

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.
- Information about Form 990 and its instructions is at www.irs.gov/form990.

2013

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

A For the 2013 calendar year, or tax year beginning		, 2013, and ending	
B Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Organization Name DYSTONIA MEDICAL RESEARCH FOUNDATION ONE EAST WACKER DRIVE #2810 CHICAGO, IL 60601-1905		D Employer Identification Number 95-3378526
	F Name and address of principal officer: JANET HIESHETTER SAME AS C ABOVE		E Telephone number 312-755-0198
I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		G Gross receipts \$ 2,175,786.	
J Website: WWW.DYSTONIA-FOUNDATION.ORG		H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	
K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other		H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If 'No,' attach a list. (see instructions)	
L Year of formation: 1977		M State of legal domicile: CA	
H(c) Group exemption number			

Part I Summary		Prior Year	Current Year
Activities & Governance	1 Briefly describe the organization's mission or most significant activities: <u>THE MISSION OF THE DMRF IS TO ADVANCE RESEARCH FOR MORE EFFECTIVE TREATMENTS AND ULTIMATELY A CURE FOR DYSTONIA, TO PROMOTE AWARENESS AND EDUCATION AND TO SUPPORT THE WELL BEING OF DYSTONIA AFFECTED INDIVIDUALS AND FAMILIES.</u>		
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	3 Number of voting members of the governing body (Part VI, line 1a)	3	18
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	18
	5 Total number of individuals employed in calendar year 2013 (Part V, line 2a)	5	9
	6 Total number of volunteers (estimate if necessary)	6	640
	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 1h)	2,899,082.	2,140,332.
	9 Program service revenue (Part VIII, line 2g)		
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	3,726.	3,034.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	5,052.	7,594.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	2,907,860.	2,150,960.
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	1,352,623.	1,047,225.
	14 Benefits paid to or for members (Part IX, column (A), line 4)		
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	810,118.	814,993.
	16a Professional fundraising fees (Part IX, column (A), line 11e)		
	b Total fundraising expenses (Part IX, column (D), line 25)	212,282.	
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	945,541.	822,470.	
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	3,108,282.	2,684,688.	
19 Revenue less expenses. Subtract line 18 from line 12	-200,422.	-533,728.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 3,676,384.	End of Year 2,992,639.
	21 Total liabilities (Part X, line 26)	1,254,120.	1,104,103.
	22 Net assets or fund balances. Subtract line 21 from line 20	2,422,264.	1,888,536.

Part II Signature Block

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

Sign Here	Signature of officer	Date	
	MARK RUDOLPH Type or print name and title.	TREASURER	
Paid Preparer Use Only	Print/Type preparer's name	Preparer's signature	Date
	GAIL L. MATHEWS	GAIL L. MATHEWS	
	Firm's name	Firm's address	Firm's EIN
GAIL L. MATHEWS & ASSOCIATES LLC	800 ROOSEVELT RD BLDG A, STE 320 GLEN ELLYN, IL 60137	27-2036685	27-2036685
		Phone no.	630-793-9390

May the IRS discuss this return with the preparer shown above? (see instructions) Yes No

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission:

SEE SCHEDULE O

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

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

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

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

4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses. Section 501(c)(3) and 501(c)(4) organizations and section 4947(a)(1) trusts are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 1,639,673. including grants of \$ 1,047,225.) (Revenue \$)

SEE SCHEDULE O

4b (Code:) (Expenses \$ 353,712. including grants of \$) (Revenue \$)

SEE SCHEDULE O

4c (Code:) (Expenses \$ 152,160. including grants of \$) (Revenue \$)

SEE SCHEDULE O

4d Other program services. (Describe in Schedule O.) SEE SCHEDULE O

(Expenses \$ 137,288. including grants of \$) (Revenue \$)

4e Total program service expenses 2,282,833.

Part IV Checklist of Required Schedules

	Yes	No
1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? If 'Yes,' complete Schedule A.....	X	
2 Is the organization required to complete Schedule B, Schedule of Contributors (see instructions)?.....	X	
3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If 'Yes,' complete Schedule C, Part I.....		X
4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? If 'Yes,' complete Schedule C, Part II.....	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.....		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.....		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.....		X
8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? If 'Yes,' complete Schedule D, Part III.....		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.....	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.....		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.....	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.....		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.....		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.....		X
e Did the organization report an amount for other liabilities in Part X, line 25? If 'Yes,' complete Schedule D, Part X.....		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.....		X
12a Did the organization obtain separate, independent audited financial statements for the tax year? If 'Yes,' complete Schedule D, Parts XI, and XII.....	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.....		X
13 Is the organization a school described in section 170(b)(1)(A)(ii)? If 'Yes,' complete Schedule E.....		X
14a Did the organization maintain an office, employees, or agents outside of the United States?.....		X
b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? If 'Yes,' complete Schedule F, Parts I and IV.....	X	
15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? If 'Yes,' complete Schedule F, Parts II and IV.....	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 III and IV.....		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 (see instructions).....		X
18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? If 'Yes,' complete Schedule G, Part II.....	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.....		X
20 a Did the organization operate one or more hospital facilities? If 'Yes,' complete Schedule H.....		X
b If 'Yes' to line 20a, did the organization attach a copy of its audited financial statements to this return?.....		

Part IV Checklist of Required Schedules (continued)

	Yes	No
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organizations or government on Part IX, column (A), line 1? <i>If 'Yes,' complete Schedule I, Parts I and II.</i>	X	
22 Did the organization report more than \$5,000 of grants or other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If 'Yes,' complete Schedule I, Parts I and III.</i>		X
23 Did the organization answer 'Yes' to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If 'Yes,' complete Schedule J.</i>	X	
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If 'Yes,' answer lines 24b through 24d and complete Schedule K. If 'No,' go to line 25a.</i>		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
d Did the organization act as an 'on behalf of' issuer for bonds outstanding at any time during the year?		
25a Section 501(c)(3) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If 'Yes,' complete Schedule L, Part I.</i>		X
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If 'Yes,' complete Schedule L, Part I.</i>		X
26 Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? <i>If so, complete Schedule L, Part II.</i>		X
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? <i>If 'Yes,' complete Schedule L, Part III.</i>		X
28 Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
a A current or former officer, director, trustee, or key employee? <i>If 'Yes,' complete Schedule L, Part IV.</i>		X
b A family member of a current or former officer, director, trustee, or key employee? <i>If 'Yes,' complete Schedule L, Part IV.</i>		X
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? <i>If 'Yes,' complete Schedule L, Part IV.</i>		X
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If 'Yes,' complete Schedule M.</i>		X
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If 'Yes,' complete Schedule M.</i>		X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If 'Yes,' complete Schedule N, Part I.</i>		X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If 'Yes,' complete Schedule N, Part II.</i>		X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If 'Yes,' complete Schedule R, Part I.</i>		X
34 Was the organization related to any tax-exempt or taxable entity? <i>If 'Yes,' complete Schedule R, Parts II, III, IV, and V, line 1.</i>		X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
b If 'Yes' to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If 'Yes,' complete Schedule R, Part V, line 2.</i>		
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If 'Yes,' complete Schedule R, Part V, line 2.</i>		X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If 'Yes,' complete Schedule R, Part VI.</i>		X
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19? Note. All Form 990 filers are required to complete Schedule O.	X	

BAA

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

		Yes	No
1 a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable. <input type="text" value="23"/>		
1 b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable. <input type="text" value="0"/>		
1 c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? <input type="checkbox"/>	X	
2 a	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. <input type="text" value="9"/>		
2 b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? <input type="checkbox"/>	X	
Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)			
3 a	Did the organization have unrelated business gross income of \$1,000 or more during the year? <input type="checkbox"/>		X
3 b	If 'Yes' has it filed a Form 990-T for this year? If 'No' to line 3b, provide an explanation in Schedule O. <input type="checkbox"/>		
4 a	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)? <input type="checkbox"/>		X
4 b	If 'Yes,' enter the name of the foreign country: <input type="text"/> See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.		
5 a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? <input type="checkbox"/>		X
5 b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? <input type="checkbox"/>		X
5 c	If 'Yes,' to line 5a or 5b, did the organization file Form 8886-T? <input type="checkbox"/>		
6 a	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? <input type="checkbox"/>		X
6 b	If 'Yes,' did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible? <input type="checkbox"/>		
7	Organizations that may receive deductible contributions under section 170(c).		
7 a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor? <input type="checkbox"/>	X	
7 b	If 'Yes,' did the organization notify the donor of the value of the goods or services provided? <input type="checkbox"/>	X	
7 c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282? <input type="checkbox"/>		X
7 d	If 'Yes,' indicate the number of Forms 8282 filed during the year. <input type="text"/>		
7 e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? <input type="checkbox"/>		X
7 f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? <input type="checkbox"/>		X
7 g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required? <input type="checkbox"/>		
7 h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C? <input type="checkbox"/>		
8	Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year? <input type="checkbox"/>		
9	Sponsoring organizations maintaining donor advised funds.		
9 a	Did the organization make any taxable distributions under section 4966? <input type="checkbox"/>		
9 b	Did the organization make a distribution to a donor, donor advisor, or related person? <input type="checkbox"/>		
10	Section 501(c)(7) organizations. Enter:		
10 a	Initiation fees and capital contributions included on Part VIII, line 12. <input type="text"/>		
10 b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities. <input type="text"/>		
11	Section 501(c)(12) organizations. Enter:		
11 a	Gross income from members or shareholders. <input type="text"/>		
11 b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.) <input type="text"/>		
12 a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041? <input type="checkbox"/>		
12 b	If 'Yes,' enter the amount of tax-exempt interest received or accrued during the year. <input type="text"/>		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
13 a	Is the organization licensed to issue qualified health plans in more than one state? <input type="checkbox"/>		
Note. See the instructions for additional information the organization must report on Schedule O.			
13 b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans. <input type="text"/>		
13 c	Enter the amount of reserves on hand. <input type="text"/>		
14 a	Did the organization receive any payments for indoor tanning services during the tax year? <input type="checkbox"/>		X
14 b	If 'Yes,' has it filed a Form 720 to report these payments? If 'No,' provide an explanation in Schedule O. <input type="checkbox"/>		

