

**Short Form**

**Return of Organization Exempt From Income Tax**

**2017**

**Open to Public Inspection**

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/Form990EZ](http://www.irs.gov/Form990EZ) for instructions and the latest information.

Department of the Treasury  
Internal Revenue Service

**A For the 2017 calendar year, or tax year beginning** 01/01, 2017, and ending 12/31, 20 17

<b>B</b> Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	<b>C</b> Name of organization <b>MLD FOUNDATION</b>		<b>D</b> Employer identification number <b>93-1320953</b>
	Number and street (or P.O. box, if mail is not delivered to street address) Room/suite <b>21345 Miles Drive</b>		<b>E</b> Telephone number <b>503-656-4808</b>
	City or town, state or province, country, and ZIP or foreign postal code <b>West Linn, OR, 97068</b>		<b>F</b> Group Exemption Number ▶
	<b>G</b> Accounting Method: <input checked="" type="checkbox"/> Cash <input type="checkbox"/> Accrual Other (specify) ▶ _____		<b>H</b> Check <input type="checkbox"/> if the organization is not required to attach Schedule B (Form 990, 990-EZ, or 990-PF).
<b>I</b> Website: ▶ <u>MLDfoundation.org</u>			
<b>J</b> Tax-exempt status (check only one) – <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) ( ) ◀ (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527			
<b>K</b> Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other _____			
<b>L</b> Add lines 5b, 6c, and 7b to line 9 to determine gross receipts. If gross receipts are \$200,000 or more, or if total assets (Part II, column (B) below) are \$500,000 or more, file Form 990 instead of Form 990-EZ . . . . . ▶ \$ <b>92,063</b>			

**Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances** (see the instructions for Part I)

Check if the organization used Schedule O to respond to any question in this Part I

<b>Revenue</b>	<b>1</b>	Contributions, gifts, grants, and similar amounts received . . . . .	<b>1</b>		<b>92,050</b>
	<b>2</b>	Program service revenue including government fees and contracts . . . . .	<b>2</b>		<b>0</b>
	<b>3</b>	Membership dues and assessments . . . . .	<b>3</b>		<b>0</b>
	<b>4</b>	Investment income . . . . .	<b>4</b>		<b>13</b>
	<b>5a</b>	Gross amount from sale of assets other than inventory . . . . .	<b>5a</b>	<b>0</b>	
	<b>b</b>	Less: cost or other basis and sales expenses . . . . .	<b>5b</b>	<b>0</b>	
	<b>c</b>	Gain or (loss) from sale of assets other than inventory (Subtract line 5b from line 5a) . . . . .	<b>5c</b>		<b>0</b>
	<b>6</b>	Gaming and fundraising events			
	<b>a</b>	Gross income from gaming (attach Schedule G if greater than \$15,000) . . . . .	<b>6a</b>	<b>0</b>	
	<b>b</b>	Gross income from fundraising events (not including \$ <u>0</u> of contributions from fundraising events reported on line 1) (attach Schedule G if the sum of such gross income and contributions exceeds \$15,000) . . . . .	<b>6b</b>	<b>0</b>	
<b>c</b>	Less: direct expenses from gaming and fundraising events . . . . .	<b>6c</b>	<b>0</b>		
<b>d</b>	Net income or (loss) from gaming and fundraising events (add lines 6a and 6b and subtract line 6c) . . . . .	<b>6d</b>		<b>0</b>	
<b>7a</b>	Gross sales of inventory, less returns and allowances . . . . .	<b>7a</b>	<b>0</b>		
<b>b</b>	Less: cost of goods sold . . . . .	<b>7b</b>	<b>0</b>		
<b>c</b>	Gross profit or (loss) from sales of inventory (Subtract line 7b from line 7a) . . . . .	<b>7c</b>		<b>0</b>	
<b>8</b>	Other revenue (describe in Schedule O) . . . . .	<b>8</b>		<b>0</b>	
<b>9</b>	<b>Total revenue.</b> Add lines 1, 2, 3, 4, 5c, 6d, 7c, and 8 . . . . . ▶	<b>9</b>		<b>92,063</b>	
<b>Expenses</b>	<b>10</b>	Grants and similar amounts paid (list in Schedule O) . . . . .	<b>10</b>		<b>13,465</b>
	<b>11</b>	Benefits paid to or for members . . . . .	<b>11</b>		<b>0</b>
	<b>12</b>	Salaries, other compensation, and employee benefits . . . . .	<b>12</b>		<b>0</b>
	<b>13</b>	Professional fees and other payments to independent contractors . . . . .	<b>13</b>		<b>602</b>
	<b>14</b>	Occupancy, rent, utilities, and maintenance . . . . .	<b>14</b>		<b>7,095</b>
	<b>15</b>	Printing, publications, postage, and shipping . . . . .	<b>15</b>		<b>500</b>
	<b>16</b>	Other expenses (describe in Schedule O) <u>.See Schedule O, Statement 1</u> . . . . .	<b>16</b>		<b>96,275</b>
<b>17</b>	<b>Total expenses.</b> Add lines 10 through 16 . . . . . ▶	<b>17</b>		<b>117,937</b>	
<b>Net Assets</b>	<b>18</b>	Excess or (deficit) for the year (Subtract line 17 from line 9) . . . . .	<b>18</b>		<b>-25,874</b>
	<b>19</b>	Net assets or fund balances at beginning of year (from line 27, column (A)) (must agree with end-of-year figure reported on prior year's return) . . . . .	<b>19</b>		<b>51,598</b>
	<b>20</b>	Other changes in net assets or fund balances (explain in Schedule O) . . . . .	<b>20</b>		<b>0</b>
	<b>21</b>	Net assets or fund balances at end of year. Combine lines 18 through 20 . . . . . ▶	<b>21</b>		<b>25,724</b>

