EIN</td>
<td>(c) IRC section if applicable</td>
<td>(d) Amount of cash grant</td>
<td>(e) Amount of non-cash assistance</td>
<td>(f) Method of valuation (book, FMV, appraisal, other)</td>
<td>(g) Description of non-cash assistance</td>
<td>(h) Purpose of grant or assistance</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
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<td>-----------------------------</td>
<td>------------------------</td>
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<td>---------------------------------</td>
<td>---------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>MA GENERAL HOSPITAL-RESEARCH</td>
<td>**-***7983</td>
<td>501(C)(3)</td>
<td>25,000.00</td>
<td>0.00</td>
<td>RESEARCH - SITE CAPACITY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P.O. BOX 414876</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BOSTON, MA 02241</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 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.

<table>
<thead>
<tr>
<th>(a) Type of grant or assistance</th>
<th>(b) Number of recipients</th>
<th>(c) Amount of cash grant</th>
<th>(d) Amount of non-cash assistance</th>
<th>(e) Method of valuation (book, FMV, appraisal, other)</th>
<th>(f) Description of noncash assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHYSICAL THERAPY STIPENDS</td>
<td>5</td>
<td>10,000.00</td>
<td>0.00</td>
<td></td>
<td>CARE PACKAGES FOR FAMILIES</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>WITH RECENTLY DIAGNOSED</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>CHILDREN</td>
</tr>
<tr>
<td>CARE PACKAGES</td>
<td>582</td>
<td>0.00</td>
<td>33,802.00</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Part IV Supplemental Information

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

**PART I, LINE 2**

**DETAILED REQUIREMENTS MADE OF RECIPIENTS IN GRANT CONTRACTS. RECIPIENTS SHALL PROVIDE THE ORGANIZATION WITH REPORTS OF THE WORK PERFORMED UNDER THIS AGREEMENT IN ACCORDANCE WITH THE FOLLOWING SCHEDULE: QUARTERLY**

**WRITTEN PROGRESS REPORTS DUE WITHIN THIRTY (30) DAYS AFTER THE END OF THE QUARTER. RECIPIENTS SHALL ALSO SUBMIT TO THE ORGANIZATION A COMPREHENSIVE FINAL REPORT WITHIN NINETY (90) DAYS OF TERMINATION OF THE RESEARCH PROJECT. FOR THE PURPOSE OF IDENTIFYING PATENTABLE INVENTIONS NOT COVERED BY PRE-EXISTING PATENTS, RECIPIENTS SHALL SUBMIT**
FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA  **-***0440

Part IV Supplemental Information

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.
Part I Questions Regarding Compensation

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

- [ ] First-class or charter travel
- [ ] Travel for companions
- [ ] Tax indemnification and gross-up payments
- [ ] Discretionary spending account
- [ ] Housing allowance or residence for personal use
- [ ] Payments for business use of personal residence
- [ ] Health or social club dues or initiation fees
- [ ] 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.

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

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

a. Receive a severance payment or change-of-control payment?

b. Participate in, or receive payment from, a supplemental nonqualified retirement plan?

c. Participate in, or receive payment from, an equity-based compensation arrangement?

If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

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

5a. 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.

5b. 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.

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

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

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

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990.
### Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

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.

<table>
<thead>
<tr>
<th>(A) Name and Title</th>
<th>(B) Breakdown of W-2 and/or 1099-MISC compensation</th>
<th>(C) Retirement and other deferred compensation</th>
<th>(D) Nontaxable benefits</th>
<th>(E) Total of columns (B)(i)-(D)</th>
<th>(F) Compensation in column (B) reported as deferred on prior Form 990</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) KENNETH HOBBY PRESIDENT</td>
<td>(i) 184,965. 0. 0. 7,692. 24,352. 217,009. 0.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) JILL JARECKI CHIEF SCIENTIFIC OFFICER</td>
<td>(i) 176,617. 8,840. 0. 6,863. 851. 193,171. 0.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
PART I, LINE 3:

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

**Part I**

**Types of Property**

<table>
<thead>
<tr>
<th>(a) Check if applicable</th>
<th>(b) Number of contributions or items contributed</th>
<th>(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g</th>
<th>(d) Method of determining noncash contribution amounts</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Art - Works of art</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Art - Historical treasures</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Art - Fractional interests</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Books and publications</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Clothing and household goods</td>
<td>X</td>
<td>31,866.</td>
<td></td>
</tr>
<tr>
<td>6 Cars and other vehicles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Boats and planes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Intellectual property</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Securities - Publicly traded</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Securities - Closely held stock</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Securities - Partnership, LLC, or trust interests</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Securities - Miscellaneous</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Qualified conservation contribution - Historic structures</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 Qualified conservation contribution - Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 Real estate - Residential</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 Real estate - Commercial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17 Real estate - Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 Collectibles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19 Food inventory</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 Drugs and medical supplies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21 Taxidermy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22 Historical artifacts</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23 Scientific specimens</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24 Archeological artifacts</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25 Other ▶ (PRINTING/SIGN)</td>
<td>x</td>
<td>11 127,243. FAIR MARKET VALUE</td>
<td></td>
</tr>
<tr>
<td>26 Other ▶ (OTHER EVENT 1)</td>
<td>x</td>
<td>81 24,422. FAIR MARKET VALUE</td>
<td></td>
</tr>
<tr>
<td>27 Other ▶ (EVENT ADMISSI)</td>
<td>x</td>
<td>64 15,875. FAIR MARKET VALUE</td>
<td></td>
</tr>
<tr>
<td>28 Other ▶ (FOOD/WATER )</td>
<td>x</td>
<td>39 10,705. FAIR MARKET VALUE</td>
<td></td>
</tr>
</tbody>
</table>