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

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

Section A. Governing Body and Management

		Yes	No
1 a	Enter the number of voting members of the governing body at the end of the tax year. 1 a 18 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.		
1 b	Enter the number of voting members included in line 1a, above, who are independent 1 b 18		
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? SEE SCHEDULE O	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?		X
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		X
5	Did the organization become aware during the year of a significant diversion of the organization's assets?		X
6	Did the organization have members or stockholders?		X
7 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?		X
7 b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or other persons other than the governing body?		X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
8 a	a The governing body?	X	
8 b	b Each committee with authority to act on behalf of the governing body?	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.		X

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

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

Section C. Disclosure

- 17** List the states with which a copy of this Form 990 is required to be filed ▶ SEE SCHEDULE O
- 18** Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (501(c)(3)s only) available for public inspection. Indicate how you make these available. Check all that apply.
 Own website Another's website Upon request Other (explain in Schedule O)
- 19** Describe in Schedule O whether (and if so, how) the organization makes its governing documents, conflict of interest policy, and financial statements available to the public during the tax year. **SEE SCHEDULE O**
- 20** State the name, physical address, and telephone number of the person who possesses the books and records of the organization:
 ▶ JANET L HIESHETTER ONE EAST WACKER DRIVE CHICAGO IL 60601-1905 312-755-0198

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

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

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

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

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter -0- in columns (D), (E), and (F) if no compensation was paid.
- List all of the organization's **current** key employees, if any. See instructions for definition of 'key employee.'
- List the organization's five **current** highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

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

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

(A) Name and Title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) ROSALIE LEWIS VICE PRESIDENT	1 0	X		X			0.	0.	0.	
(2) SAMUEL BELZBERG CHAIRMAN	2 0	X		X			0.	0.	0.	
(3) DENNIS KESSLER VICE PRESIDENT	2 0	X		X			0.	0.	0.	
(4) ARTHUR KESSLER PRESIDENT	5 0	X		X			0.	0.	0.	
(5) BARBARA KESSLER VICE PRESIDENT	2 0	X		X			0.	0.	0.	
(6) DEBORAH KILPATRICK VICE PRESIDENT	1 0	X		X			0.	0.	0.	
(7) MARK RUDOLPH TREASURER	3 0	X		X			0.	0.	0.	
(8) KAREN ROSS VICE PRESIDENT	1 0	X		X			0.	0.	0.	
(9) PAULA SCHNEIDER DIRECTOR	3 0	X					0.	0.	0.	
(10) NANCY HARRIS DIRECTOR	1 0	X					0.	0.	0.	
(11) RICHARD LEWIS VICE PRESIDENT	2 0	X		X			0.	0.	0.	
(12) MARILYNNE HERBERT DIRECTOR	1 0	X					0.	0.	0.	
(13) ERWIN JACKSON DIRECTOR	1 0	X					0.	0.	0.	
(14) JOHN SYMONDS DIRECTOR	1 0	X					0.	0.	0.	

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below dotted line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)					(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee			
(15) DONNA DRISCOLL DIRECTOR	1 0	X					0.	0.	0.
(16) DIANE RUDOLPH DIRECTOR	1 0	X					0.	0.	0.
(17) FRANCES BELZBERG DIRECTOR	1 0	X					0.	0.	0.
(18) SANDRA WEIL DIRECTOR	3 0	X					0.	0.	0.
(19) JANET HIESHETTER EXECUTIVE DIREC	59 0			X			132,141.	0.	27,943.
(20) JAN TELLER SCIENCE OFFICER	50 0				X		118,930.	0.	11,572.
(21)									
(22)									
(23)									
(24)									
(25)									
1 b Sub-total							251,071.	0.	39,515.
c Total from continuation sheets to Part VII, Section A							0.	0.	0.
d Total (add lines 1b and 1c)							251,071.	0.	39,515.
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 ▶ 2									

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

Section B. Independent Contractors

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

(A) Name and business address	(B) Description of services	(C) Compensation

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

Part VIII Statement of Revenue

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

		(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
CONTRIBUTIONS, GIFTS, GRANTS AND OTHER SIMILAR AMOUNTS	1 a Federated campaigns	1 a 21,792.				
	b Membership dues	1 b				
	c Fundraising events	1 c 172,388.				
	d Related organizations	1 d				
	e Government grants (contributions)	1 e				
	f All other contributions, gifts, grants, and similar amounts not included above	1 f 1,946,152.				
	g Noncash contributions included in lines 1a-1f: \$					
h Total. Add lines 1a-1f	▶	2,140,332.				
PROGRAM SERVICE REVENUE	Business Code					
	2 a -----					
	b -----					
	c -----					
	d -----					
	e -----					
	f All other program service revenue					
g Total. Add lines 2a-2f	▶					
OTHER REVENUE	3 Investment income (including dividends, interest and other similar amounts)	▶	3,034.		3,034.	
	4 Income from investment of tax-exempt bond proceeds..	▶				
	5 Royalties	▶				
	6 a Gross rents	(i) Real				
		(ii) Personal				
		b Less: rental expenses				
		c Rental income or (loss)				
	d Net rental income or (loss)	▶				
	7 a Gross amount from sales of assets other than inventory..	(i) Securities				
		(ii) Other				
		b Less: cost or other basis and sales expenses				
		c Gain or (loss)				
	d Net gain or (loss)	▶				
	8 a Gross income from fundraising events (not including.. \$ 172,388. of contributions reported on line 1c). See Part IV, line 18	a	24,826.			
		b Less: direct expenses	b 24,826.			
c Net income or (loss) from fundraising events		▶				
9 a Gross income from gaming activities. See Part IV, line 19	a					
	b Less: direct expenses	b				
	c Net income or (loss) from gaming activities	▶				
10 a Gross sales of inventory, less returns and allowances	a					
	b Less: cost of goods sold	b				
	c Net income or (loss) from sales of inventory	▶				
Miscellaneous Revenue		Business Code				
11 a <u>MERCHANDISE SALES</u>	900099	7,594.	7,594.			
b -----						
c -----						
d All other revenue						
e Total. Add lines 11a-11d	▶	7,594.				
12 Total revenue. See instructions	▶	2,150,960.	7,594.	0.	3,034.	

Part IX Statement of Functional Expenses

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

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

Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1 Grants and other assistance to governments and organizations in the United States. See Part IV, line 21	753,892.	753,892.		
2 Grants and other assistance to individuals in the United States. See Part IV, line 22				
3 Grants and other assistance to governments, organizations, and individuals outside the United States. See Part IV, lines 15 and 16	293,333.	293,333.		
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees	160,084.	152,080.	3,202.	4,802.
6 Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)	0.	0.	0.	0.
7 Other salaries and wages	536,304.	340,934.	103,805.	91,565.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	16,626.	10,294.	3,367.	2,965.
9 Other employee benefits	49,859.	30,615.	7,433.	11,811.
10 Payroll taxes	52,120.	36,554.	8,201.	7,365.
11 Fees for services (non-employees):				
a Management	34,613.	34,613.		
b Legal	500.		500.	
c Accounting	19,516.	2,051.	17,465.	
d Lobbying	46,783.	46,783.		
e Professional fundraising services. See Part IV, line 17				
f Investment management fees				
g Other. (If line 11g amt exceeds 10% of line 25, column (A) amount, list line 11g expenses on Schedule O)	32,761.	27,050.	2,831.	2,880.
12 Advertising and promotion				
13 Office expenses	34,951.	25,450.	2,762.	6,739.
14 Information technology				
15 Royalties				
16 Occupancy	105,163.	75,790.	17,733.	11,640.
17 Travel	146,449.	132,403.	1,092.	12,954.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings	156,185.	148,828.	2,358.	4,999.
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	3,505.	2,381.	483.	641.
23 Insurance	9,004.	6,116.	1,241.	1,647.
24 Other expenses. Itemize expenses not covered above (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule O.)				
a <u>PRINTING AND PUBLICATIONS</u>	71,827.	53,152.	82.	18,593.
b <u>POSTAGE AND SHIPPING</u>	58,545.	44,157.	2,548.	11,840.
c <u>MISCELLANEOUS</u>	51,307.	30,941.	12,092.	8,274.
d <u>COMMUNICATIONS</u>	41,110.	35,416.	2,378.	3,316.
e All other expenses	10,251.			10,251.
25 Total functional expenses. Add lines 1 through 24e	2,684,688.	2,282,833.	189,573.	212,282.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

Part X Balance Sheet

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

		(A) Beginning of year		(B) End of year
ASSETS	1 Cash – non-interest-bearing	594,923.	1	520,385.
	2 Savings and temporary cash investments	2,776,316.	2	2,157,787.
	3 Pledges and grants receivable, net	278,760.	3	291,077.
	4 Accounts receivable, net		4	
	5 Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5	
	6 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 instructions). Complete Part II of Schedule L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges		9	
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 36,325.		
	b Less: accumulated depreciation	10b 32,128.	4,933.	10c 4,197.
	11 Investments – publicly traded securities		11	
	12 Investments – other securities. See Part IV, line 11		12	
	13 Investments – program-related. See Part IV, line 11		13	
	14 Intangible assets		14	
	15 Other assets. See Part IV, line 11	21,452.	15	19,193.
16 Total assets. Add lines 1 through 15 (must equal line 34)	3,676,384.	16	2,992,639.	
LIABILITIES	17 Accounts payable and accrued expenses	697,434.	17	631,630.
	18 Grants payable		18	
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D	556,686.	21	472,473.
	22 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		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D		25	
	26 Total liabilities. Add lines 17 through 25	1,254,120.	26	1,104,103.
NET ASSETS OR FUND BALANCES	Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.			
	27 Unrestricted net assets	824,633.	27	636,938.
	28 Temporarily restricted net assets	1,597,631.	28	1,251,598.
	29 Permanently restricted net assets		29	
	Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34.			
	30 Capital stock or trust principal, or current funds		30	
	31 Paid-in or capital surplus, or land, building, or equipment fund		31	
	32 Retained earnings, endowment, accumulated income, or other funds		32	
	33 Total net assets or fund balances	2,422,264.	33	1,888,536.
34 Total liabilities and net assets/fund balances	3,676,384.	34	2,992,639.	