**Part II Balance Sheets** (see the instructions for Part II)

Check if the organization used Schedule O to respond to any question in this Part II

		(A) Beginning of year	(B) End of year	
<b>22</b>	Cash, savings, and investments	<b>56,697</b>	<b>22</b>	<b>25,813</b>
<b>23</b>	Land and buildings	<b>0</b>	<b>23</b>	<b>0</b>
<b>24</b>	Other assets (describe in Schedule O)	<b>0</b>	<b>24</b>	<b>0</b>
<b>25</b>	<b>Total assets</b>	<b>56,697</b>	<b>25</b>	<b>25,813</b>
<b>26</b>	<b>Total liabilities</b> (describe in Schedule O)	<b>5,099</b>	<b>26</b>	<b>89</b>
<b>27</b>	<b>Net assets or fund balances</b> (line 27 of column (B) must agree with line 21)	<b>51,598</b>	<b>27</b>	<b>25,724</b>

**Part III Statement of Program Service Accomplishments** (see the instructions for Part III)

Check if the organization used Schedule O to respond to any question in this Part III

What is the organization's primary exempt purpose? **See Schedule O, Statement 2**

Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. In a clear and concise manner, describe the services provided, the number of persons benefited, and other relevant information for each program title.

**Expenses**  
(Required for section 501(c)(3) and 501(c)(4) organizations; optional for others.)

<b>28</b>	<b>COMPASSION &amp; EDUCATION ... Organized and hosted MLD Family Conference(tm) in Plymouth Meeting, PA with 76 people in attendance. Brought together families, researchers, doctors, service providers and</b> <b>(Continued on Schedule O, Statement 3)</b> (Grants \$ <b>24,750</b> ) If this amount includes foreign grants, check here <input type="checkbox"/>	<b>28a</b>	<b>53,820</b>
<b>29</b>	<b>INFLUENCE RESEARCH &amp; AWARENESS - Attended medical and scientific conferences including the NIH/RDCRN-Lysosomal Disease Network's WORLD meeting, facilitated and attended GLIA meeting, visited</b> <b>(Continued on Schedule O, Statement 4)</b> (Grants \$ <b>0</b> ) If this amount includes foreign grants, check here <input type="checkbox"/>	<b>29a</b>	<b>28,792</b>
<b>30</b>	<b>COMPASSION ... MLD Family Compassion Fund(tm) and Compassion grants support many families. Meet with families and small family groups where a MLD Family Conference is not possible. These visits and</b> <b>(Continued on Schedule O, Statement 5)</b> (Grants \$ <b>0</b> ) If this amount includes foreign grants, check here <input type="checkbox"/>	<b>30a</b>	<b>15,354</b>
<b>31</b>	Other program services (describe in Schedule O) <b>See Schedule O, Statement 6.</b> (Grants \$ <b>0</b> ) If this amount includes foreign grants, check here <input type="checkbox"/>	<b>31a</b>	<b>2,714</b>
<b>32</b>	<b>Total program service expenses</b> (add lines 28a through 31a)	<b>32</b>	<b>100,680</b>

**Part IV List of Officers, Directors, Trustees, and Key Employees** (list each one even if not compensated—see the instructions for Part IV)

Check if the organization used Schedule O to respond to any question in this Part IV

(a) Name and title	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC) (if not paid, enter -0-)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
<b>Christine Hoffmann</b> Director	<b>2</b>	<b>0</b>	<b>0</b>	<b>0</b>
<b>Rob Teach</b> Director	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>
<b>Marc Patterson MD</b> Director	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>
<b>Wilson Smith</b> Director	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>
<b>Teryn Suhr</b> Executive Director	<b>20</b>	<b>0</b>	<b>0</b>	<b>0</b>
<b>Dean Suhr</b> President	<b>35</b>	<b>0</b>	<b>0</b>	<b>0</b>

Part V Other Information (Note the Schedule A and personal benefit contract statement requirements in the instructions for Part V.) Check if the organization used Schedule O to respond to any question in this Part V