**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**

**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?**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

**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?**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

**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.**

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**LHA**

For Paperwork Reduction Act Notice, see the Instructions for Form 990.
## Part I, Other Types of Property:

### PHOTO SESSION

- **(A) Check if Applicable = X**
- **(B) Number of Contributions = 4**
- **(C) Revenue reported on Form 990, Part VIII $9295.**
- **(D) Method of Determining Revenue: Fair Market Value**

### HOTEL/AIRFARE/SPA

- **(A) Check if Applicable = X**
- **(B) Number of Contributions = 16**
- **(C) Revenue reported on Form 990, Part VIII $9163.**
- **(D) Method of Determining Revenue: Fair Market Value**

### EQUIPMENT

- **(A) Check if Applicable = X**
- **(B) Number of Contributions = 2**
- **(C) Revenue reported on Form 990, Part VIII $5000.**
- **(D) Method of Determining Revenue: Fair Market Value**

### JEWELRY

- **(A) Check if Applicable = X**
- **(B) Number of Contributions = 4**
- **(C) Revenue reported on Form 990, Part VIII $623.**
- **(D) Method of Determining Revenue: Fair Market Value**
FAMILIES OF SPINAL MUSCULAR ATROPHY
DBA CURE SMA

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

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

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

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
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 BIANNUAL 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:
FROM ITS MEDICAL ADVISORY COUNCIL. A MULTI-CENTER CLINICAL DATA REGISTRY WITHIN AN ACCREDITED SMA CARE CENTER NETWORK IS IN DEVELOPMENT. RESOURCES WERE ALSO DEVOTED TO MAINTAINING A WEBSITE LIST OF CARE CENTERS OFFERING AN FDA-APPROVED THERAPY FOR PATIENTS.

CURRENTLY, THERE IS ONE APPROVED DRUG FOR SMA, WITH ANOTHER 20 DRUG PROGRAMS IN DEVELOPMENT, INCLUDING SIX IN CLINICAL TRIALS. CURE SMA HAS FUNDED HALF OF ALL THE ONGOING DRUG PROGRAMS IN SMA.

FORM 990, PART III, LINE 4C, PROGRAM SERVICE ACCOMPLISHMENTS:
SCIENTIFIC DATA, ACCELERATING THE PACE OF RESEARCH. THE MEETING ALSO FURTERS RESEARCH BY BUILDING PRODUCTIVE COLLABORATIONS—INCLUDING CROSS-DISCIPLINARY DIALOGUE, PARTNERSHIPS, INTEGRATION OF NEW RESEARCHERS AND DRUG COMPANIES, AND EDUCATIONAL OPPORTUNITIES FOR 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 A, LINE 2:

THE BOARD CHAIR, RICHARD RUBENSTEIN AND DIRECTOR, PETER STATILE HAVE A FAMILY RELATIONSHIP.

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

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

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

MEMBERS OF THE BOARD OF DIRECTORS ARE REQUIRED TO SIGN AN ANNUAL STATEMENT DISCLOSING ANY POSSIBLE CONFLICTS OF INTEREST. ON AN ANNUAL BASIS, THE EXECUTIVE COMMITTEE REVIEWS THE CONFLICT OF INTEREST FORMS DISCLOSURE FORMS FILED BY THE TRUSTEES, OFFICERS AND EMPLOYEES FOR POTENTIAL CONFLICTS. ADDITIONALLY, ALL COVERED PERSON HAVE AN ONGOING DUTY TO DISCLOSE POTENTIAL CONFLICTS TO MANAGEMENT. POTENTIAL CONFLICTS OF INTEREST ARE PRESENTED TO THE EXECUTIVE COMMITTEE FOR REVIEW. WHERE POTENTIAL CONFLICT EXIST, A CONFLICT RESOLUTION REPORT IS CREATED AND THE TRUSTEE, OFFICER OR EMPLOYEE IS NOT ALLOWED TO PARTICIPATE IN ANY VOTE OR DISCUSSION OF THE DISCLOSED MATTER. AT THE CURRENT TIME, NO POTENTIAL CONFLICTS OF INTEREST HAVE BEEN IDENTIFIED.
FORM 990, PART VI, SECTION B, LINE 15:

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

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

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

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

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

FORM 990, PART XII, LINE 2C:

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