BAA

Form 990 (2013)

Part XI Reconciliation of Net Assets

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

1	Total revenue (must equal Part VIII, column (A), line 12)	1	2,150,960.
2	Total expenses (must equal Part IX, column (A), line 25)	2	2,684,688.
3	Revenue less expenses. Subtract line 2 from line 1	3	-533,728.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4	2,422,264.
5	Net unrealized gains (losses) on investments	5	
6	Donated services and use of facilities	6	
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain in Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	10	1,888,536.

Part XII Financial Statements and Reporting

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

		Yes	No
1	Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked 'Other,' explain in Schedule O.		
2 a	Were the organization's financial statements compiled or reviewed by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
2 b	Were the organization's financial statements audited by an independent accountant? If 'Yes,' check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	X	
2 c	If 'Yes' to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.	X	
3 a	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133?		X
3 b	If 'Yes,' did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits.....		

BAA

Form 990 (2013)

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.

▶ Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2013

Open to Public Inspection

Name of the organization DYSTONIA MEDICAL RESEARCH FOUNDATION	Employer identification number 95-3378526
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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 11, 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.)
- 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 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.)
- 10 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 11 An organization organized and operated exclusively for the benefit of, to perform the functions of, or 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 that describes the type of supporting organization and complete lines 11e through 11h.
 - a Type I b Type II c Type III – Functionally integrated d Type III – Non-functionally integrated
- e By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
- f If the organization received a written determination from the IRS that is a Type I, Type II or Type III supporting organization, check this box
- g Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?

	Yes	No
(i) A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?	<input type="checkbox"/>	<input type="checkbox"/>
(ii) A family member of a person described in (i) above?	<input type="checkbox"/>	<input type="checkbox"/>
(iii) A 35% controlled entity of a person described in (i) or (ii) above?	<input type="checkbox"/>	<input type="checkbox"/>

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-9 above or IRC section (see instructions))	(iv) Is the organization in column (i) listed in your governing document?		(v) Did you notify the organization in column (i) of your support?		(vi) Is the organization in column (i) organized in the U.S.?		(vii) Amount of monetary support
			Yes	No	Yes	No	Yes	No	
(A)									
(B)									
(C)									
(D)									
(E)									
Total									

BAA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ. Schedule A (Form 990 or 990-EZ) 2013

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) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any 'unusual grants'.)	2,731,455.	2,494,622.	2,790,859.	2,899,082.	2,140,332.	13,056,350.
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf.						0.
3 The value of services or facilities furnished by a governmental unit to the organization without charge.						0.
4 Total. Add lines 1 through 3.	2,731,455.	2,494,622.	2,790,859.	2,899,082.	2,140,332.	13,056,350.
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).						3,869,618.
6 Public support. Subtract line 5 from line 4.						9,186,732.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
7 Amounts from line 4.	2,731,455.	2,494,622.	2,790,859.	2,899,082.	2,140,332.	13,056,350.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources.	48,388.	25,924.	6,034.	3,726.	3,034.	87,106.
9 Net income from unrelated business activities, whether or not the business is regularly carried on.						0.
10 Other income. Do not include gain or loss from the sale of capital assets. (Explain in Part IV.) SEE PART IV.	16,123.	8,931.	10,840.	5,052.	7,594.	48,540.
11 Total support. Add lines 7 through 10.						13,191,996.
12 Gross receipts from related activities, etc (see instructions).					12	0.
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 .						<input type="checkbox"/>

Section C. Computation of Public Support Percentage

14 Public support percentage for 2013 (line 6, column (f) divided by line 11, column (f)).	14	69.64 %
15 Public support percentage from 2012 Schedule A, Part II, line 14.	15	72.33 %
16a 33-1/3% support test – 2013. If the organization did not check the box on line 13, and the line 14 is 33-1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization.	<input checked="" type="checkbox"/>	
b 33-1/3% support test – 2012. If the organization did not check a box on line 13 or 16a, and line 15 is 33-1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization.	<input type="checkbox"/>	
17a 10%-facts-and-circumstances test – 2013. 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 IV how the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization.	<input type="checkbox"/>	
b 10%-facts-and-circumstances test – 2012. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the 'facts-and-circumstances' test, check this box and stop here. Explain in Part IV how the organization meets the 'facts-and-circumstances' test. The organization qualifies as a publicly supported organization.	<input type="checkbox"/>	
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions.	<input type="checkbox"/>	

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

(Complete only if you checked the box on line 9 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 yr beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions and membership fees received. (Do not include any 'unusual grants.')						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose.						
3 Gross receipts from activities that are not an unrelated trade or business under section 513.						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf.						
5 The value of services or facilities furnished by a governmental unit to the organization without charge.						
6 Total. Add lines 1 through 5.						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons.						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year.						
c Add lines 7a and 7b.						
8 Public support (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal yr beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
9 Amounts from line 6.						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources.						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975.						
c Add lines 10a and 10b.						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on.						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total Support. (Add lns 9,10c, 11 and 12.)						

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

Section C. Computation of Public Support Percentage

15 Public support percentage for 2013 (line 8, column (f) divided by line 13, column (f)).	15	%
16 Public support percentage from 2012 Schedule A, Part III, line 15.	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2013 (line 10c, column (f) divided by line 13, column (f)).	17	%
18 Investment income percentage from 2012 Schedule A, Part III, line 17.	18	%

19a 33-1/3% support tests – 2013. 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 – 2012. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33-1/3%, and line 18 is not more than 33-1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization.

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

PART II, LINE 10 - OTHER INCOME

<u>NATURE AND SOURCE</u>	<u>2013</u>	<u>2012</u>	<u>2011</u>	<u>2010</u>	<u>2009</u>
MISCELLANEOUS	\$ 7,594.	\$ 5,052.	\$ 10,840.	\$ 8,931.	\$ 16,123.
TOTAL	<u>\$ 7,594.</u>	<u>\$ 5,052.</u>	<u>\$ 10,840.</u>	<u>\$ 8,931.</u>	<u>\$ 16,123.</u>

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

Department of the Treasury
Internal Revenue Service

PUBLIC DISCLOSURE COPY
Schedule of Contributors

► **Attach to Form 990, Form 990-EZ, or Form 990-PF**
► Information about Schedule B (Form 990, 990-EZ, 990-PF) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2013

Name of the organization

DYSTONIA MEDICAL RESEARCH FOUNDATION

Employer identification number

95-3378526

Organization type (check one):

Filers of:

Form 990 or 990-EZ

Section:

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, \$5,000 or more (in money or property) from any one contributor. (Complete Parts I and II.)

Special Rules

For a section 501(c)(3) organization 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) and received from any one contributor, during the year, a contribution 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 a section 501(c)(7), (8), or (10) organization filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 for use *exclusively* for religious, charitable, scientific, literary, or educational purposes, or the prevention of cruelty to children or animals. Complete Parts I, II, and III.

For a section 501(c)(7), (8), or (10) organization filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions for use *exclusively* for religious, charitable, etc, purposes, but these contributions did not total to 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. Do not complete any of the parts unless the **General Rule** applies to this organization because it received nonexclusively religious, charitable, etc, contributions of \$5,000 or more during the year. ► \$ _____

Caution: An organization that is not covered by the General Rule and/or the Special Rules does not 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 does not meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

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

Schedule **B** (Form 990, 990-EZ, or 990-PF) (2013)

or 990-PF.

Name of organization

DYSTONIA MEDICAL RESEARCH FOUNDATION

Employer identification number

95-3378526

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

(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
<u>1</u>	----- ----- -----	\$ 100,100.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
<u>2</u>	----- ----- -----	\$ 75,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
<u>3</u>	----- ----- -----	\$ 50,668.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
<u>4</u>	----- ----- -----	\$ 50,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
<u>5</u>	----- ----- -----	\$ 50,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
<u>6</u>	----- ----- -----	\$ 121,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization

Employer identification number

DYSTONIA MEDICAL RESEARCH FOUNDATION

95-3378526

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

(a) Number	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	----- ----- -----	\$ 172,999.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
8	----- ----- -----	\$ 145,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
9	----- ----- -----	\$ 173,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
10	----- ----- -----	\$ 161,281.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
---	----- ----- -----	\$ -----	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
---	----- ----- -----	\$ -----	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization

Employer identification number

DYSTONIA MEDICAL RESEARCH FOUNDATION

95-3378526

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

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
-----	N/A ----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----
-----	----- ----- -----	\$-----	-----

Name of organization DYSTONIA MEDICAL RESEARCH FOUNDATION	Employer identification number 95-3378526
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Part III Exclusively religious, charitable, etc., individual contributions to section 501(c)(7), (8) or (10) organizations that total more than \$1,000 for the year. Complete columns (a) through (e) and the following line entry.

For organizations completing Part III, enter total of *exclusively* religious, charitable, etc., contributions of **\$1,000 or less** for the year. (Enter this information once. See instructions.) ▶ \$ **N/A**

Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
N/A			

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
-----	-----
-----	-----
-----	-----

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
-----	-----
-----	-----
-----	-----

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
-----	-----
-----	-----
-----	-----

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee
-----	-----
-----	-----
-----	-----

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

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

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

4-Year Averaging Period Under Section 501(h)
(Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period					
Calendar year (or fiscal year beginning in)	(a) 2010	(b) 2011	(c) 2012	(d) 2013	(e) Total
2 a Lobbying non-taxable amount.....					
b Lobbying ceiling amount (150% of line 2a, column (e)).....					
c Total lobbying expenditures.....					
d Grassroots nontaxable amount.....					
e Grassroots ceiling amount (150% of line 2d, column (e)).....					
f Grassroots lobbying expenditures.....					