		Yes	No
33	Did the organization engage in any significant activity not previously reported to the IRS? If "Yes," provide a detailed description of each activity in Schedule O		<input checked="" type="checkbox"/>
34	Were any significant changes made to the organizing or governing documents? If "Yes," attach a conformed copy of the amended documents if they reflect a change to the organization's name. Otherwise, explain the change on Schedule O (see instructions)		<input checked="" type="checkbox"/>
35a	Did the organization have unrelated business gross income of \$1,000 or more during the year from business activities (such as those reported on lines 2, 6a, and 7a, among others)?		<input checked="" type="checkbox"/>
b	If "Yes" to line 35a, has the organization filed a Form 990-T for the year? If "No," provide an explanation in Schedule O		
35c	Was the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization subject to section 6033(e) notice, reporting, and proxy tax requirements during the year? If "Yes," complete Schedule C, Part III		<input checked="" type="checkbox"/>
36	Did the organization undergo a liquidation, dissolution, termination, or significant disposition of net assets during the year? If "Yes," complete applicable parts of Schedule N		<input checked="" type="checkbox"/>
37a	Enter amount of political expenditures, direct or indirect, as described in the instructions ▶ <b>37a</b> 0		
b	Did the organization file Form 1120-POL for this year?		<input checked="" type="checkbox"/>
38a	Did the organization borrow from, or make any loans to, any officer, director, trustee, or key employee or were any such loans made in a prior year and still outstanding at the end of the tax year covered by this return?		<input checked="" type="checkbox"/>
b	If "Yes," complete Schedule L, Part II and enter the total amount involved <b>38b</b>		
39	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on line 9 <b>39a</b>		
b	Gross receipts, included on line 9, for public use of club facilities <b>39b</b>		
40a	Section 501(c)(3) organizations. Enter amount of tax imposed on the organization during the year under: section 4911 ▶ 0 ; section 4912 ▶ 0 ; section 4955 ▶ 0		
b	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year, or did it engage in an excess benefit transaction in a prior year that has not been reported on any of its prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I		<input checked="" type="checkbox"/>
c	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958 ▶ 0		
d	Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Enter amount of tax on line 40c reimbursed by the organization ▶ 0		
e	All organizations. At any time during the tax year, was the organization a party to a prohibited tax shelter transaction? If "Yes," complete Form 8886-T		<input checked="" type="checkbox"/>
41	List the states with which a copy of this return is filed ▶ OR		
42a	The organization's books are in care of ▶ Dean Suhr Telephone no. ▶ 503-656-4808 Located at ▶ 21345 Miles Drive, West Linn, OR 97068 ZIP + 4 ▶ 97068		
b	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)? If "Yes," enter the name of the foreign country: ▶ See the instructions for exceptions and filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).	Yes	No
42b			<input checked="" type="checkbox"/>
c	At any time during the calendar year, did the organization maintain an office outside the United States? If "Yes," enter the name of the foreign country: ▶		<input checked="" type="checkbox"/>