BAA

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

	(a)		(b)
	Yes	No	Amount
<i>For each 'Yes' response to lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity.</i>			
1 During the year, did the filing organization attempt to influence foreign, national, state or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of:			
a Volunteers?	X		
b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)?	X		
c Media advertisements?		X	
d Mailings to members, legislators, or the public?	X		
e Publications, or published or broadcast statements?		X	
f Grants to other organizations for lobbying purposes?		X	
g Direct contact with legislators, their staffs, government officials, or a legislative body?	X		18,713.
h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means?		X	
i Other activities?		X	
j Total. Add lines 1c through 1i.			18,713.
2 a Did the activities in line 1 cause the organization to be not described in section 501(c)(3)?		X	
b If 'Yes,' enter the amount of any tax incurred under section 4912.			
c If 'Yes,' enter the amount of any tax incurred by organization managers under section 4912.			
d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year?			

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

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

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

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

Part IV Supplemental Information

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

**SCHEDULE D
(Form 990)**

Department of the Treasury
Internal Revenue Service

Supplemental Financial Statements

▶ Complete if the organization answered 'Yes,' to Form 990, Part IV, lines 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.
▶ Attach to Form 990.

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

OMB No. 1545-0047

2013

Open to Public Inspection

Name of the organization

Employer identification number

DYSTONIA MEDICAL RESEARCH FOUNDATION

95-3378526

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.

Complete if the organization answered 'Yes' to Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate contributions to (during year)		
3 Aggregate 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?	<input type="checkbox"/> Yes	<input type="checkbox"/> 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?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

Part II Conservation Easements.

Complete if the organization answered 'Yes' to Form 990, Part IV, line 7.

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

<input type="checkbox"/> Preservation of land for public use (e.g., recreation or education)	<input type="checkbox"/> Preservation of an historically important land area
<input type="checkbox"/> Protection of natural habitat	<input type="checkbox"/> Preservation of a certified historic structure
<input type="checkbox"/> Preservation of open space	

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

	Held at the End of the Tax Year
a Total number of conservation easements	2 a
b Total acreage restricted by conservation easements	2 b
c Number of conservation easements on a certified historic structure included in (a)	2 c
d Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register	2 d

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, and enforcing conservation easements during the year ▶ _____

7 Amount of expenses incurred in monitoring, inspecting, 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

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

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

Complete if the organization answered 'Yes' to Form 990, Part IV, line 8.

1 a 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) Revenues included in 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 Revenues included in 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
- d Loan or exchange programs
- e Other _____

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

5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? Yes No

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

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

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

	Amount
c Beginning balance	1 c
d Additions during the year	1 d
e Distributions during the year	1 e
f Ending balance	1 f 0.

2 a Did the organization include an amount on Form 990, Part X, line 21? Yes No

b If 'Yes,' explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII. Yes No

SEE PART XIII

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

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1 a 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					

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

- a Board designated or quasi-endowment _____ %
 - b Permanent endowment _____ %
 - c Temporarily restricted endowment _____ %
- The percentages in lines 2a, 2b, and 2c should equal 100%.

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

	Yes	No
(i) unrelated organizations	3a(i)	
(ii) related organizations	3a(ii)	
b If 'Yes' to 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' to Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1 a Land				
b Buildings				
c Leasehold improvements				
d Equipment		34,880.	31,009.	3,871.
e Other		1,445.	1,119.	326.
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				4,197.

BAA

Part VII Investments – Other Securities.

N/A

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

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

Part VIII Investments – Program Related.

N/A

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

(a) Description of investment type	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(1)		
(2)		
(3)		
(4)		
(5)		
(6)		
(7)		
(8)		
(9)		
(10)		
Total. (Column (b) must equal Form 990, Part X, column (B) line 13.)		

Part IX Other Assets.

N/A

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

(a) Description	(b) Book value
(1)	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
Total. (Column (b) must equal Form 990, Part X, column (B), line 15.)	

Part X Other Liabilities.

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

(a) Description of liability	(b) Book value
(1) Federal income taxes	
(2)	
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
(10)	
(11)	
Total. (Column (b) must equal Form 990, Part X, column (B) line 25.)	

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII.

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

Complete if the organization answered 'Yes' to Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements	1	2,188,341.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
	a Net unrealized gains on investments	2a	
	b Donated services and use of facilities	2b	
	c Recoveries of prior year grants	2c	
	d Other (Describe in Part XIII.) SEE PART XIII	2d	37,381.
	e Add lines 2a through 2d	2e	37,381.
3	Subtract line 2e from line 1	3	2,150,960.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
	a Investment expenses not included on Form 990, Part VIII, line 7b	4a	
	b Other (Describe in Part XIII.)	4b	
	c Add lines 4a and 4b	4c	
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)	5	2,150,960.

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

Complete if the organization answered 'Yes' to Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements	1	2,722,069.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
	a Donated services and use of facilities	2a	
	b Prior year adjustments	2b	
	c Other losses	2c	
	d Other (Describe in Part XIII.) SEE PART XIII	2d	37,381.
	e Add lines 2a through 2d	2e	37,381.
3	Subtract line 2e from line 1	3	2,684,688.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
	a Investment expenses not included on Form 990, Part VIII, line 7b	4a	
	b Other (Describe in Part XIII.)	4b	
	c Add lines 4a and 4b	4c	
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)	5	2,684,688.

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 IV, LINE 2B - EXPLANATION OF ESCROW ACCOUNT LIABILITY

THE FOUNDATION SERVES AS THE ADMINISTRATIVE CENTER FOR THE DYSTONIA COALITION (THE COALITION), A NETWORK OF CLINICAL RESEARCH CENTERS WORKING TO ADVANCE THE UNDERSTANDING OF PRIMARY DYSTONIAS THAT IS SUPPORTED THROUGH A FIVE YEAR GRANT FROM THE NATIONAL INSTITUTES OF HEALTH'S (NIH) OFFICE OF RARE DISEASE RESEARCH AND THE NATIONAL INSTITUTES OF NEUROLOGICAL DISORDERS & STROKE. IN THIS ROLE, THE FOUNDATION WORKS WITH THE GRANT'S PRINCIPAL INVESTIGATOR, DR. HYDER A. JINNAH OF EMORY UNIVERSITY AND ALL COALITION MAIN CLINICAL PROJECT LEADERS TO SUPPORT THE ACTIVITIES

Part XIII Supplemental Information (continued)

PART IV, LINE 2B - EXPLANATION OF ESCROW ACCOUNT LIABILITY (CONTINUED)

OF THE COALITION, INCLUDING BUT NOT LIMITED TO: MEETING PLANNING; MANAGING PAYMENTS TO CLINICAL SITES PARTICIPATING IN THE COALITION'S MAIN CLINICAL PROJECTS AS WELL AS TO COALITION CONSULTANTS AND RECIPIENTS OF THE COALITION'S CAREER DEVELOPMENT AND PILOT PROJECTS AWARDS; MANAGING PRIVATE FUNDS GIVEN IN SUPPORT OF THE COALITION'S ACTIVITIES OR PROGRAMS; PARTICIPATING IN MONTHLY ADMINISTRATIVE PLANNING MEETINGS; PARTICIPATING IN THE COALITION'S EXECUTIVE COMMITTEE; AND OTHER DUTIES AS REQUESTED BY THE PRINCIPAL INVESTIGATOR AND/OR THE COALITION'S MAIN CLINICAL PROJECT LEADERS OR THE COALITION EXECUTIVE COMMITTEE. TOTAL COALITION PAYMENTS ADMINISTERED WERE \$506,859 IN 2013.

THE FOUNDATION ALSO SERVES AS THE ADMINISTRATIVE CENTER FOR OTHER DYSTONIA COMMUNITY PROJECTS SUCH AS THE GLOBAL DYSTONIA REGISTRY AND THE DYSTONIA BRAIN COLLECTIVE WHICH ARE SUPPORTED BY THE DMRF AND OTHER DYSTONIA PATIENT ADVOCACY GROUPS. TOTAL RECEIPTS FOR DYSTONIA COMMUNITY PROJECTS WERE \$13,500 IN 2013. TOTAL DISBURSEMENTS FOR DYSTONIA COMMUNITY PROJECTS WERE \$13,500. AT DECEMBER 31, 2013, \$1,255 OF DYSTONIA COMMUNITY PROJECTS DISBURSEMENTS HAD BEEN ADVANCED BY PRIVATE FUNDS GIVEN IN SUPPORT OF COALITION ACTIVITIES.

2013

SCHEDULE D, PART XIII - SUPPLEMENTAL INFORMATION PAGE 4

DYSTONIA MEDICAL RESEARCH FOUNDATION

95-3378526

**SCHEDULE D, PART XI, LINE 2D
OTHER REVENUE INCLUDED IN F/S BUT NOT INCLUDED ON FORM 990**

CANADIAN REIMBURSEMENTS.....	\$	37,381.
TOTAL	\$	<u>37,381.</u>

**SCHEDULE D, PART XII, LINE 2D
OTHER EXPENSES AND LOSSES PER AUDITED F/S**

CANADIAN REIMBURSEMENTS.....	\$	37,381.
TOTAL	\$	<u>37,381.</u>

**Schedule F
(Form 990)**

Department of the Treasury
Internal Revenue Service

Statement of Activities Outside the United States

- ▶ Complete if the organization answered 'Yes' on Form 990, Part IV, line 14b, 15, or 16.
 - ▶ Attach to Form 990. ▶ See separate instructions.
 - ▶ Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2013

Open to Public Inspection

Name of the organization

DYSTONIA MEDICAL RESEARCH FOUNDATION

Employer identification number

95-3378526

Part I General Information on Activities Outside the United States. Complete if the organization answered 'Yes' on Form 990, Part IV, line 14b.

- 1 For grantmakers.** Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? . . . **Yes** **No**
- 2 For grantmakers.** Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States. **PART V**
- 3 Activities per Region.** (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e.g., fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for and investments in region
(1) NORTH AMERICA			PROGRAM SERVICES	TRAVEL REIMBURSEMENT	6,692.
(2) EUROPE			PROGRAM SERVICES	PROGRAM EXPENSES	14,556.
(3) EUROPE			PROGRAM SERVICE	TRAVEL REIMBURSEMENT	7,971.
(4) EUROPE			MEDICAL RESEARCH	MEDICAL RESEARCH	180,000.
(5) NORTH AMERICA			MEDICAL RESEARCH	MEDICAL RESEARCH	40,000.
(6) SOUTH AMERICA			MEDICAL RESEARCH	MEDICAL RESEARCH	45,833.
(7) AFRICA			MEDICAL RESEARCH	MEDICAL RESEARCH	15,000.
(8) PACIFIC			MEDICAL RESEARCH	MEDICAL RESEARCH	12,500.
(9)					
(10)					
(11)					
(12)					
(13)					
(14)					
(15)					
(16)					
(17)					
3 a Sub-total					322,552.
b Total from continuation sheets to Part I					
c Totals (add lines 3a and 3b) . . .	0	0			322,552.

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

Schedule F (Form 990) 2013

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

1	(a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
(1)			EAST ASIA & PAC	MED RESEARCH	12,500.	EFT			
(2)			EUROPE	MED RESEARCH	15,000.	EFT			
(3)			EUROPE	MED RESEARCH	40,000.	EFT			
(4)			EUROPE	MED RESEARCH	50,000.	EFT			
(5)			EUROPE	MED RESEARCH	75,000.	EFT			
(6)			MIDDLE EAST	MED RESEARCH	15,000.	EFT			
(7)			NORTH AMERICA	MED RESEARCH	40,000.	CHECK			
(8)			SOUTH AMERICA	MED RESEARCH	45,833.	EFT			
(9)									
(10)									
(11)									
(12)									
(13)									
(14)									
(15)									
(16)									

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. ▶ 8

3 Enter total number of other organizations or entities ▶ 0

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.

(a) Type of grant or assistance	(b) Region	(c) Number of recipients	(d) Amount of cash grant	(e) Manner of cash disbursement	(f) Amount of non-cash assistance	(g) Description of non-cash assistance	(h) Method of valuation (book, FMV, appraisal, other)
(1)							
(2)							
(3)							
(4)							
(5)							
(6)							
(7)							
(8)							
(9)							
(10)							
(11)							
(12)							
(13)							
(14)							
(15)							
(16)							
(17)							
(18)							

Part IV Foreign Forms

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If 'Yes,' the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926).* Yes No

- 2 Did the organization have an interest in a foreign trust during the tax year? *If 'Yes,' the organization may be required to 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).* Yes No

- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If 'Yes,' the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain Foreign Corporations. (see Instructions for Form 5471).* Yes No

- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If 'Yes,' the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund. (see Instructions for Form 8621).* Yes No

- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If 'Yes,' the organization may be required to file Form 8865, Return of U.S. Persons With Respect To Certain Foreign Partnerships. (see Instructions for Form 8865).* Yes No

- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If 'Yes,' the organization may be required to file Form 5713, International Boycott Report (see Instructions for Form 5713).* Yes No

Part V Supplemental Information

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

PART I, LINE 2 - GRANTMAKERS EXPLANATION FOR MONITORING USE OF FUNDS OUTSIDE US

GRANTS AND RESEARCH FELLOWSHIPS

GRANTS AND RESEARCH FELLOWSHIPS ARE INVESTIGATOR-INITIATED RESEARCH PROJECTS

MONITORED BY THE DMRF'S GRANTS MANAGER AND CHIEF SCIENTIFIC OFFICER WITH REGULAR

REPORTS PROVIDED TO THE DMRF SCIENCE COMMITTEE. ALL INVESTIGATORS ARE EXPECTED TO

PUBLISH ALL MEANINGFUL RESEARCH RESULTS AND FINDINGS IN AN EXPEDITIOUS MANNER AND

REQUIRED TO SHARE ANY TOOLS AND MATERIALS DEVELOPED SO THAT OTHER RESEARCHERS CAN

BENEFIT FROM THEIR RESEARCH.

GRANTS AND RESEARCH FELLOWSHIPS ARE AWARDED FOR ONE, TWO OR THREE YEAR TERMS. THE

START DATE FOR ALL GRANTS AND RESEARCH FELLOWSHIPS IS APRIL 15TH UNLESS THE FUNDED

APPLICANT HAS REQUESTED A DELAYED START. PER THE AWARD TERMS AND CONDITIONS,

PAYMENTS ARE MADE TO THE RECIPIENT INSTITUTION IN EQUAL QUARTERLY INSTALLMENTS, ON OR

ABOUT THE 15TH OF APRIL, JULY, OCTOBER, AND JANUARY OF THE FOLLOWING YEAR.

IF IT IS A TWO OR THREE YEAR AWARD, RENEWAL FOR THE NEXT YEAR OF FUNDING IS APPROVED

AFTER A REVIEW OF THE PROGRESS TO DATE BY THE CHIEF SCIENTIFIC OFFICER AND SCIENTIFIC

DIRECTOR AND AUTHORIZED BY THE DMRF'S BOARD OF DIRECTORS. IF APPROVED, THE PAYMENT

SCHEDULE FOR THE NEXT YEAR REMAINS THE SAME.

INTERIM PROGRESS REPORTS INCLUDE INFORMATION ON HOW THE FUNDS RECEIVED TO DATE HAVE

BEEN UTILIZED AND PROGRESS WITH REGARD TO THE SPECIFIC AIMS OUTLINED IN THE GRANT

APPLICATION. PROGRESS REPORTS ARE DUE AS FOLLOWS:

ONE YEAR AWARDS-5 1/2 MONTHS AND 9 MONTHS AFTER RECEIPT OF THE INITIAL DISBURSEMENT.

TWO YEAR AWARDS-5 1/2 MONTHS, 9 MONTHS AND 18 MONTHS AFTER RECEIPT OF THE INITIAL

DISBURSEMENT.

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 - GRANTMAKERS EXPLANATION FOR MONITORING USE OF FUNDS OUTSIDE US (CONTINUED)

THREE YEAR AWARDS-5 1/2 MONTHS, 9 MONTHS, 18 MONTHS AND 30 MONTHS AFTER RECEIPT OF THE INITIAL DISBURSEMENT.

FINAL REPORTS ARE DUE FIVE MONTHS AFTER THE FINAL DISBURSEMENT AND MUST INCLUDE THE FOLLOWING:

DISCUSSION OF WHETHER THE PROJECT HAS ACHIEVED THE SPECIFIC MILESTONES, AIMS, AND OBJECTIVES OUTLINED IN THE ORIGINAL APPLICATION.

INFORMATION ON HOW THE FUNDS HAVE BEEN SPENT.

A PLAN FOR PUBLICATION OF RESULTS AND FINDINGS WITHIN ONE YEAR AFTER THE END OF THE PROJECT.

A LIST OF OTHER RESEARCH PROPOSALS EITHER SUBMITTED OR IN PREPARATION THAT HAVE RESULTED FROM THE PROJECT.

CLINICAL TRAINING FELLOWSHIPS

CLINICAL TRAINING FELLOWSHIPS ARE AWARDED TO FIRST AND SECOND YEAR CLINICAL FELLOWS TO HELP PREPARE THEM FOR A CLINICAL CAREER IN MOVEMENT DISORDERS WITH A SPECIAL COMPETENCE IN THE TREATMENT OF DYSTONIA INCLUDING: CLINICAL DIAGNOSIS AND EVALUATION, ONGOING PATIENT CARE AND MANAGEMENT, PHARMACOTHERAPY WITH A SPECIAL EMPHASIS ON NEUROTOXIN THERAPY, AND NEUROSURGICAL INTERVENTIONS, SUCH AS DEEP BRAIN STIMULATION.

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 - GRANTMAKERS EXPLANATION FOR MONITORING USE OF FUNDS OUTSIDE US (CONTINUED)

CLINICAL FELLOWSHIPS ARE AWARDED FOR ONE YEAR. THE START DATE FOR ALL CLINICAL FELLOWSHIPS IS JULY 1. PAYMENTS ARE MADE TO THE RECIPIENT INSTITUTION IN TWO EQUAL INSTALLMENTS ON OR ABOUT THE 1ST OF JULY AND 1ST OF JANUARY OF THE FOLLOWING YEAR.

REPORTS ARE DUE 6 MONTHS AFTER RECEIPT OF THE FIRST DISBURSEMENT AND UPON COMPLETION OF THE FELLOWSHIP. REPORTS MUST PROVIDE INFORMATION ABOUT THE RECIPIENT'S EXPERIENCE RELATED TO THE GOALS OF THE PROGRAM, INCLUDING THE PERCENTAGE OF TIME SPENT ON DYSTONIA, THE DIFFERENT FORMS OF DYSTONIA THAT THEY WERE EXPOSED TO IN THE CLINIC, AS WELL AS ATTENDANCE AT DYSTONIA-RELATED MEETINGS.

CONTRACTS

CONTRACTS REPRESENT RESEARCH INITIATED BY THE DMRF AND CONDUCTED FOR SPECIFIC MILESTONE PROJECTS BY SELECTED INVESTIGATORS. CONTRACTS ARE NEGOTIATED AND MONITORED BY THE DMRF'S CHIEF SCIENTIFIC OFFICER AFTER BEING AUTHORIZED BY THE DMRF BOARD OF DIRECTORS. PER THE TERMS OF THE RESEARCH SERVICES AGREEMENT, PAYMENTS FOR CONTRACTS ARE DISBURSED QUARTERLY, WITH THE FIRST PAYMENT BEING DISBURSED IMMEDIATELY UPON EXECUTION OF THE AGREEMENT. THE REMAINING THREE QUARTERLY PAYMENTS ARE DISBURSED AFTER THE RECEIPT OF QUARTERLY MILESTONE REPORTS AND APPROVAL FROM THE CHIEF SCIENTIFIC OFFICER TO RELEASE THE PAYMENT. MILESTONE REPORTS INCLUDE THE FOLLOWING:

A SUMMARY OF WORK COMPLETED, INCLUDING A DESCRIPTION OF PROGRESS TOWARD COMPLETION OF RESEARCH MILESTONES.