42c			<input checked="" type="checkbox"/>
43	Section 4947(a)(1) nonexempt charitable trusts filing Form 990-EZ in lieu of Form 1041—Check here and enter the amount of tax-exempt interest received or accrued during the tax year ▶ 43		<input type="checkbox"/>
44a	Did the organization maintain any donor advised funds during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ		<input checked="" type="checkbox"/>
b	Did the organization operate one or more hospital facilities during the year? If "Yes," Form 990 must be completed instead of Form 990-EZ		<input checked="" type="checkbox"/>
44b			<input checked="" type="checkbox"/>
c	Did the organization receive any payments for indoor tanning services during the year?		<input checked="" type="checkbox"/>
44c			<input checked="" type="checkbox"/>
d	If "Yes" to line 44c, has the organization filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O		
44d			
45a	Did the organization have a controlled entity within the meaning of section 512(b)(13)?		<input checked="" type="checkbox"/>
b	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," Form 990 and Schedule R may need to be completed instead of Form 990-EZ (see instructions)		<input checked="" type="checkbox"/>
45b			<input checked="" type="checkbox"/>

	<b>Yes</b>	<b>No</b>
<b>46</b> Did the organization engage, directly or indirectly, in political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I . . . . .	46	<input checked="" type="checkbox"/>

**Part VI Section 501(c)(3) organizations only**

All section 501(c)(3) organizations must answer questions 47-49b and 52, and complete the tables for lines 50 and 51.

Check if the organization used Schedule O to respond to any question in this Part VI . . . . .

	<b>Yes</b>	<b>No</b>
<b>47</b> 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 . . . . .	47	<input checked="" type="checkbox"/>
<b>48</b> Is the organization a school as described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E . . . . .	48	<input checked="" type="checkbox"/>
<b>49a</b> Did the organization make any transfers to an exempt non-charitable related organization? . . . . .	49a	<input checked="" type="checkbox"/>
<b>b</b> If "Yes," was the related organization a section 527 organization? . . . . .	49b	<input type="checkbox"/>

**50** Complete this table for the organization's five highest compensated employees (other than officers, directors, trustees, and key employees) who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and title of each employee	(b) Average hours per week devoted to position	(c) Reportable compensation (Forms W-2/1099-MISC)	(d) Health benefits, contributions to employee benefit plans, and deferred compensation	(e) Estimated amount of other compensation
None				

**f** Total number of other employees paid over \$100,000 . . . . . ▶ \_\_\_\_\_


**51** Complete this table for the organization's five highest compensated independent contractors who each received more than \$100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and business address of each independent contractor	(b) Type of service	(c) Compensation
None		

**d** Total number of other independent contractors each receiving over \$100,000 . . . . . ▶ \_\_\_\_\_

**52** Did the organization complete Schedule A? **Note:** All section 501(c)(3) organizations must attach a completed Schedule A . . . . .  **Yes**  **No**