DISCLOSURE OF ALL RESULTS OBTAINED SINCE SUBMISSION OF THE PRIOR REPORT AND IDENTIFICATION OF RESULTS THAT MAY BE PATENTABLE OR OTHERWISE PROTECTABLE AS

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 - GRANTMAKERS EXPLANATION FOR MONITORING USE OF FUNDS OUTSIDE US (CONTINUED)

INTELLECTUAL PROPERTY.

A SUMMARY OF WORK IN PROGRESS AND PLANS FOR THE UPCOMING REPORTING PERIOD.

DISCLOSURE OF ANY NEW PROJECT INTELLECTUAL PROPERTY.

DISCLOSURE OF ANY NEW APPLICATIONS FOR COPYRIGHT OR PATENT PROTECTION FILED DURING THE REPORTING PERIOD OR INTENDED TO BE FILED IN THE UPCOMING REPORTING PERIOD.

A FINAL REPORT IS DUE WITHIN 30-90 DAYS OF THE COMPLETION OF THE PROJECT, DEPENDING ON THE TERMS OF THE RESEARCH SERVICES AGREEMENT, AND INCLUDES A WRITTEN DESCRIPTION OF RESULTS AND AN OUTLINE OF POSSIBLE FUTURE STUDIES.

Part II Fundraising Events. Complete if the organization answered 'Yes' to 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.

REVENUE	(a) Event #1	(b) Event #2	(c) Other events	(d) Total events		
	<u>DYSTANCE 4 DYS</u> (event type)	<u>NYC MARATHON</u> (event type)	<u>7</u> (total number)	(add column (a) through column (c))		
1	Gross receipts	39,943.	34,790.	101,098.	175,831.	
2	Less: Charitable contributions	33,274.	26,818.	90,913.	151,005.	
3	Gross income (line 1 minus line 2)	6,669.	7,972.	10,185.	24,826.	
DIRECT EXPENSES	4	Cash prizes				
	5	Noncash prizes				
	6	Rent/facility costs				
	7	Food and beverages				
	8	Entertainment				
	9	Other direct expenses	6,669.	7,972.	10,185.	24,826.
	10	Direct expense summary. Add lines 4 through 9 in column (d)				24,826.
11	Net income summary. Subtract line 10 from line 3, column (d)					

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

REVENUE	(a) Bingo	(b) Pull tabs/Instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming
	(add column (a) through column (c))	(add column (a) through column (c))	(add column (a) through column (c))	(add column (a) through column (c))
1	Gross revenue			
DIRECT EXPENSES	2	Cash prizes		
	3	Noncash prizes		
	4	Rent/facility costs		
	5	Other direct expenses		
	6	Volunteer labor	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No
7	Direct expense summary. Add lines 2 through 5 in column (d)			
8	Net gaming income summary. Subtract line 7 from line 1, column (d)			

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

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

b If 'No,' explain: _____

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

b If 'Yes,' explain: _____

11 Does the organization operate gaming activities with nonmembers? Yes No

12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? Yes No

13 Indicate the percentage of gaming activity operated in:

a The organization's facility	13 a	%
b An outside facility	13 b	%

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

Name ▶ _____

Address ▶ _____

15 a Does the organization have a contact with a third party from whom the organization receives gaming revenue? Yes No

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

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

Name ▶ _____

Address ▶ _____

16 Gaming manager information:

Name ▶ _____

Gaming manager compensation ▶ \$ _____.

Description of services provided ▶ _____

Director/officer Employee Independent contractor

17 Mandatory distributions

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

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

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

**SCHEDULE I
(Form 990)**

Department of the Treasury
Internal Revenue Service

**Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States**
Complete if the organization answered 'Yes' to Form 990, Part IV, line 21 or 22.
▶ Attach to Form 990.

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

OMB No. 1545-0047

2013

**Open to Public
Inspection**

Name of the organization

DYSTONIA MEDICAL RESEARCH FOUNDATION

Employer identification number

95-3378526

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. **SEE PART IV**

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

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance
(1) BETH ISRAEL DEACONESS MED CTR 3 BLACKFAN CIRCLE BOSTON, MA 02215	04-2103881		75,000.	0.			MEDICAL RESEARCH
(2) BETH ISRAEL MEDICAL CENTER 1ST AVENUE AT 18TH ST NEW YORK, NY 10003	13-5564934		75,000.	0.			MEDICAL RESEARCH
(3) DUKE UNIVERSITY MEDICAL CENTE 2200 W MAIN STREET DURHAM, NC 27710	56-0532129		63,838.	0.			MEDICAL RESEARCH
(4) EMORY UNIVERSITY 1599 CLIFTON ROAD NE ATLANTA, GA 30322	58-0566256		75,000.	0.			MEDICAL RESEARCH
(5) MASSACHUSETTS GENERAL HOSPITA PO BOX 414876 BOSTON, MA 02241	04-2697983		20,000.	0.			MEDICAL RESEARCH
(6) MASSACHUSETTS INSTITUE OF TEC 600 MEMORIAL DRIVE CAMBRIDGE, MA 02139	04-2103594		65,000.	0.			MEDICAL RESEARCH
(7) MOUNT SINAI SCHOOL OF MEDICIN ONE GUSTAVE L. LEVY PLACE NEW YORK, NY 10029	13-6171197		65,000.	0.			MEDICAL RESEARCH
(8) NATL INST OF NEUROLOGICAL DIS 31 CENTER DRIVE ROCKVILLE, MD 20892	52-0858115		75,000.	0.			MEDICAL RESEARCH

2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table **11**

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

Part III Grants and Other Assistance to Individuals in the United States. Complete if the organization answered 'Yes' to Form 990, Part IV, line 22.
Part III can be duplicated if additional space is needed.

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non-cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of non-cash assistance
1					
2					
3					
4					
5					
6					
7					

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 - PROCEDURES FOR MONITORING USE OF GRANTS FUNDS IN U.S.

DOMESTIC GRANTS AND FELLOWSHIPS ARE MONITORED FOLLOWING THE SAME PROCEDURES AS

DESCRIBED IN SCHEDULE F, PART 1, LINE 2 FOR GRANTS AND FELLOWSHIPS FUNDED OUTSIDE OF

THE US.

**SCHEDULE J
(Form 990)**

Compensation Information

OMB No. 1545-0047

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees
 ▶ Complete if the organization answered 'Yes' on Form 990, Part IV, line 23.
 ▶ Attach to Form 990. ▶ See separate instructions.
 ▶ Information about Schedule J (Form 990) and its instructions is at www.irs.gov/form990.

2013

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Name of the organization

DYSTONIA MEDICAL RESEARCH FOUNDATION

Employer identification number

95-3378526

Part I Questions Regarding Compensation

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

- | | |
|--|--|
| <input type="checkbox"/> First-class or charter travel | <input type="checkbox"/> Housing allowance or residence for personal use |
| <input type="checkbox"/> Travel for companions | <input type="checkbox"/> Payments for business use of personal residence |
| <input type="checkbox"/> Tax indemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees |
| <input type="checkbox"/> Discretionary spending account | <input type="checkbox"/> Personal services (e.g., 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 officers, directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked in line 1a?

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

- | | |
|--|---|
| <input type="checkbox"/> Compensation committee | <input checked="" type="checkbox"/> Written employment contract |
| <input type="checkbox"/> Independent compensation consultant | <input checked="" type="checkbox"/> Compensation survey or study |
| <input type="checkbox"/> Form 990 of other organizations | <input checked="" type="checkbox"/> Approval by the board or compensation committee |

4 During the year, did any person listed in 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? **4 a**
- b** Participate in, or receive payment from, a supplemental nonqualified retirement plan? **4 b**
- c** Participate in, or receive payment from, an equity-based compensation arrangement? **4 c**
- If 'Yes' to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

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

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

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

6 For persons listed in 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? **6 a**
- b** Any related organization? **6 b**
- If 'Yes' to line 6a or 6b, describe in Part III.

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

8 Were any amounts reported in 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**

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

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

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

Schedule J (Form 990) 2013

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

For each individual whose compensation must be reported in 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 are not 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 columns (D) and (E) amounts for that individual.

(A) Name and Title		(B) Breakdown of W-2 and/or 1099-MISC compensation			(C) Retirement and other deferred compensation	(D) Nontaxable benefits	(E) Total of columns(B)(i)-(D)	(F) Compensation reported as deferred in prior Form 990
		(i) Base compensation	(ii) Bonus and incentive compensation	(iii) Other reportable compensation				
1 JANET HIESHETTER EXECUTIVE DIREC	(i)	132,141.	0.	0.	5,691.	22,252.	160,084.	0.
	(ii)	0.	0.	0.	0.	0.	0.	0.
2	(i)							
	(ii)							
3	(i)							
	(ii)							
4	(i)							
	(ii)							
5	(i)							
	(ii)							
6	(i)							
	(ii)							
7	(i)							
	(ii)							
8	(i)							
	(ii)							
9	(i)							
	(ii)							
10	(i)							
	(ii)							
11	(i)							
	(ii)							
12	(i)							
	(ii)							
13	(i)							
	(ii)							
14	(i)							
	(ii)							
15	(i)							
	(ii)							
16	(i)							
	(ii)							

SCHEDULE L
(Form 990 or 990-EZ)

Transactions With Interested Persons

OMB No. 1545-0047

2013

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

- ▶ Complete if the organization answered 'Yes' on Form 990, Part IV, line 25a, 25b, 26, 27, 28a, 28b, 28c, or Form 990-EZ, Part V, line 38a or 40b.
- ▶ Attach to Form 990 or Form 990-EZ. ▶ See separate instructions.
- ▶ Information about Schedule L (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

Name of the organization DYSTONIA MEDICAL RESEARCH FOUNDATION	Employer identification number 95-3378526
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Part I Excess Benefit Transactions (section 501(c)(3) and section 501(c)(4) organizations only).
Complete if the organization answered 'Yes' on Form 990, Part IV, line 25a or 25b, or Form 990-EZ, Part V, line 40b.