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

<b>Sign Here</b>		Date
	Dean Suhr, President Type or print name and title	

<b>Paid Preparer Use Only</b>	Print/Type preparer's name	Preparer's signature	Date	Check <input type="checkbox"/> if self-employed	PTIN
	Firm's name ▶	Firm's EIN ▶			
	Firm's address ▶	Phone no. ▶			

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

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

Department of the Treasury  
Internal Revenue Service

**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](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

**2017**

**Open to Public Inspection**

Name of the organization <b>MLD FOUNDATION</b>	Employer identification number <b>93-1320953</b>
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**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<sup>1</sup>/<sub>3</sub>% 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<sup>1</sup>/<sub>3</sub>% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 11  An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12  An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2)**. See **section 509(a)(3)**. Check the box 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).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1–10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
(A)						
(B)						
(C)						
(D)						
(E)						
<b>Total</b>						

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

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

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ►	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") . . . . .						
<b>2</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . . .						
<b>3</b> The value of services or facilities furnished by a governmental unit to the organization without charge . . . . .						
<b>4 Total.</b> Add lines 1 through 3 . . . . .						
<b>5</b> The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f) . . . . .						
<b>6 Public support.</b> Subtract line 5 from line 4						

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ►	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
<b>7</b> Amounts from line 4 . . . . .						
<b>8</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources . . . . .						
<b>9</b> Net income from unrelated business activities, whether or not the business is regularly carried on . . . . .						
<b>10</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . . .						
<b>11 Total support.</b> Add lines 7 through 10						
<b>12</b> Gross receipts from related activities, etc. (see instructions) . . . . .					<b>12</b>	
<b>13 First five years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and <b>stop here</b> . . . . .						<input type="checkbox"/>

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

<b>14</b> Public support percentage for 2017 (line 6, column (f) divided by line 11, column (f)) . . . . .	<b>14</b>	%
<b>15</b> Public support percentage from 2016 Schedule A, Part II, line 14 . . . . .	<b>15</b>	%
<b>16a 33 1/3% support test—2017.</b> If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization . . . . .		<input type="checkbox"/>
<b>b 33 1/3% support test—2016.</b> If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and <b>stop here.</b> The organization qualifies as a publicly supported organization . . . . .		<input type="checkbox"/>
<b>17a 10%-facts-and-circumstances test—2017.</b> If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and <b>stop here.</b> Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization . . . . .		<input type="checkbox"/>
<b>b 10%-facts-and-circumstances test—2016.</b> If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and <b>stop here.</b> Explain in Part VI how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization . . . . .		<input type="checkbox"/>
<b>18 Private foundation.</b> If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions . . . . .		<input type="checkbox"/>

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

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

**Section A. Public Support**

Calendar year (or fiscal year beginning in) ►	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
<b>1</b> Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	116,108	150,170	157,206	152,548	93,267	669,299
<b>2</b> Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose . . . .	1,132	778	0	0	0	1,910
<b>3</b> Gross receipts from activities that are not an unrelated trade or business under section 513	0	0	0	0	0	0
<b>4</b> Tax revenues levied for the organization's benefit and either paid to or expended on its behalf . . . .	0	0	0	0	0	0
<b>5</b> The value of services or facilities furnished by a governmental unit to the organization without charge . . . .	0	0	0	0	0	0
<b>6 Total.</b> Add lines 1 through 5 . . . .	117,240	150,948	157,206	152,548	93,267	671,209
<b>7a</b> Amounts included on lines 1, 2, and 3 received from disqualified persons . . . .	0	0	0	0	0	0
<b>b</b> Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year	0	0	0	6,214	10,958	17,172
<b>c</b> Add lines 7a and 7b . . . .	0	0	0	6,214	10,958	17,172
<b>8 Public support.</b> (Subtract line 7c from line 6.) . . . .						654,037

**Section B. Total Support**

Calendar year (or fiscal year beginning in) ►	(a) 2013	(b) 2014	(c) 2015	(d) 2016	(e) 2017	(f) Total
<b>9</b> Amounts from line 6 . . . .	117,240	150,948	157,206	152,548	93,267	671,209
<b>10a</b> Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources . . . .	21	18	30	15	13	97
<b>b</b> Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 . . . .	0	0	0	0	0	0
<b>c</b> Add lines 10a and 10b . . . .	21	18	30	15	13	97
<b>11</b> Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on	0	0	0	0	0	0
<b>12</b> Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) . . . .	0	0	0	0	0	0
<b>13 Total support.</b> (Add lines 9, 10c, 11, and 12.) . . . .	117,261	150,966	157,236	152,563	93,280	671,306
<b>14 First five years.</b> If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and <b>stop here</b> . . . .						<input type="checkbox"/>

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

<b>15</b> Public support percentage for 2017 (line 8, column (f) divided by line 13, column (f)) . . . .	15	97.43 %
<b>16</b> Public support percentage from 2016 Schedule A, Part III, line 15 . . . .	16	99.03 %

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

<b>17</b> Investment income percentage for <b>2017</b> (line 10c, column (f) divided by line 13, column (f)) . . . .	17	0.01 %
<b>18</b> Investment income percentage from <b>2016</b> Schedule A, Part III, line 17 . . . .	18	0.02 %
<b>19a 33 1/3% support tests—2017.</b> 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 <b>stop here.</b> The organization qualifies as a publicly supported organization . . . .		<input checked="" type="checkbox"/>
<b>b 33 1/3% support tests—2016.</b> 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 <b>stop here.</b> The organization qualifies as a publicly supported organization . . . .		<input type="checkbox"/>
<b>20 Private foundation.</b> If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions . . . .		<input type="checkbox"/>

**Part IV Supporting Organizations**

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

**Section A. All Supporting Organizations**

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



**Part IV Supporting Organizations** (continued)

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

**Section B. Type I Supporting Organizations**

	Yes	No
<b>1</b> Did the directors, trustees, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the tax year? <i>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.</i>	<b>1</b>	
<b>2</b> Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? <i>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.</i>	<b>2</b>	

**Section C. Type II Supporting Organizations**

	Yes	No
<b>1</b> Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>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).</i>	<b>1</b>	

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

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

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

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

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

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

<b>Section A - Adjusted Net Income</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b> Net short-term capital gain	<b>1</b>		
<b>2</b> Recoveries of prior-year distributions	<b>2</b>		
<b>3</b> Other gross income (see instructions)	<b>3</b>		
<b>4</b> Add lines 1 through 3.	<b>4</b>		
<b>5</b> Depreciation and depletion	<b>5</b>		
<b>6</b> Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	<b>6</b>		
<b>7</b> Other expenses (see instructions)	<b>7</b>		
<b>8 Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4).	<b>8</b>		
<b>Section B - Minimum Asset Amount</b>		(A) Prior Year	(B) Current Year (optional)
<b>1</b> Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):			
<b>a</b> Average monthly value of securities	<b>1a</b>		
<b>b</b> Average monthly cash balances	<b>1b</b>		
<b>c</b> Fair market value of other non-exempt-use assets	<b>1c</b>		
<b>d Total</b> (add lines 1a, 1b, and 1c)	<b>1d</b>		
<b>e Discount</b> claimed for blockage or other factors (explain in detail in <b>Part VI</b> ):			
<b>2</b> Acquisition indebtedness applicable to non-exempt-use assets	<b>2</b>		
<b>3</b> Subtract line 2 from line 1d.	<b>3</b>		
<b>4</b> Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount, see instructions).	<b>4</b>		
<b>5</b> Net value of non-exempt-use assets (subtract line 4 from line 3)	<b>5</b>		
<b>6</b> Multiply line 5 by .035.	<b>6</b>		
<b>7</b> Recoveries of prior-year distributions	<b>7</b>		
<b>8 Minimum Asset Amount</b> (add line 7 to line 6)	<b>8</b>		
<b>Section C - Distributable Amount</b>			Current Year
<b>1</b> Adjusted net income for prior year (from Section A, line 8, Column A)	<b>1</b>		
<b>2</b> Enter 85% of line 1.	<b>2</b>		
<b>3</b> Minimum asset amount for prior year (from Section B, line 8, Column A)	<b>3</b>		
<b>4</b> Enter greater of line 2 or line 3.	<b>4</b>		
<b>5</b> Income tax imposed in prior year	<b>5</b>		
<b>6 Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	<b>6</b>		
<b>7</b> <input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).			