1	(a) Name of disqualified person	(b) Relationship between disqualified person and organization	(c) Description of transaction	(d) Corrected?	
				Yes	No
(1)					
(2)					
(3)					
(4)					
(5)					
(6)					

2 Enter the amount of tax incurred by the organization managers or disqualified persons during the year under section 4958 ▶ \$ _____

3 Enter the amount of tax, if any, on line 2, above, reimbursed by the organization ▶ \$ _____

Part II Loans to and/or From Interested Persons.
Complete if the organization answered 'Yes' on Form 990-EZ, Page V, line 38a or Form 990, Part IV, line 26; or if the organization reported an amount on Form 990, Part X, line 5, 6, or 22.

(a) Name of interested person	(b) Relationship with organization	(c) Purpose of loan	(d) Loan to or from the organization?		(e) Original principal amount	(f) Balance due	(g) In default?		(h) Approved by board or committee?		(i) Written agreement?	
			To	From			Yes	No	Yes	No	Yes	No
			(1)									
(2)												
(3)												
(4)												
(5)												
(6)												
(7)												
(8)												
(9)												
(10)												
Total						▶ \$ _____						

Part III Grants or Assistance Benefiting Interested Persons.
Complete if the organization answered 'Yes' on Form 990, Part IV, line 27.

(a) Name of interested person	(b) Relationship between interested person and the organization	(c) Amount of assistance	(d) Type of Assistance	(e) Purpose of assistance
(1)				
(2)				
(3)				
(4)				
(5)				
(6)				
(7)				
(8)				
(9)				
(10)				

SCHEDULE O
(Form 990 or 990-EZ)

Supplemental Information to Form 990 or 990-EZ

OMB No. 1545-0047

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

2013

▶ Attach to Form 990 or 990-EZ.

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

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

Name of the organization

DYSTONIA MEDICAL RESEARCH FOUNDATION

Employer identification number

95-3378526

FORM 990, PART V, LINE 2A-EMPLOYEES

THE NUMBER OF EMPLOYEES REPORTED ON FORM W-3 FOR 2013 WAS 9 WHICH TRANSLATES INTO 8 FULL TIME EQUIVALENTS.

FORM 990, PART VII, SECTION A-COMPENSATION

THE EXECUTIVE DIRECTOR IS OFFERED THE SAME BENEFIT PACKAGE AS ALL OTHER EMPLOYEES. CONSISTENT WITH PAST YEARS, THE EMPLOYEE BENEFITS OFFERED INCLUDE HEALTH INSURANCE, LONG-TERM DISABILITY INSURANCE, LIFE INSURANCE, PRE-TAX PARKING BENEFITS, AND 401(K) EMPLOYER MATCHING. IN ADDITION, THE FOUNDATION UNDERWRITES A MODEST DENTAL BENEFIT PLAN IN WHICH THEY REIMBURSE EMPLOYEES FOR DENTAL EXPENSES. THE COST OF PROVIDING EMPLOYEE HEALTH INSURANCE CONTINUES TO BE THE PREDOMINANT EXPENSE IN THE EMPLOYEE BENEFIT PACKAGE. OTHER COMPENSATION OF \$27,943 INCLUDES \$10,132 OF PRETAX CONTRIBUTIONS FOR HEALTH AND TRANSIT BENEFITS PAID BY THE EXECUTIVE DIRECTOR.

FORM 990, PART III, LINE 1 - ORGANIZATION MISSION

THE FOUNDATION HAS THREE MAIN PURPOSES: (1) TO ADVANCE RESEARCH BY AWARDING GRANTS TO BASIC, TRANSLATIONAL, AND CLINICAL INVESTIGATORS AND TO MEDICAL/SCIENTIFIC INSTITUTIONS COMMITTED TO FINDING THE CAUSE AND CURE FOR DYSTONIA; (2) TO PROMOTE AWARENESS BY SPONSORING WORKSHOPS AND SYMPOSIUMS FOR MEDICAL PROFESSIONALS AND PATIENTS, BY EDUCATING MEMBERS OF CONGRESS ABOUT DYSTONIA AND THE NEEDS OF THE DYSTONIA COMMUNITY AND ADVOCATING FOR THOSE AFFECTED BY DYSTONIA AND THEIR FAMILIES, AND BY PRODUCING AND DISTRIBUTING EDUCATIONAL MATERIALS, BOTH PRINTED AND ELECTRONIC; AND (3) TO SPONSOR PATIENT AND FAMILY SUPPORT GROUPS AND EDUCATION PROGRAMS INCLUDING THE CREATION AND PROMOTION OF VIRTUAL EDUCATIONAL MEETINGS AND ELECTRONIC SOCIAL NETWORKS FOR DYSTONIA-AFFECTED PERSONS WHO ARE UNABLE TO ATTEND MEETINGS AND FORUMS.

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FORM 990, PART III, LINE 4A - PROGRAM SERVICE ACCOMPLISHMENTS

SCIENCE-INCLUDES:

ISSUING 2 REQUESTS FOR APPLICATIONS, MANAGING THE PEER-REVIEW PROCESS OF 72 SUBMITTED GRANT, RESEARCH FELLOWSHIP AND CLINICAL FELLOWSHIP APPLICATIONS, SELECTING, FUNDING AND MANAGING 9 RESEARCH GRANTS, 2 RESEARCH FELLOWSHIPS, 5 CLINICAL FELLOWSHIPS, AND 3 RESEARCH CONTRACTS, ALL AIMED AT CREATING A BETTER UNDERSTANDING OF THE MECHANICS AND PATHOPHYSIOLOGY OF DYSTONIA, IDENTIFYING GENES, AND DEVELOPING IMPROVED TREATMENTS AND ULTIMATELY A CURE;

MEETING WITH PHARMACOLOGICAL AND BIOTECH COMPANIES TO ENGAGE THEM IN THE DEVELOPMENT OF TREATMENTS FOR DYSTONIA;

CONTINUED FUNDING OF A CLINICAL FELLOWSHIP PROGRAM DESIGNED TO SUPPORT TRAINING OF PHYSICIANS IN PREPARATION FOR A CLINICAL AND/OR RESEARCH CAREER IN MOVEMENT DISORDERS WITH SPECIAL FOCUS ON DYSTONIA;

SPONSORING AND PARTICIPATING IN DOMESTIC AND INTERNATIONAL SCIENTIFIC MEETINGS INCLUDING "2ND MYOCLONUS DYSTONIA WORKSHOP", "TOWARD DISCOVERY OF NOVEL TREATMENTS FOR DYSTONIA", "CIRCUITS AND PATHWAYS IN DYSTONIA AND PARKINSONISM", AND A CLINICAL TRIALS MEETING WHICH WERE ATTENDED BY RESEARCHERS FROM ALL OVER THE WORLD;

REVIEWING CURRENT RESEARCH DATA AND EXPLORING STUDIES NEEDED TO ACCELERATE IMPROVED TREATMENTS;

FACILITATING CONSENSUS WORK WITH DYSTONIA EXPERTS RESULTING IN THE PUBLICATION OF A JOURNAL ARTICLE FEATURING AN UPDATED DEFINITION AND CLASSIFICATION OF DYSTONIA;

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FORM 990, PART III, LINE 4A - PROGRAM SERVICE ACCOMPLISHMENTS

PARTICIPATING AS A SPEAKER AT FORUMS WITH THE NATIONAL INSTITUTES OF HEALTH (NIH) OFFICE OF RARE DISEASES RESEARCH (ORDR) TO PROMOTE RESEARCH AND PATIENT GROUP RELATIONSHIPS OR COLLABORATIONS;

SUPPORTING AND MAINTAINING THE AVAILABILITY OF RESOURCES TO ACCELERATE DYSTONIA RESEARCH GLOBALLY SUCH AS THE DYSTONIA BRAIN COLLECTIVE, GLOBAL DYSTONIA REGISTRY, AND DYSTONIA INTERNATIONAL PATIENT REGISTRY FOR USE BY THE INTERNATIONAL DYSTONIA COMMUNITY;

SERVING IN THE FOURTH YEAR AS THE ADMINISTRATIVE CENTER FOR THE DYSTONIA COALITION WHICH WAS AWARDED A FIVE-YEAR NATIONAL INSTITUTES OF HEALTH (NIH) GRANT TO DEVELOP AN INTERNATIONAL DYSTONIA CLINICAL NETWORK CONSISTING OF THREE PROJECTS: 1) DEVELOPING A NATURAL HISTORY STUDY AND BIOREPOSITORY; 2) REVISING THE TWSTRS RATING SCALE FOR CERVICAL DYSTONIA; AND 3) DEVELOPING, TESTING AND REFINING A NEW DIAGNOSTIC TOOL FOR SPASMODIC DYSPHONIA. THE FOUNDATION CO-FUNDED THE DYSTONIA COALITION'S CAREER DEVELOPMENT AWARD AND WAS RESPONSIBLE FOR MANAGING \$978,000 RESTRICTED FOR DYSTONIA COALITION WORK NOT INCLUDED IN THE FOUNDATION'S REVENUES AND EXPENSES.

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

AWARENESS AND EDUCATION-INCLUDES:

PUBLISHING THE "DYSTONIA DIALOGUE" NEWS MAGAZINE THREE TIMES A YEAR UNDER THE DIRECTION OF THE VOLUNTEER EDITORIAL BOARD AND DISTRIBUTING IT VIA MAIL OR ELECTRONIC COPY TO OVER 44,000 PATIENTS, FAMILIES, AND INTERESTED PERSONS TO INFORM THEM OF THE LATEST RESEARCH AND FOUNDATION ACTIVITIES;

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

CREATING AND DISSEMINATING OVER FIFTEEN DYSTONIA-RELATED EDUCATIONAL RESOURCES AS WELL AS PROMOTING AND DISTRIBUTING A CHILDREN'S BOOK ABOUT DYSTONIA AND CD/DVD'S TO REQUESTING INDIVIDUALS TO EDUCATE THEM ABOUT THE VARIOUS FORMS OF DYSTONIA AND TREATMENT OPTIONS;

PROMOTING DYSTONIA AWARENESS THROUGH AN EXTENSIVE WEBSITE, WEBINARS, AND ELECTRONIC SOCIAL NETWORKS SUCH AS THE ONLINE DYSTONIA BULLETIN BOARD, TWITTER, FACEBOOK, AND YOUTUBE;

CREATING AND DISSEMINATING A MONTHLY ENEWSLETTER AND PERIODIC EMAIL ALERTS TO SHARE INFORMATION ON EVENTS, NEWS, AND ACTIVITIES;

AND PARTICIPATING IN ADVOCACY ACTIVITIES TO PROMOTE AWARENESS AMONGST LAWMAKERS ON TOPICS IMPORTANT TO DYSTONIA PATIENTS. SEE SCHEDULE O, PART III 4C FOR DETAILS.