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

<b>Section D - Distributions</b>	<b>Current Year</b>
<b>1</b> Amounts paid to supported organizations to accomplish exempt purposes	
<b>2</b> Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	
<b>3</b> Administrative expenses paid to accomplish exempt purposes of supported organizations	
<b>4</b> Amounts paid to acquire exempt-use assets	
<b>5</b> Qualified set-aside amounts (prior IRS approval required)	
<b>6</b> Other distributions (describe in <b>Part VI</b> ). See instructions.	
<b>7 Total annual distributions.</b> Add lines 1 through 6.	
<b>8</b> Distributions to attentive supported organizations to which the organization is responsive (provide details in <b>Part VI</b> ). See instructions.	
<b>9</b> Distributable amount for 2017 from Section C, line 6	
<b>10</b> Line 8 amount divided by line 9 amount	

<b>Section E - Distribution Allocations (see instructions)</b>	<b>(i) Excess Distributions</b>	<b>(ii) Underdistributions Pre-2017</b>	<b>(iii) Distributable Amount for 2017</b>
<b>1</b> Distributable amount for 2017 from Section C, line 6			
<b>2</b> Underdistributions, if any, for years prior to 2017 (reasonable cause required—explain in <b>Part VI</b> ). See instructions.			
<b>3</b> Excess distributions carryover, if any, to 2017			
<b>a</b>			
<b>b From 2013</b> . . . . .			
<b>c From 2014</b> . . . . .			
<b>d From 2015</b> . . . . .			
<b>e From 2016</b> . . . . .			
<b>f Total</b> of lines 3a through e			
<b>g</b> Applied to underdistributions of prior years			
<b>h</b> Applied to 2017 distributable amount			
<b>i</b> Carryover from 2012 not applied (see instructions)			
<b>j</b> Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
<b>4</b> Distributions for 2017 from Section D, line 7: <span style="float: right;">\$</span>			
<b>a</b> Applied to underdistributions of prior years			
<b>b</b> Applied to 2017 distributable amount			
<b>c</b> Remainder. Subtract lines 4a and 4b from 4.			
<b>5</b> Remaining underdistributions for years prior to 2017, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>6</b> Remaining underdistributions for 2017. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in <b>Part VI</b> . See instructions.			
<b>7 Excess distributions carryover to 2018.</b> Add lines 3j and 4c.			
<b>8</b> Breakdown of line 7:			
<b>a Excess from 2013</b> . . . . .			
<b>b</b> Excess from 2014 . . . . .			
<b>c</b> Excess from 2015 . . . . .			
<b>d</b> Excess from 2016 . . . . .			
<b>e</b> Excess from 2017 . . . . .			



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

Department of the Treasury  
Internal Revenue Service

**Supplemental Information to Form 990 or 990-EZ**

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

▶ Attach to Form 990 or 990-EZ.

▶ Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

OMB No. 1545-0047

**2017**

**Open to Public  
Inspection**

Name of the organization

**MLD FOUNDATION**

Employer identification number

**93-1320953**

**Form 990-EZ, Part II, Line 26 - Current liabilities**

Lined area for supplemental information.

Other Expenses Structured Explanation

Description	Amount
Awareness	3,342
Bank fees	694
Family Conference Expenses	53,797
Conferences research policy awareness	26,364
Education	881
Government fees	256
Research	10,941
<b>Total:</b>	<b>96,275</b>

**Primary Exempt Purpose**

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**Primary Exempt Purpose**

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MLD Foundation works with families, researchers, regulators, industry, and policy makers to improve the quality of life for those with MLD including standards of clinical care and clinical research excellence, develop and improve therapies for MLD, and influence & fund research for a cure.

Metachromatic leukodystrophy (MLD) is a rare genetic neuro-metabolic degenerative terminal condition affecting people, predominantly infants and children, throughout the world. Our slogan, "We C.A.R.E."(tm) reflects our mission of Compassion, Awareness, Research and Education. Today there are not adequate therapies and there is no cure. Clinical care and diagnostics, including newborn screening, are improving but have much more to improve upon. The MLD Foundation was formed in May 2001.

**First Program Service Accomplishments Description**

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**Description**

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other resources for two-day meetings with the common goal of providing insight to improving the quality of life for those with MLD and their caregivers. We share research and clinical trial updates, answer questions, and allocate the bulk of the time to facilitating the building relationships between the families. (approx 30 families directly affected - hundreds more when they view the live webcast and conference videos freely posted on the MLD Foundation website). Visited numerous other families in their hometowns during our other travels.



**Second Program Service Accomplishments Description**

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**Description**

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the FDA, NIH, NINDS, World RARE Disease Day events in DC, HHS/NICHHD Newborn Screening meetings, organized two RUSP Roundtable meetings (newborn screening policy and technology), continued MLD newborn screening pilot study, transferred a set of mice from the US MLD mouse colony that we established to a new biotech firm, and visited researchers at their home facilities representing the interests of MLD families and other researchers. Supported global clinical trial recruiting and development of MLD standards of care. Working towards standards for clinical research excellence to improve quality of life for patients/families and further lysosomal and leukodystrophy research.

**Third Program Service Accomplishments Description**

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**Description**

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Third Program Service Accomplishments Description MLD Family Gatherings(tm) bring families in a geography together to meet each other - often for the very first time to educate and further connect those families with the MLD Foundation and other families. We share research and clinical trial updates, answer questions, and allocate the bulk of the time to building relationships between the families. (approx 20 families). Direct Quality of Life case management for several families. Direct family financial support through our independently managed MLD Family Compassion Fund.

## Other Program Service Accomplishments

Description	Grants And Allocations	Includes Foreign Grants	Program Service Expenses
<p>COMPASSION &amp; RESEARCH - PATIENT POWERED SUPPORT AND RESEARCH ... The MLD Family Discussion List is the world's largest electronic gathering of families affected by MLD. They share experiences, compassion, support, and ideas with each other to provide the highest quality of life to those affected by MLD. Partnered with Genetic Alliance on a PCORI funded patient powered research network which will result in a next generation registry launch to supplement the MLD Family Profile registry which captures family demographic information and is quickly becoming the largest international database of MLD family histories. This data will be compiled and shared in a de-identified manner to improve MLD research, natural history studies, and clinical trials. Also includes electronic and paper publications. (700+ families)</p>	0		1,549
<p>EDUCATION ... Visited NIH, FDA, Capitol Hill to educate on issues of importance to MLD affected families, researchers, and industry. World RARE disease day events, FDA rare disease workshops, HHS/ACHDNC (newborn screening) testimony. Focus on the implementation of electronic medical records, orphan disease research, registries, and newborn screening for rare diseases. Host numerous websites to inform, educate, influence, and support MLD families and research.</p>	0		881
<p>Rare Honor/Gifting With Purpose ... licensed patent and supporting implementation of fund raising platform for MLD Foundation. Have rights to make available to all 501c3s with a royalty stream to MLD Foundation.</p>	0		284
<b>Total:</b>			<b>2,714</b>