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

MEMBERSHIP AND SUPPORT-INCLUDES:

PLANNING AND SUPPORTING PATIENT SYMPOSIA, REGIONAL EDUCATIONAL MEETINGS, AND COMMUNITY FORUMS ATTENDED BY PATIENTS AND THEIR FAMILIES WHICH PROVIDE INFORMATION ABOUT CURRENT RESEARCH AND TREATMENT OPTIONS AND AN OPPORTUNITY TO DEVELOP PERSONAL NETWORKS;

CREATING VIRTUAL EDUCATIONAL FORUMS FOR DYSTONIA-AFFECTED PERSONS WHO ARE UNABLE TO ATTEND MEETINGS AND FORUMS;

PROMOTING SUPPORT RESOURCES TO AID IN DISEASE MANAGEMENT AND QUALITY OF LIFE SUCH AS

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

A NETWORK OF SUPPORT GROUPS AND AN ELECTRONIC SOCIAL NETWORK, INCLUDING BULLETIN BOARDS AND TELEPHONE COMMUNICATIONS WITH INDIVIDUALS AFFECTED BY DYSTONIA AND INTERESTED PARTIES;

PROVIDING ONGOING LEADERSHIP TRAINING FOR VOLUNTEER SUPPORT LEADERS BY HOSTING A LEADERSHIP CONFERENCE, CREATING ELECTRONIC FORUMS FOR LEADERS TO UTILIZE IN SHARING EXPERIENCES AND PROVIDING PEER SUPPORT, AND DEVELOPING A SUPPORT GROUP MANUAL WHICH PROVIDES VALUABLE INFORMATION AND RESOURCES FOR EFFECTIVE SUPPORT LEADERSHIP.

PROVIDING MEETING MANAGEMENT SUPPORT SUCH AS EMAIL AND POSTAL NOTIFICATIONS ABOUT UPCOMING SUPPORT GROUP MEETINGS INCLUDING SUPPLYING DYSTONIA BROCHURES TO ALL SUPPORT GROUPS.

FORM 990, PART III, LINE 4D - OTHER PROGRAM SERVICES DESCRIPTION

ADVOCACY-THE DMRF PROVIDES THE STAFF AND ADMINISTRATIVE SUPPORT FOR DYSTONIA ADVOCACY NETWORK, A COLLABORATION OF FIVE DYSTONIA ORGANIZATIONS WORKING TO MEET THE POLICY NEEDS OF THE DYSTONIA COMMUNITY. FOR THE PAST SEVEN YEARS, THE DYSTONIA ADVOCACY NETWORK HAS BEEN INSTRUMENTAL IN EDUCATING CONGRESS ABOUT THE BENEFITS OF LISTING DYSTONIA AS A CONDITION ELIGIBLE FOR STUDY ON THE DEPARTMENT OF DEFENSE (DOD) PEER-REVIEWED MEDICAL RESEARCH PROGRAM, RESULTING IN THEM MAKING THE CONDITION ELIGIBLE FOR INVESTIGATORS TO COMPETE FOR RESEARCH FUNDING. ON BEHALF OF THE FIVE DYSTONIA ADVOCACY NETWORK ORGANIZATIONS, THE DMRF UTILIZES A LEGISLATIVE CONSULTANT TO TRACK LEGISLATIVE ACTIVITIES ON CAPITOL HILL, MAINTAINS AN ADVOCACY WEBSITE, AND ELECTRONICALLY DISSEMINATES ACTION ALERTS TO STAY CONNECTED WITH KEY LEGISLATORS. THE DMRF ALSO SUPPORTS A NATIONWIDE NETWORK OF VOLUNTEER ADVOCATES WHO CONTINUALLY WORK TO EDUCATE MEMBERS OF CONGRESS ABOUT DYSTONIA AND ADVANCE THE COMMUNITY'S LEGISLATIVE AGENDA. VOLUNTEERS MEET WITH POLICYMAKERS DURING THE ANNUAL ADVOCACY

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FORM 990, PART III, LINE 4D - OTHER PROGRAM SERVICES DESCRIPTION

DAY AND AS NEEDED THROUGHOUT THE YEAR TO ADVOCATE ON BEHALF OF THE DYSTONIA COMMUNITY ON ISSUES SUCH AS INCREASED RESEARCH FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH, ACCESS TO HEALTHCARE, AND APPROPRIATE, AFFORDABLE REIMBURSEMENT FOR DYSTONIA TREATMENTS.

FORM 990, PART VI, LINE 2 - BUSINESS OR FAMILY RELATIONSHIP OF OFFICERS, DIRECTORS, ETC.

SAMUEL BELZBERG IS THE SPOUSE OF FRANCES BELZBERG.

FRANCES BELZBERG IS THE SPOUSE OF SAMUEL BELZBERG.

ART KESSLER IS THE SON OF DENNIS AND BARBARA KESSLER.

DENNIS KESSLER IS THE SPOUSE OF BARBARA KESSLER AND FATHER OF ART KESSLER.

BARBARA KESSLER IS THE SPOUSE OF DENNIS KESSLER AND MOTHER OF ART KESSLER.

ROSALIE LEWIS IS THE SPOUSE OF RICHARD LEWIS.

RICHARD LEWIS IS THE SPOUSE OF ROSALIE LEWIS.

MARK RUDOLPH IS THE SPOUSE OF DIANE RUDOLPH.

DIANE RUDOLPH IS THE SPOUSE OF MARK RUDOLPH.

JOHN SYMONDS IS THE SPOUSE OF KAREN ROSS.

KAREN ROSS IS THE SPOUSE OF JOHN SYMONDS.

FORM 990, PART VI, LINE 11B - FORM 990 REVIEW PROCESS

THE BOARD OF DIRECTORS HAS DELEGATED THE REVIEW OF THE FORM 990 TO THE TAX REVIEW TASK FORCE WHICH IS COMPRISED OF THE PRESIDENT, TREASURER AND CHAIRPERSON OF THE AUDIT COMMITTEE. PRIOR TO THE SIGNING AND FILING OF THE FORM 990, MANAGEMENT, OUTSIDE CPA, THE TAX REVIEW TASK FORCE AND THE INDEPENDENT ACCOUNTANT WHO PREPARES THE FORM 990 MEET TO REVIEW THE ENTIRE FORM. UPON APPROVAL BY THE TAX REVIEW TASK FORCE, THE FORM 990 IS MADE AVAILABLE TO ALL MEMBERS OF THE BOARD OF DIRECTORS FOR REVIEW, AFTER WHICH IT IS SIGNED BY THE TREASURER AND IS FILED.

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FORM 990, PART VI, LINE 12C - EXPLANATION OF MONITORING AND ENFORCEMENT OF CONFLICTS

ON AN ANNUAL BASIS, DMRF REQUESTS WRITTEN STATEMENT OF ANY CONFLICTS FROM MEMBERS OF THE BOARD. THE BOARD PRESIDENT, ALONG WITH EXECUTIVE DIRECTOR, MONITOR AND REPORT POTENTIAL CONFLICTS TO CHAIR OF AUDIT COMMITTEE. ANY CONFLICTS THAT ARE DETERMINED TO EXIST ARE REPORTED TO THE BOARD.

FORM 990, PART VI, LINE 15A - COMPENSATION REVIEW & APPROVAL PROCESS - CEO, TOP MANAGEMENT

ANNUALLY, THE DMRF BOARD PRESIDENT CONSULTS WITH THE BOARD OF DIRECTORS REGARDING THE PERFORMANCE OF THE EXECUTIVE DIRECTOR AND PREPARES A WRITTEN PERFORMANCE EVALUATION. THE BOARD PRESIDENT, AFTER CONSULTATION WITH THE BOARD, DETERMINES SALARY ACTION, IF ANY, AND MEETS WITH THE EXECUTIVE DIRECTOR TO DISCUSS THE PERFORMANCE EVALUATION. COMPARATIVE SALARY INFORMATION IS OBTAINED ABOUT ORGANIZATIONS OF SIMILAR SCOPE AND SIZE THROUGH INFORMATION FROM THE ASSOCIATION FORUM OF CHICAGOLAND AND THROUGH OTHER PUBLICLY AVAILABLE INFORMATION.

FORM 990 , PART VI, LINE 17 - LIST OF STATES WHICH THIS RETURN IS FILED

IL CA CT FL GA NJ NY PA MD MA MI MN MO NC OH OK OR WA CO AL KS RI UT AZ VA WI KY
ME AR SC AK MS NH TX

FORM 990, PART VI, LINE 19 - OTHER ORGANIZATION DOCUMENTS PUBLICLY AVAILABLE

FORM 990, AUDITED FINANCIAL STATEMENTS, AND THE BOARD APPROVED ANNUAL OPERATING PLAN ARE AVAILABLE ON THE FOUNDATION'S WEBSITE. CONFLICT OF INTEREST, GOVERNING DOCUMENTS AND POLICIES ARE AVAILABLE UPON REQUEST.

DYSTONIA MEDICAL RESEARCH FOUNDATION

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FORM 990

PART II, LINE 42-DEPRECIATION EXPENSE

PART IV, LINE 57A & 57B-FIXED ASSETS AND ACCUMULATED DEPRECIATION

DEPRECIATION IS COMPUTED ON THE STRAIGHT LINE BASIS OVER THE ESTIMATED USEFUL LIVES OF THE ASSETS, GENERALLY 3-5 YEARS.